

In the Shadow of Misperception: Assistive Technology Use and Social Interactions

Kristen Shinohara and Jacob O. Wobbrock

The Information School
DUB Group
University of Washington
Seattle, WA 98195
{kshino, wobbrock}@uw.edu

ABSTRACT

Few research studies focus on how the use of assistive technologies is affected by social interaction among people. We present an interview study of 20 individuals to determine how assistive technology use is affected by social and professional contexts and interactions. We found that specific assistive devices sometimes marked their users as having disabilities; that functional access took priority over feeling self-conscious when using assistive technologies; and that two misperceptions pervaded assistive technology use: (1) that assistive devices could functionally eliminate a disability, and (2) that people with disabilities would be helpless without their devices. Our findings provide further evidence that accessibility should be built into mainstream technologies. When this is not feasible, assistive devices should incorporate cutting edge technologies and strive to be designed for social acceptability, a new design approach we propose here.

Author Keywords: Accessibility, product design, interface design, stigma, social interactions, assistive devices.

ACM Classification Keywords: K.4.2 [Computers and society]: Social issues—*assistive technologies for persons with disabilities*.

General Terms: Design, Human Factors.

INTRODUCTION

People with disabilities use assistive technologies for various tasks in their everyday lives. Assistive technologies are defined by the Technical Assistance to the States Act as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities” [6]. This definition describes any technology appropriated for the specific purpose of aiding people with disabilities, created with the express purpose of enabling access to environment, technology, information, and services. But assistive technologies are abandoned at high rates [20,22], and surprisingly, this is often due to personal meaning

associated with such devices [18]. If assistive technologies are built to be functional and usable, but people are abandoning them, how effective are they in helping people with disabilities accomplish daily tasks? Research involving assistive technologies generally focuses on functionality and usability [10], yet technology use does not happen in a social vacuum. Rather, personal preferences in social contexts may dictate whether and how a device is used [24]. This implies an effect on technology use arising from social contexts. We present this study investigating the effects of assistive technology use in social and professional contexts from the perspective of people with disabilities, a perspective often lacking in assistive technology research.

We conducted an interview study to find how 20 people with disabilities feel about using assistive technologies in social and professional contexts. We found that while assistive technology empowers and enables people to work, socialize, and orchestrate their lives, it still lives in the shadow of social misperceptions. These misperceptions may perpetuate social barriers to accessibility. Assistive technologies are used in social situations and not in isolated laboratories; therefore, design of such technologies must be assessed for impacts on social and professional interactions.

BACKGROUND

In previous work [24], it was found that unwanted attention brought on by an assistive device made the individual feel self-conscious in some social contexts. Indeed, assistive technologies often bridge functionally *and* socially-situated experiences. To understand how social contexts may affect assistive technology use, we turn to literature on the disabilities rights movement, the meaning of objects, and the psychology of stigma.

Disability Rights: An Enabling Environment

As researchers who do not have disabilities, we believe it is important to endeavor to understand social and cultural issues of disability rights, and how these affect assistive technology adoption and use. In *Nothing About Us Without Us*, Charlton describes the social issues which drove the disabilities rights movement [5]. Fueled by the Civil Rights Movements of the 1960s in the United States, people with disabilities rallied for equal rights and equal access. The movement rejected the idea of disability as a medical condition, and instead adopted a socially constructed view, emphasizing that disability lies not in the person, but in the

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee.

CHI 2011, May 7–12, 2011, Vancouver, BC, Canada.

Copyright 2011 ACM 978-1-4503-0267-8/11/05...\$10.00.

environment; access or in-access are situational and societal constructs. Rather than creating technologies and environments excluding people of varying abilities, this socially constructed view says the environment should be built to *enable* access. We take this one step further: *technology* should also be built not to disable, but to enable.

Personal Objects and Meaning

To understand how the built environment affects social interactions, we turn to literature on objects and meaning. People associate personal meaning with objects they use in everyday life [7] and may view their objects as defining part of their identity in some way. We negotiate how we present ourselves to others, cultivating our own desired identity [14]. Thus, we associate identifying characteristics with things others use and ways they present themselves. Through these social expectations, people determine and interpret social norms in order to navigate relationships with others. In this way, we make judgments based on first impressions and unconscious expectations [9], determining socially acceptable ways of interacting with others.

Disability and Social Stigma

If a person's self-presentation does not meet expected social norms, that person may be found to deviate from others and social interaction is disrupted. It is then that people may be marked for their difference from social norms. Goffman defines this as *stigma*: when an "attribute that is deeply discrediting" is associated with an individual [15]. He emphasizes that crediting or discrediting individuals occurs when negotiating social relationships. Thus, stigma is a socially constructed phenomenon; social norms influence the way social interactions are negotiated. Many social norms are based in societal underpinnings, which are out of scope to enumerate for this paper. However, we do focus on how people identify themselves and others through objects (assistive technologies) they use, and how objects affect perceived differences among people. If assistive devices mark users as "other," this may create social barriers to access even while such devices should help overcome them.

Elliot *et al.* [11] explain that people with disabilities lose legitimacy (are discredited) and incur stigma when it is determined, through social interaction, that they may not meet the implicit expectations of others. Elements of discrediting attributes include: visibility, pervasiveness in everyday life, centrality of a "problematic" attribute, and an inability to remove stigma. When these characteristics come together, they bring attention to the bearer, interrupting social discourse. Fine and Asch [12] argue that disability is a socially constructed phenomena. The environment and attitudes of others create "barriers of discrimination" and inaccessibility, and not necessarily physical impairment. In this way, it is a social responsibility to provide for accessibility in the creation of environments and artifacts.

