"I can do everything but see!" – How People with Vision Impairments Negotiate their Abilities in Social Contexts

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ABSTRACT

This research takes an orientation to visual impairment (VI) that does not regard it as fixed or determined alone in or through the body. Instead, we consider (dis)ability as produced through interactions with the environment and configured by the people and technology within it. Specifically, we explore how abilities become negotiated through video ethnography with six VI athletes and spectators during the Rio 2016 Paralympics. We use generated in-depth examples to identify how technology can be a meaningful part of ability negotiations, emphasizing how these embed into the social interactions and lives of people with VI. In contrast to treating technology as a solution to a 'sensory deficit', we understand it to support the triangulation process of sense-making through provision of appropriate additional information. Further, we suggest that technology should not try and replace human assistance, but instead enable people with VI to better identify and interact with other people in-situ.

Author Keywords

Ability; vision impairment; blindness; accessibility; assistive technology; social technology; collaboration; ethnography.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Vision impairment (VI) is often defined as a functional limitation of the eyes or vision system, indicating the extent of vision that cannot be corrected to a 'normal' level [16]. Much existing HCI accessibility research has focused on assisting people with VI to circumvent visual problems, to adapt to a world that assumes vision, and to carry out daily activities more independently [i.e. 14, 25, 38]. Our research takes a different orientation to VI that builds on a definition by the World Health Organization [60], describing disability as "a

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complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives". This recognizes disability as something that is not fixed or manifested alone through the body (e.g., an impaired sense), but created through interactions between a person and their environment. In line with the "social model" of disability [39, 45], this orientation places the responsibility of addressing disability on everyone collectively [cf. 9, 10], including technology designers.

To build an understanding of the interactions that create disability, we draw on work by Ingunn Moser [37], who describes how disability is configured through the social and material environment. It is through a person's continuous interactions within the social and material world that ability or disability is constructed [cf. 23]. As a result, ability or "disability is not something a person is, but something a person becomes" [37, p.668]. For example, whether a person is more or less able to climb a mountain may not only be determined by bodily fitness, but by how they interact with the physical world (using e.g. ladders, climbing tools or GPS devices) and other people, who may offer help in critical moments. By understanding how such situated negotiations occur, our interests lie not just in overcoming bodily limits or disabilities, but in extending ability, or enlarging capability.

Our research therefore seeks to provide insights into how people with VI build an understanding of, and construct their own abilities in interaction with, different contexts. To this end, we present ethnographic video research capturing the experiences of two Paralympic athletes and four spectators with VI who attended the Rio 2016 Paralympic games. The Paralympics exposes VI spectators and athletes to new experiences whilst travelling to and engaging in activities surrounding the event. These can present challenges to how they construct their abilities in different situations, and thus, can make processes of ability negotiation more visible. At the same time, the event is an inspiring one for many, drawing attention to the multiple ways people exhibit abilities and capabilities. Our research aims to identify how technology can assist in negotiations of ability and serve to extend capability.

Our findings contribute examples that describe in rich detail how people with varying types of VI build an understanding of different contexts. We demonstrate how abilities are negotiated through fluid, continuous processes and interactions in the world. The examples present a rich and complex picture that highlights: the importance of information access and triangulation in sense-making; how ability negotiations are often accomplished with, and through, other people; and how ability is bound up with interpersonal relationships and social experiences. We discuss these findings and present design sensitivities for extending the capabilities of people with VI.

We begin by describing how our research builds on other work and recent shifts in assistive technology (AT) towards a stronger focus on the social interactions and experiences of people with VI, beyond any individual or functional uses.

RELATED WORK: DESIGN TO ASSIST PEOPLE WITH VI

The majority of existing AT seeks to support people with VI to carry out everyday activities independently. Examples include systems to support spatial awareness and navigation [12, 13, 21, 22, 26, 62], to aid the identification of specific objects or their characteristics [5, 14, 15], to assist the detection and identification of text [17], barcodes [31], signs [18, 51], or currency [32], and help with handwriting [43]. For digital user interfaces, there are numerous applications for the input and recognition of Braille on touchscreens [3, 27, 34, 52], and alternatives for text-entry or navigating digital menus [7, 38, 24, 25, 63]. These technologies have been oriented towards assisting practical, well-defined functional tasks that are often treated in isolation from the wider social contexts in which they occur. Only a few examples extend the relationship with a system beyond an individual user, to include i.e. social support through a crowd [5, 8, 15], or with a teacher [43], family and friends [34].

In recent years, we have started to witness a shift in focus from the design of tools to assist the independent, often mechanistic fulfillment of pragmatic needs towards research that gives greater consideration to how people with VI are inter-connected with others [i.e. 20, 53, 57, 65]. Next, we discuss three areas of early work in this particular space: *design for richer social experiences, social acceptability of AT*, and *socially co-constructed accessibility practices*.

Design for Richer Social Experiences

Progressively, AT design is targeted at enabling richer social experiences for people with VI by assisting them, for example, in the capture of quality photos to make photography more appealing [56]; and to help them preserve memories, express creativity, and socialize [28]. Recent research by Wu et al. [61] further shows how a system that automatically integrates accessible alt-text information with Facebook photos allowed blind participants to feel more included and engaged with conversation around photos; and thereby supported their ability to interact with their social network more fully. Still, far more research in this space is needed.

Social Acceptability of Assistive Technology

Exploring reasons for a frequent abandoning of AT use [cf. 47], Shinohara and Wobbrock [49], for example, explored perceptions of social acceptability and stigma associated with AT use. They found that many specialized devices drew unwanted attention, thereby marking people out as 'different' or 'less able' and reinforcing stereotypes of disability.

This is especially salient for interactions in public spaces, and has been echoed in other research [1, 2, 30, 41, 44, 53]. Recent work [50] extends descriptions of how the form and uses of AT are observable and perceived by others, and thus affect whether people with sensory disabilities feel self-conscious or self-confident using AT. It proposes that AT design be understood not only as creating a functional aid, but also consider peoples' social needs and what is conveyed about their ability and social identity through their interactions in the world. Some users and designers of AT suggest how a strong aesthetic style of the device can become a creative expression of self, promoting pride in AT use [4, 45]. Much of this research suggests that to achieve a socially more acceptable design, we need to develop a better understanding of how people with VI negotiate their abilities in 'social contexts' and through unfolding relations.

Socially Co-Constructed Accessibility Practices

Taking on this 'relational' view, a small number of works explore how people with different visual abilities collaborate to co-create more accessible environments [i.e. 9, 10, 55, 58].

Branham and Kane [9] for instance interviewed people with VI and their sighted partners to understand how they jointly constructed accessibility in their homes. They describe this as a dynamic process that involves configuring objects or activities in predictable ways; spatially organizing and adding tactile markings to items; or rehearsing routines. For primarily sighted office contexts, the authors [10] further describe how VI employees experience difficulty collaborating with others in a meeting whilst having to listen to a screen reader. They describe how involving others as assistants was carefully negotiated, describing concerns that work colleagues may perceive a blind person as needy rather than competent [10]; and how creating shared, accessible experiences between partners at home [9] serves not only practical means, but is entangled with inter-personal intimacies. Together these qualities of interaction begin to foreground the relevance of social and material aspects of accessibility and, ultimately, ability.

In the context of navigation, Williams et al. [58] studied how sighted people provided verbal guidance to those with VI. They found that sighted people are often unaware of the type of information that is helpful, which created complications. For example, sighted people often warned VI people of obstacles to avoid, such as a curb or parked vehicle. However, when tapped with a cane, the presence of these 'obstacles' served as helpful physical cues for orientation. The work shows how navigation is often a social activity, yet its focus remains on accurate, safe wayfinding rather than wider social experiences bound up with seemingly more functional tasks.

Extending prior research that considers aspects of the social and material context for accessibility, technology use and experience, we explore (i) how people with VI negotiate their abilities with, and through, others; (ii) how this is entangled with their relationships; and (iii) how technology can be part of such negotiations and serve to extend capabilities.

Name	Age	Gender	Paralympics	Information a	bout their vision	Mobility aid	AT use
Tim	26	M	Professional	Low vision	Little central vision, no color vision, difficulty to see in	/	/
			athlete		dark; sight deterioration since birth (macular dystrophy).		
Sally	26	F	Professional	Low vision	No central vision, very limited peripheral vision in left	Guide dog	/
			athlete		eye; sight deterioration since birth (macular dystrophy).	(at home)	<u>'</u>
Jerry	26	M	Spectator	Blind	Little light perception, some short-distance vision in his	Cane	Voice over + screen
					right eye; severe vision loss at age 19.		reader software
Amy	21	F	Spectator	Blind	Light perception in right eye, low peripheral vision in left	Cane + guide dog	Voice over + screen
					eye; sight deterioration since birth (retina dysfunction).	(at home)	reader software
Aaron	21	M	Spectator	Low vision	Can read text if held close to his eyes or magnified.	/	Pocket magnifier
Pia	25	F	Spectator	Blind	Little central but no peripheral vision; sight deterioration	Cane	Voice over + screen
					since birth (retina dysfunction).		reader software

Table 1. Participant information including their age, gender, vision, mobility aids, and AT use (all names are pseudonyms).

OBSERVATIONAL FIELDWORK

To gain a better understanding of how technology can assist in extending the capabilities of people with VI, we conducted a video ethnography to explore how they manage and negotiate their abilities within different situations. As a team of four researchers with mixed backgrounds in HCI, Design and Disability Studies, we travelled for one week to the Rio 2016 Paralympics. One of the researchers is blind and thus had relevant overlapping experiences. Accompanied by an ethnographic filmmaker, we joined the activities of two Paralympic athletes and four spectators with VI as they travelled, attended events, visited restaurants, and went sight-seeing.

Participants

Time was spent with six participants, in total. Tim and Sally, a couple, both have low vision and are active in their sports. They both competed in the London 2012 Paralympic games, and Sally also qualified for Rio. We connected with Tim through a university program with a Paralympic themeⁱ. Tim put us in touch with Sally, who joined our field research in Rio after she had finished competing. Four VI spectators, all friends, were also involved in the study. We met Jerry (our main contact), through his involvement in a local charity for the blind. He had long planned travelling to the Paralympics with partner Amy, and their friends Pia and partner Aaron. All of them are active players and fans of Goalball – a team sport specific to VI. Jerry, Amy and Pia have only very little vision, whereas Aaron can read text if held close or magnified. Table 1 provides additional details.