RELATED WORK

Most research regarding assistive technologies focus on improving functionality or user interaction [10]. Some

focus on how assistive technologies are used from the perspective of those who use them [16,23]. Few examine the effect of social situations, or the perceptions of those who use them. Here, we discuss some studies that do, and how this study differs.

Meaning of Assistive Technologies

Pape *et al.* [18] surveyed previous rehabilitation and assistive technology literature, examining where *meaning* and *significance* were reported as factors affecting assistive technology abandonment or use. They found that people with disabilities were more likely to abandon an assistive device if they did not accept their disability, if the device socially excluded them (made them feel different from peers), or if the device significantly clashed with cultural values. Pape *et al.* concluded that many social factors pervade choices in using assistive technologies, not just usability and functionality.

Assistive Technology and Stigma

Parette and Scherer [19] evaluated previous rehabilitation studies where individuals felt stigmatized by assistive devices. Elements contributing to stigmatization included aesthetics, gender and age, social acceptability and deference of rehabilitation professionals. While their paper is a thorough description of how assistive technologies may stigmatize individuals, it retains a rehabilitation perspective and does not describe its own empirical study, as we do here. Jacobson [17] explores modifications individuals incorporate as a way to manage stigma. Through individual cases illustrating how devices are personalized, she focuses on customization, supporting our work here on image and identity. Bispo and Branco [2,3] propose to eliminate stigmatizing effects of devices through design. Their work does not cite an empirical study, but their idea of "replacing the prejudices and the assumptions related to disability with an image of normality" by creating "new symbolic imagery" via design supports work we have done here.

Assistive technology is used in and around social interactions, and is subject to social expectations, but how? How much does perception shape meaning of assistive technologies in socially situated contexts? In what ways might assistive technologies mark users, perpetuating misperceptions about people with disabilities? These are some of the questions our empirical investigation addresses.

STUDY METHOD

Twenty participants were interviewed in sessions ranging from 60 to 90 minutes. Interviews were held in our university facility or at participants' place of work or home. Participants were recruited through various local assistive technology center email lists and were compensated for their time. Eleven participants were blind; 3 lost their sight later in life. Three participants had low vision, 1 due to macular degeneration. Four participants were deaf or hard of hearing, 1 lost hearing later in life. One participant was deaf-blind, 1 had cerebral palsy. Table 1 lists participants and technologies discussed or shared.

	Disability	Age	Sex	Employment	Technology (previously used devices)
1	Totally blind, born with vision in one eye	57	M	Retired fisherman, Sports Supervisor	JAWS, BrailleNote, HTC Touch Pro cell phone with MobileSpeak & MobileGeo, white cane, netbook, (Victor Reader), (Perkins Brailler), BookSense, guide dog
2	Leber's Congenital Amaurosis (blind)	28	M	Assistive Technology Specialist	accessible cell phone, BrailleNote, KNFBReader, Victor Reader Stream
3	Congenitally blind, losing hearing	58	M	Retired	JAWS, hearing aids, Perkins Brailler, (slate and stylus), (BrailleLite), Braille Display, (Duxbury), (books on record), (Optacon), white cane, cell phone - not accessible, talking watch
4	Lost sight 5 years prior, totally blind	30	F	Student	JAWS, talking watch, Nokia cell phone with MobileSpeak, white cane, Victor Reader
5	Born with low vision	44	F	Mental Health Counselor	ZoomText, Victor Reader, monocular, (books on CD), (books on cassette), (books on record), glasses for low vision, (CCTV), (large print typewriter)
6	Lost sight due to Retinitis Pigmentosa	71	F	Retired Librarian	VoiceNote, JAWS, Screen magnification, Screen contrast, CCTV, books on tape, Victor Reader Stream, Verizon LG cell phone - not voice accessible
7	Congenitally blind	58	F	Unemployed	JAWS, Braille, Victor Reader Stream, Slate and Stylus, (books on reel-to-reel books), (books on tape), Braille Display, (Braille N Speak), (portable typewriter)
8	Congenitally blind	58	F	Transition and Independent Living Specialist	(books on reel-to-reel tape), (books on tape), (books on record), BrailleNote, white cane, Nokia 6682 cell phone with Talks accessibility program, (Optacon), scanner with Kurzweil software, Duxbury
9	Low vision	49	F	Assistive Technology Instructor	white cane, speech program on computer, Nokia N86 with voice accessibility, BrailleNote, talking scale, (tape player for note taking), (Perkins Brailler), (Slate and Stylus), (regular typewriter), (books on reel-to-reel tape), (CCTV)
10	Congenitally blind, losing hearing	56	F	Unemployed	Perkins Brailler, hearing aids, Screen Reader, (optacon), Slate and Stylus, (portable typewriter)
11	Congenitally blind	61	F	Retired Social Worker	PacMate, iPhone, KNFBReader, scanner, Braille Display, talking microwave
12	Low vision, Macular Degeneration	72	F	Retired Professor	iPhone, iPad, magnifying glasses, glasses, monocular, JAWS
13	Deaf-blind, Usher's Syndrome	39	M	between jobs	Deaf-Blind Communicator, white cane, TTY, ZoomText
14	Deaf	38	F	Director, Human Services	iPod, videophones, phone captioning, pager with IP relay, TTY, Video Relay Service, (FM System), netbook, cell phone, flashing doorbell, flashing and vibrating bed alarm
15	Hard of hearing	59	M	Salesman	hearing aids, iPhone, headphones for home use, captioning, (ASL)
16	Hard of hearing, low vision (Usher's Syndrome)	52	M	Retired	hearing aids, white cane, Computer Aided Real Time captioning, guide dog, cell phone
17	Hard of hearing	56	F	Freelance Editor	cell phone with bluetooth, TTY, hearing aids,
18	Cerebral palsy	69	F	Advocate	Pathfinder Communication device
19	Congenitally blind	59	M	Singer	Victor Reader Stream, talking watch, BrailleLite, (Perkin's Brailler)
20	Lost sight due to Retinitis Pigmentosa	48	F	Unemployed/ Retired	CCTV, ZoomText, JAWS

Table 1. Participants and assistive technologies.

Participants were asked about assistive technologies used, how technologies were used, and what they thought of their technologies. Wherever possible, they were encouraged to show their technologies. If participants had a disability since birth or childhood, they were asked to compare past and current devices. They were asked what it was like to use assistive devices around others in social or work contexts. They were also asked if they thought there were misperceptions surrounding their technologies, and if they ever felt self-empowered or self-conscious when using their assistive devices.

Analysis

All interviews were recorded and transcribed verbatim. Using a grounded theory approach [13,25], transcripts were coded using open and axial coding; similar categories and concepts were combined, then compared with concepts in subsequent interviews. Early interviews were initially open coded for specific concepts to pursue in later interviews.

From the developed categories, dimensions and properties were drawn out as well as connections to other categories.

RESULTS

We found that people with disabilities balance complex relationships with their environment and with others while using their assistive technologies. When using their devices, participants negotiated feeling self-conscious with the desire to be independent and the need to be productive, especially at work. Participants used a wide variety of proprietary and mainstream technologies, as shown in Table 1, over a range of social and personal activities, including: for education, traveling, entertainment, engaging with friends, at work, and safety. Devices discussed included electronic note takers, hearing aids, the Victor Reader Stream (digital book player), monoculars, magnifying glasses, and video relay services. Some participants also used mainstream devices, such as the Apple iPhone and iPad, netbooks, cell phones, laptops, and desktop

computers. A range of devices and systems bridged proprietary and mainstream technologies, including Bluetooth-compatible hearing aids, and JAWS (Job Access With Speech) software. Even proprietary devices such as the Victor Reader Stream integrated with SD (Secure Digital memory) cards, and several blind participants used scanners with OCR (Optical Character Recognition) technology to access print books.

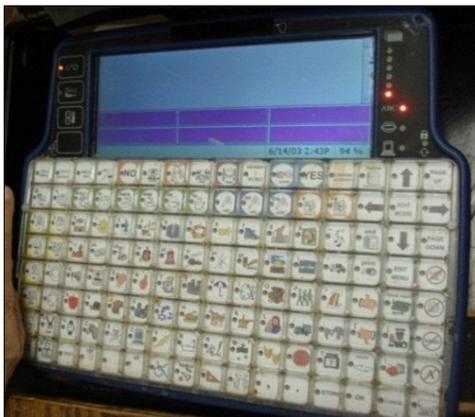


Figure 1. The Pathfinder Communication Device used by P18.

Assistive Technology in a Social World

We found assistive devices played both central and peripheral roles in social interactions. For instance, the Pathfinder (Figure 1) and the Deaf-Blind Communicator were used as primary communication tools for P18 and P13, respectively. In comparison, the Victor Reader Stream and software like ZoomText and JAWS were peripheral in most social interactions. Technologies in central social roles were more conspicuous than others. While peripheral technologies were not usually central to interactions, many influenced how social interactions played out, particularly at work. If peripheral technologies were more visible and “weird” or “strange” looking, they tended to attract attention from others. Smaller devices and those that looked like mainstream counterparts attracted the least attention.

Participants were aware their devices attracted attention by the kinds of questions and comments they received. In some cases, participants were sensitive to the reactions of others around them, for instance, taking note when another person seemed uncomfortable, sent furtive looks, or by their tone of voice. Despite this, participants did not significantly alter device use, although they reported feeling self-conscious about attention in a few situations: (1) if they had an “invisible disability,” one that may not be apparent without explicit disclosure; (2) when using traditional and socially recognizable devices, such as a white cane or hearing aids; and (3) when design attracted attention to differences from mainstream counterparts, for example, voice accessible phones that spoke aloud commands everyone could hear.

Just Like Everyone Else

Participants valued technology enabling equal access because it allowed them to do things *just like everyone else*.

Two caveats to this perspective were that participants felt they should retain disability-specific training (for example, blindness skills, or American Sign Language), and that not all technologies leveled the playing field of access. P18 explained that her device allowed others to “see I can communicate like any person,” resulting in improved social interactions. P7 felt empowered because she had access just like everyone else:

... it's just neat that I can do things, ... that other people can do. Like, I can have books to read that I want to read... when I first got my scanner I was really excited about it because then I could ... buy books that weren't available, and I could read those books, ... I would say your technology is your lifeline ... it opens up worlds of opportunity.

Still, participants reported assistive technologies lagged behind current technical standards, meaning they did not truly have access like everyone else. P2 discusses the appeal of mainstream technologies and how people feel about assistive technology always being a step behind:

You know, if someone's using an iPhone, and I'm using an iPhone, that's normal, right? It's the same thing... like universal design, you build the accessibility directly into the products, then you're not using some clunky, blindness specific product. A term that gets thrown around sometimes is blind ghetto products. ... cell phones have, like, all these neat features and stuff, but, ... the BrailleNote's just catching up. When you know, it doesn't even have like, 802.11n, which is the new networking standard. You know, but it costs six grand. I mean, come on.

An important point must be made: participants recognized that no assistive technology would fully replace sight, hearing, or any kind of functioning. Rather, they most valued *having access* to the information and services *everyone else had*. Finally, as seen in these comments, many participants expressed the importance of *being seen* with assistive or mainstream devices in order to demonstrate how they were capable of doing just as much as anyone else.

Design and Aesthetics

As mentioned previously, participants were aware of how their technologies differed from the mainstream status quo in quality of access and function. They were also aware how their technologies looked different than mainstream technologies. Device design and aesthetics were divided into appealing and unappealing characteristics, based on look and feel. It was noted that manufacturers of proprietary technology do not appear to make an effort to make their devices aesthetically appealing. P2 described his experience upon discovering the color of his BrailleNote¹ earbuds:

The original BrailleNote used to ship- I don't remember what color they were- but they were the ugliest earbuds you

¹ <http://www.humanware.com>

could possibly- like, bright orange or something. It came with these hideous earbuds. And, I had one of my friends-sighted friends- is like, 'man, you- those things are awful, dude. You should never² use those.' And I had no idea. But, of course, they just thought, since it was a bunch of blind people they're shipping this stuff to, it didn't matter.

P10 explained she cared about the design of things she used because it could be a reflection on her:

I like things attractive. Whatever adaptive equipment, I want it to look nice. You know, you got everybody with their iPods and their iPads and their Blackberries, you know, and they're whipped out, they're small... and they're nice looking. Cause –Apple would not be selling their “i” stuff if it wasn't good looking. And, as a blind person, yeah, maybe I don't see it, but other people see it, and I want it to be, you know, just as glamorous as the next guy.

If a device looked similar to mainstream devices, or if few alternatives existed (for instance, electronic note takers are the only devices providing portable refreshable Braille), participants did not report feeling self-conscious. But, if devices looked unlike anything else (monoculars), or were altered versions of mainstream counterparts (extra thick glasses, large print typewriters), participants were more likely to report feeling self-conscious (Figure 2). This last category was compounded by the fact that many who used such devices also had “invisible disabilities” and could pass as having no disability (if they were not using assistive devices). Illustrating this point, P8, a transition specialist for young blind and low vision students, observed:

So anything that might be cosmetic, is a real big--... like the monoculars, or big thick glasses, or a hand held magnifier, you know. Some of those things are more of a cosmetic kind of thing. They're real visual... And even the large print books, because if you're carrying those around, they're probably, legal size paper, if not bigger. You know, so they really are huge compared to what other kids carry around. And so they don't like to carry those around.

Two of the three participants with low-vision reported they could pass as non-disabled if they were not using their devices. Speaking to this, P5 explained how she negotiated self-consciousness and utility:

...a device is no use to you if you won't use it. So, I think there's some holes between shame and utilitarianism... Like, this is gonna be efficient for me, and I'm gonna do it. You know, and on the other end of it is, I'll just figure out any way to do this where I won't be noticed. And I've been on both ends of that and everywhere in between.

Internal battles between self-consciousness and utility were most prominent among the low-vision participants. Other participants also overcame feelings of self-consciousness through adopting utilitarian viewpoints, but to a lesser

extent. Like P5, participants recognized their devices as tools enabling them to do things such as write papers for school or contact work clients. Finally, while acknowledging different-looking devices attracted attention, some participants reported not feeling self-conscious.



Figure 2. From left: Victor Reader Stream, monocular, glasses.

Avoidance

Many participants reported they avoided using certain technologies as much as possible at one time or another. P8 describes what she perceived cane-use to mean and how she did not want “that” to be her:

...when I was a teenager I wasn't gonna use a white cane because I was blind and I didn't want – The only example I had of a blind person using a cane, it sounded like they were shuffling their feet, and they had their head down, and they were... you know? ...so I wasn't gonna use the cane.

Similarly, P9 explained why she refused to use a cane at first: “because I felt it really caused me to stand out.” She wanted to avoid being marked as the blind person P8 envisioned. Many of the blind and low-vision participants echoed this sentiment. But where P8 and P9 eventually did start using their canes, it was something P12, who had macular degeneration, still had not adopted:

The kind of thing that I have a problem with, and I do not use, is a white cane. I mean, that is – that is a hurdle that, boy, that's gonna be awhile before I get over that one... Because, it just immediately, kind of marks you out as different, as having vision problems. Most people who meet me, until I tell them, have no idea. And, I guess I kind of prefer that.

Although not as prevalent, some participants with hearing loss also experienced a reluctance to wearing hearing aids so often associated with the elderly. P15 describes why:

...it's just the acceptance of it, which is much harder, compared to, say like, glasses, which you know,... it's universal, it's socially accepted... Again, the frame of reference being that the people you knew who wore hearing aids was your grandfather. And, so there's that part of it.

² All emphasis in original.

...I think it's some sort of social stigma. And I still experience that now.

While P15 felt glasses were more socially acceptable than hearing aids, P10, herself congenitally blind, had a hard time accepting hearing loss and hearing aids:

The hardest thing for me was to accept – was having to use a hearing aid. And, it took me a really long time. I was really kind of surprised at myself, 'cause I am pretty matter of fact. But it was just coming to terms with the fact that I wasn't hearing as well as I used to... I was afraid it would look awful.

Although the white cane is not an electronic assistive technology, it is an assistive device, and connotations our participants associated with it tell us much about the social meaning they attributed to this device. They were aware of the social stigma of these devices, and it did not matter if the participants were totally blind, had low vision, were born deaf or became deaf later in life. This tells us some assistive devices do, in fact, have strong social meaning associated with them. It is hard to guess how such perceptions came to be a part of these devices, but we can see our participants did not want to be associated with these perceptions. As we saw in P8's comment about using the white cane, they felt such perceptions did not represent who they were at all.

Safety

In contrast to avoidance, some participants purposefully chose to call attention to their disability, usually for safety reasons, through the use of their devices. P9 describes how she began to use her cane:

...once I kind of... got over my inhibitions, and all the concerns that I felt about what people would think of me in high school, I found that it was so much easier. I mean, a cane gives information to the world. It says to people, 'this person is blind'... You know, 'give her another couple seconds before you blast on your horn when she's crossing the street,' you know? Um, 'just go easy.' ... So, to me, the cane was one of the most empowering things, but it was also... one of the most difficult things for me to sort of admit that I needed.

Not all assistive technology used for safety reasons were appropriated to identify the person with a disability. For instance, P14 used a pager with an IP address service in case of an emergency where she might need to call for help. P1 avoided any technology with wearable straps, wary that such devices might invite attackers to “yank” them off his neck. P20 explains why safety was an important concern:

I would say it's a more perceived feeling of being threatened, or being less safe. And a lot of that is because there's a realization, first of all, we don't know our surroundings. Other than from what we can hear. And we can't run. And, maybe you can fight, but... you don't know who you're fighting and what they may have in their hand.

And if you fight, you gotta get up close, and then – even then, what happens if you win? You still – what are you gonna do, grab your cane, and click clack, click clack, click clack down the street? So... you start thinking of all the implications, like, okay, hmm, I just need to be more aware of – that I keep myself out of situations that may be unsafe.

These descriptions give credence to the safety concerns of people with disabilities, while also highlighting important concepts of device design, use, and safety. It is important for people with disabilities to be able to identify and communicate something about their disability, depending on the context, but only *if they so choose*. Recall that P9 used her cane to identify her as visually-impaired so people would know she may not see them. At the same time, P1 did not want people to recognize his blindness-specific technologies; thus, he did not wear them visibly for others to see, and he was wary of designs implicating a device be worn. Finally, expensive proprietary technologies are hard to replace and require extra security.

Help

Themes of help arose out of many of the social interactions participants described. Not all kinds of help involved assistive technology directly, but we include them because they were strongly tied to perspectives on identity, which in turn, was tied to assistive technology use. Participants negotiated when they asked for help, especially if they had an assistive device at hand. P4 was careful when asking for help so as not to burden friends or family, and also because she did not want them to think less of her. Here, P4 associates asking for help with her own abilities, and consequently, how she wants others to identify her. She is concerned with what is portrayed about her if she asks for help too much:

I don't want people to – just view me as a disabled person. I want them to view me as Karen,³ so, it's like when I ask them questions, it's like, okay, I'm this disabled person asking questions. It's not Karen asking questions. And it's just sort of like – sometimes if I ask questions a lot, then it's like my – it's like I'm losing my... personality.

Participants reported that strangers offered unwanted help, grabbing, pushing or pulling blind participants, assuming they knew where the participant was headed. People over-articulated or spoke loudly, trying to compensate for deaf participants' hearing loss. P5 received emails in large font by people who knew she had low vision and assumed she had no accommodations (in fact, she used ZoomText⁴). This “discombobulated” her (her word), requiring her to adjust software settings. In unwanted help, the helper identified the participant as having a disability, was unaware of the participant's abilities or accommodations, made assumptions, and took it upon themselves to “help.”

³ Names changed to maintain confidentiality of participants.

⁴ <http://www.aisquared.com/zoomtext>

Issues of help were significant because they occurred often and because participants felt that if others saw them getting help, they would consider them less able. Issues of help have implications for assistive technology design. As we have seen, participants did not want to be identified as helpless, they wanted others to see how assistive devices made them independent and capable. Thus, it was important for participants to be able to use devices confidently, and it was just as important for others to see this as well.

Ignorance and Misperceptions

When participants were offered unwanted help, it was often because others did not know what the participants could do. Many social interactions involved participants answering questions about their disability or devices; some questions overstepped social and privacy boundaries, such as, “how did you lose your sight?” or, “What’s that?” interrupting participants about an assistive device they were using. Most participants welcomed the chance to educate others about having a disability, although some felt such questions were too personal and an invasion of privacy.

People asked questions because they were unfamiliar with assistive technology. One problem with this general unfamiliarity was that people then made incorrect assumptions. P6 described how the reactions of others made her feel self-conscious about what they were actually thinking about her using a VoiceNote⁵:

When you’re in a group of sighted – especially sighted people, you know, and you bring out something like this. They’ll say, ‘Oh, what’s that? What’s that? Oh, isn’t that wonderful?’ And they’ll get sort of patronizing. They’ll say, ‘oh, isn’t that wonderful? You can have that?’

P6 discusses how this patronizing perspective from others leads to misperceptions about what her device can do:

I have a friend and we were talking about being disabled. She said, ‘well, you have your VoiceNote.’ It’s like people think you can be normal... because you have some technology...you’re still not visually normal. But... I don’t know, she had the misperception that, well, I could just live a normal life because I had a VoiceNote... Well, I can live better. But I don’t... see, I’m comparing it to a visual life. And, I thought, I still don’t live a visual life, even though I have assistive technology. But, I know the difference between sighted life and not sighted life.

While others think her device is “wonderful” and will make her “normal,” P6 instead views her device as just another tool that improves her life. P6’s encounters were not unique among our participants. They felt empowered and grateful to have assistive technologies, but as P10 explains, most participants considered their devices just another tool:

I don’t think it represents me as a person. It’s a device. The same way as a sighted person using a blackberry or

whatever – it doesn’t represent them. It’s just a tool that they have, it’s a toy they play with all the time... that makes life a little bit more convenient... and that’s the way I look at whatever adaptive technology I use. It’s the same thing as my sighted neighbor using their computer toys.

Our participants rejected supercilious comments about their devices because they patronized what participants felt was their ability to do just as anyone else. Thus, the perspective that assistive devices were “wonderful” and could make people with disabilities “normal” was a charitable view on assistive technology use, and was not accurate or realistic. The two most commonly reported misperceptions by others about assistive technologies were that (1) assistive technologies functionally eliminated a person’s disability (made them “normal”), and (2) that without an assistive technology, a person was helpless and could do nothing. The first misperception was rooted in ignorance about what assistive technologies do; the second was an assumption that the presence of an assistive technology meant a continual need for assistance.

Employment

Participants viewed assistive technologies as a means to an end in employment situations. As important as having access and the ability to work was the *perception* on the part of others that participants had the ability to get a job done. For example, P4’s employer, a small firm, was unaware of the technologies that would allow P4 access at work. Although she received a large monitor and JAWS software, her employer knew little about what might help her access print material with her sight nearly gone. In the end, she was demoted and given fewer responsibilities. P20 purchased his own assistive technology for work, and negotiated office interactions in new ways as a result:

...you have to put your earphones on, so you don’t annoy everybody around... and I didn’t necessarily like ...being cut off from people. I like to sit in a room and hear what’s going on... you know, get a sense of what’s going on in... my team around me. And so that was my way of keeping track without being, you know, nosy. And so when I... was working with JAWS and had the earphones in, then I kind of felt a little cut off, and so that... took some getting used to.

Similarly, P14, who was deaf, found small workarounds so her vibrating pager would not attract unwanted attention at the office: “I finally got a mouse pad just to put the pager on so it *wouldn’t* vibrate all over the table and make a loud noise and have people look at me.” As an example of how choices affected work, P1 was hired for one job only when he described how he could get the job done:

In the individual interview, they asked me one question, ‘How you gonna do the paperwork and stuff we have?’ I says, ‘I got a Dell laptop that has screen reading software and if you can send it to me I can do it.’ The head of human resources says, ‘Well, you got the job, congratulations.’ I says, ‘What about the rest of the interview?’ He says, ‘You

⁵ <http://www.humanware.com>

don't need it. You impressed us at the group interview, so we only had one question for you.'

At one point, he opted to use the BrailleNote, but eventually abandoned it for his Dell. The BrailleNote's proprietary software was incompatible with his employer's software.

The most serious concerns were about losing jobs, not based on abilities, but on *perceptions* of disabilities by others. For these reasons, if they could, participants chose not to disclose their disabilities. P6 explains why she did not tell her employer she was losing her sight, and that technologies could alleviate the perceptions she feared:

I must admit, I kept it from them so they didn't know. ...because I didn't want to lose my job. Because I know this was back in the 80s, and I saw how the workplace was. The people with disabilities were often... let go for various reasons. So... I think if you look more mainstream, you look more able, then you're more likely ... to be employed.

The reported barriers to employment seemed to have little to do with participants' actual abilities. Incompatibility issues and negotiating new office norms added to the effort required to gain access at work. However, more serious misperceptions about ability and the unfamiliarity with assistive technologies significantly affected employment.

DISCUSSION

People with disabilities feel empowered when using their devices, but they are also aware of misperceptions others have about assistive technologies. These misperceptions may be inherent to social stereotypes about disabilities, but how are they influenced by assistive technologies? Some participants did not want to use white canes and hearing aids because the social stigma associated with these identified them as less capable. While they did not associate the same stereotypes with current electronic assistive devices, they acknowledged aesthetic and design issues distinguished their devices from mainstream devices with similar functionality. How does this affect access? We discuss here why we think electronic assistive technologies run the risk of perpetuating social barriers, and what we believe this means for assistive technology design.

Implications of Misperceptions

We found two common misperceptions of assistive technologies: (1) that assistive technologies functionally eliminate a disability, and (2) the presence of assistive technologies mean that people with disabilities are helpless without assistive technologies. Although our participants were not concerned that electronic assistive technologies marked them in the way white canes and hearing aids might, we believe these misperceptions are problematic because they incorrectly draw assumptions about the abilities of the people who use them.

Misperceptions about Ability

Several participants were concerned about appearing unable to use their technologies; they did not want to contribute to

misperceptions that they were not capable. For example, some assistive technologies had steep learning curves or required special training. Although participants patiently learned to use their technologies, as we saw in issues with help, they were concerned that making mistakes would make them appear less capable. Appearing incompetent might perpetuate the misperception that people with disabilities were unable to do things for themselves.

Misperceptions about Mainstream Technologies

Misperceptions also support stereotypes that people with disabilities cannot use mainstream technologies due to disability. We recall P2 mentioned, "if someone's using an iPhone, and I'm using an iPhone, that's normal, right? It's the same thing." This implies a special, proprietary cell phone indicates the *person* using it is not normal. In turn, it implies that person's disability precludes them from using mainstream phones like everyone else. But, if a person cannot use a device because the device is inaccessible, and not necessarily because of the person's disability, this becomes an unfair and inaccurate misperception. P10 explains why device appeal is important for social perception:

I'm a person. Not... you know? That's why I like to see things a little more attractive, compact... where people might not notice them as much. So that they treat it ... like anybody else's toys.

Misperceptions imply an ambiguous social construct. As we have seen, electronic assistive technologies are relatively unknown to many people. Despite the fact that our participants felt enabled by the technologies they used, ambiguous social constructs gave way to supercilious and patronizing misunderstandings on the part of others of what assistive technologies do. We contrast this misperception with evidence that two of our blind and low-vision participants used the iPhone, an example of mainstream technologies usable by people with disabilities because of its accessibility features. Given this, misperceptions about assistive technologies may run the risk of marking people with disabilities by implying an inability to use comparable, mainstream technologies.

A Case for Mainstream Accessibility

The misperceptions reported in this study appear to do little to assuage common stereotypes, and may perpetuate them instead. We believe this means social misperceptions hinder true access. Ideally, there would be no misperceptions of disability, and stereotypes of people with disabilities would be that they are technically savvy and employable. Yet, this is not so. And while we may not be able change social misperceptions of disability, perhaps we can design technologies to alleviate such misperceptions by making mainstream technologies more accessible, or proprietary technologies more socially acceptable. *Design for social acceptance* could be a new design approach that goes beyond functionality and usability to prioritize the social

contexts in which assistive technologies are used, thereby avoiding the creation of designs that mark or stigmatize.

Functional differences between assistive technologies and their mainstream counterparts influenced misperceptions. For example, when participants described assistive devices using mainstream terminology, such as “iPod-like” or “iPod-esque,” it illuminated differences. Why is a device iPod-like, but not an iPod? Whether functional or perceived, inequalities perpetuated the notion that assistive technologies are built only for people with disabilities because they cannot use mainstream devices. In addition, both functional and perceived differences do nothing to indicate what abilities people with disabilities *have*.



Figure 3. P1's BookSense digital MP3 player.

We do not believe this means all devices and services must be mainstream technologies. The Victor Reader Stream was a popular device among participants, partly because of the free downloadable book service offered by the National Library Service (NLS) [1]. Still, P1 preferred to use the smaller BookSense⁶ (Figure 3), as he describes here: “Half the size of the Victor Stream ... But this is like, cool. See I like this 'cause I can put this in a coat pocket... on a bus if I'm going a long way somewhere.” The BookSense is a proprietary device and P1 still used the NLS for free books to load on his device. While both the BookSense and the Victor Reader have phone keypads, in almost all other ways, the BookSense is aesthetically more appealing. P1's preference for the BookSense demonstrates that the proprietary nature of a device does not mean it should not have a better design. Therefore, the social acceptability of assistive device design should not be overlooked.

Limitations

Due to random recruitment, this study lacks representation from people other than those with sensory disabilities. We took pains to combat this by paying careful attention to the concepts that arose through each interview using the

grounded theory approach. However, we recognize the importance of appropriate sampling. Therefore, future work will include more interviews or surveys to compare concepts for people with other disabilities. We also did not examine perspectives of non-disabled people who witness the use of assistive devices. What do they think of these devices, and how are their perceptions shaped? We consider this an equally important perspective, but this study's goals were to focus on what people with disabilities thought about social interactions around their devices. Another interview study of a non-disabled population to find out their perceptions would address this limitation.

FUTURE WORK

We believe more socially acceptable design might draw less unnecessary attention and change misperceptions about assistive devices. If “strange looking” devices mark a person as being disabled, perhaps socially acceptable, “cool” devices would indicate a person is capable of as much as everyone else. As Pullin emphasizes, addressing creative tensions between function and “fashion” in assistive technology may support “positive images of disability” [21]. Therefore, we plan to develop *design for social acceptance* (DSA), an approach considering not only functionality and usability, but perception, misperception, stigma, affect, and aesthetics to maximize a device's social acceptability. A three-part DSA methodology will help determine how to incorporate social inclusiveness through design, prototyping, and *in situ* study. First, analyzing differences between mainstream and proprietary devices with similar functioning will be done through mock-up prototypes embodying design differences of varying degrees, as done in prior work [8]. Evaluations by people with and without disabilities will empirically determine aspects of design contributing to different perceptions. Next, iterative prototyping with people with disabilities will evaluate systems on both traditional HCI metrics, such as time and usability [4], and on social-acceptability metrics, like appeal, familiarity, and identity-assessment. This part may involve modifying existing design practices, such as paper prototyping with blind participants. Lastly, prototypes will be tested *in situ*, over an extended period of time and in social spaces where reactions can be gauged. Longitudinal evaluation will determine how prototypes fare in socially situated situations.

CONCLUSION

In this study, we found that misperceptions rooted in differences between assistive and mainstream technologies led to socially constructed ambiguities around a person's ability. To that end, we found two common misperceptions of assistive technologies. First, that assistive technologies eliminate a person's disability, making them functionally equivalent to a person with no disability. And second, that people with disabilities can do nothing without their devices. We believe these indicate assistive technologies do not bridge social misperceptions of disability, and therefore may not meet their potential for enabling access. Design of

⁶ <http://www.gwmicro.com/Booksense/>

assistive technology, whether proprietary or mainstream, should address not only function, usability, and cost, but also aesthetics and social acceptance. Furthermore, if people with disabilities use the same technology as everyone else, perceptions of what they can and cannot do may be re-aligned. After all, the technology now exists to provide them with this access, we should consider what this means for reducing stigma and changing perceptions. We introduced *design for social acceptance* as one possibility for combating this tendency. We end with a quote from P5, encapsulating social implications uncovered in this study:

*Well, it's difficult being a disabled person in this society, and people are...not kind. But you get this sense of- there's something wrong with me, people don't like me, I'm unappealing, I look pathetic, I look un-sexy, you know, whatever it is. And, people are staring at me, and they are. I'm not making this up. I'm not paranoid. I mean, they are! And, it's because they wonder what that is (points to device). They haven't seen that before. They want to know what's up with the person using it...I don't want to look helpless, I don't want to look pathetic, or something... so it took me a long time to...now I think I can just do it without really worrying about it at all, but what I had to do at first—this was many years of work—but what I had to do at first was cultivate this sort of 'f*** you' attitude, you know?*

ACKNOWLEDGMENTS

Thanks to Michael Lee, Shaun K. Kane, Parmit K. Chilana, Eun Kyoung Choe, and Batya Friedman. This work was supported in part by Intel and by National Science Foundation grant IIS-0952786.

REFERENCES

- National Library Service for the Blind and Physically Handicapped. <http://www.loc.gov/nls/>. September 2010.
- Bispo, R. and Branco, R. (2008). Designing out stigma: the role of objects in the construction of disabled people's identity. *Dare to Desire: 6th Int'l Design & Emotion Conf.* Hong Kong.
- Bispo, R. and Branco, V. (2009). Designing out stigma: the potential of contradictory symbolic imagery. *Proc. Include 2009*. London.
- Card, S. K., Moran, T. P. and Newell, A. (1983). *The Psychology of Human-Computer Interaction*. Lawrence Erlbaum Associates, Hillsdale, NJ.
- Charlton, J. I. (1998). *Nothing about us without us: disability oppression and empowerment*. Univ. of California Press, Berkeley, CA.
- Cook, A. M. and Hussey, S. M. (2002). *Assistive Technologies: Principles and Practice*. Second Ed. Mosby, Inc., St. Louis, MO.
- Csikszentmihalyi, M. and Rochberg-Halton, E. (1981). *The meaning of things*. Cambridge Univ. Press, NY.
- Denning, T., Borning, A., Friedman, B., Gill, B. T., Kohno, T. and Maisel, W. H. (2010). Patients, pacemakers, and implantable defibrillators: human values and security for wireless implantable medical devices. *Proc. CHI '10*. Atlanta, GA, ACM, 917-926.
- Dijksterhuis, A. and Nordgren, L. F. (2006). A theory of unconscious thought. *Persp. on Psych. Sci.* 1 (2), 95-109.
- Edwards, A. D. N. (1995). *Extra-Ordinary Human-Computer Interaction: Interfaces for Users with Disabilities*. Univ. of Cambridge Press, Cambridge.
- Elliott, G. C., Ziegler, H. L., Altman, B. M. and Scott, D. R. (1982). Understanding stigma. *Deviant Behavior*. 3 (3), 275-300.
- Fine, M. and Asch, A. (1988). Disability Beyond Stigma: Social Interaction, Discrimination, and Activism. *Journal of Social Issues*. 44 (1), 3-21.
- Glaser, B. G. and Strauss, A. L. (1967). *The Discovery of Grounded Theory*. Aldine Publishing Co, Chicago, IL.
- Goffman, E. (1959). *The presentation of self in everyday life*. Doubleday, Garden City, NY.
- Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Prentice-Hall, Englewood Cliffs, NJ.
- Gray, D. B., Quatrano, L. A. and Lieberman, M. L. (1998). *Designing and using assistive technology: the human perspective*. P.H. Brookes Pub. Co., Baltimore.
- Jacobson, S. (2010). Overcoming Stigma Associated with Assistive Devices. *7th Int'l Conf. on Design and Emotion*. Chicago, IL.,
- Pape, T. L.-B., Kim, J. and Weiner, B. (2002). The shaping of individual meanings assigned to assistive technology: a review of personal factors. *Disability and Rehabilitation*. 24 (1/2/3), 5-20.
- Parette, P. and Scherer, M. (2004). Assistive Technology Use and Stigma. *Education and Training in Developmental Disabilities*. 39 (3), 217-226.
- Phillips, B. and Zhao, H. (1993). Predictors of assistive technology abandonment. *Assistive technology: the official journal of RESNA*. 5 (1), 36-45.
- Pullin, G. (2009). *Design meets disability*. MIT Press, Cambridge, MA.
- Riemer-Reiss, M. L. and Wacker, R. R. (2000). Factors Associated with Assistive Technology Discontinuance Among Individuals with Disabilities. *Journal of Rehabilitation*. 66 (3), 44-50.
- Scherer, M. J. (1993). *Living in the state of stuck: how technologies affect the lives of people with disabilities*. Brookline Books, Cambridge, MA.
- Shinohara, K. and Tenenberg, J. (2009). A blind person's interactions with technology. *Comm. ACM*. 52 (8), 58-66.
- Strauss, A. L. and Corbin, J. M. (1998). *Basics of qualitative research*. Sage Publications, Thousand Oaks, CA.