Captured Research Material

Our research was captured in video by an ethnographic film maker, and in photos and field notes taken by the researchers. Across seven days, we filmed in total 35 hours of activities. Most of this time involved Tim (26 hours, across six days). On three of these days Sally joined us; and we spent one full day (9 hours) with the four friends as they went sight-seeing, visited restaurants and attended the Goalball finals. Video was chosen as the predominant tool to collect and preserve relevant features in a naturalistic way, and to produce short films to help communicate key scenarios and the nuance of experiences, from which to build new technologies.

Throughout our engagements, we were mindful that both our own involvement as participant-observers and the shooting of video were potential sources of bias. However, our presence was broadly seen to compliment our approach that mixed shadowing and interacting with participants [33]. The camera and the perspectives chosen for the video became an integral part of the social activity of interest and our analysis [35]. Having awareness of the camera meant, for example, that our participants at times displayed behaviors to it—most apparent in them giving running commentaries. Interleaved with our occasional requests for clarifications of motivations or actions, the presence of the video and recording equipment provided rich snapshots into sense-making processes.

Lastly, we must acknowledge that not all of the phenomena that we captured occurred naturally. For example, the researchers organised the sight-seeing events and orchestrated some situations that may not have taken place in the same way, if we had been absent. For instance, on occasion, we explicitly asked participants to choose a restaurant for lunch, or to self-organise travel using public transport rather than arranging a private driver.

Analysis of the Research Material

Captured video footage was edited to include key scenarios and conversations of interest that represented both breadth and depth across the different activities and participants. This was achieved through a joint, on-going review of the footage by the ethnographer and members of the research team; a process that provided a rich and detailed means to re-engage with the material and social interactions that were observed in the different contexts [6, 42]. To further assist in the identification of patterns in the research material, we followed a Thematic Analysis approach [11]. To this end, one of the researchers systematically reviewed the edited video, attaching descriptive labels to individual scenes at first, which were then developed into codes and overarching themes. As the analysis progressed, these were reviewed and adapted in discussions with three additional researchers with combined backgrounds in HCI, Sociology, Disability Studies, and personal experiences with vision impairment.

Our joint analysis revealed a nuanced and socially complex picture of how participants manage different situations. To illustrate this, our findings present detailed examples demonstrating approaches of how sense-making and effective participation are enabled or hindered in various contexts.

FINDINGS: HOW PEOPLE WITH VI NEGOTIATE ABILITY

Our findings are organized into three sections summarizing key observations of how participants negotiate their ability. Jointly, they reveal a socially complex picture that shows how ability negotiations present a fluid, continuous process that often involves other people. They show how participants (i) employ *mechanisms of triangulation* that include social cues to build an understanding of their surroundings, (ii) how they *convey ability*, and *negotiate it through others*, and how this relates to self and social experiences; and (iii) how they negotiate *assistance from other people*, which reveals misperceptions of their abilities by others, and how providing assistance can be entangled with their social relationships. Whilst presented in three individual sections, the approaches described in each section are often found to be intertwined or shifting between one another.

Triangulation: Material & Social Interactions as Resource

As a research methodology, the term triangulation is broadly defined as "the combination of methodologies in the study of the same phenomenon" [19, p.291]. In integrating data collected through different methods, judgements made on the phenomenon can be more accurate and enhance credibility that the results are valid [29], or deepen and widen one's understanding about a phenomenon through use of multiple methods [36, 40]. In cross-checking different information sources that lead to the same result, the idea is that one can be more confident with an interpretation. As such, we take up this sense-making method to show how our participants gather and enact information from multiple sources.

We demonstrate how triangulation is particularly salient, but not always full-proof for our VI participants as resources are inaccessible or insufficient. Describing two examples in detail, we show how participants build on multiple senses, and material and social interactions to formulate assumptions about the world; and how these are tested, confirmed, or revisited through a triangulation with additional information. The first example depicts the seeking and integration of material cues, and related challenges for triangulation. The second shows how dialogue assists in sense-making.

Multiple Senses & Information Resources

Tim has only little central vision and no color vision. In this example, we describe how Tim navigates a UK airport; how he gains information and deepens his understanding of the space; and also how misjudgments – due to insufficient triangulation – lead to disorientation and frustration:

Following security clearance, Tim has 30 minutes to locate his departure gate. Using the vision he has, Tim identifies one of the large, bright, high-contrast airport signs that hang just above the level of his head. Having difficulty reading it, he stops to activate the camera on his iPhone, points it towards the sign and uses the zoom to magnify its text and symbols. An arrow next to 'Gate A18' directs Tim to keep moving forward. Here, the phone serves to augment his vision, and thereby allows him to gather directional information. Despite this information, Tim opts to approach a person with a

bright yellow safety-vest (indicating his potential role as airport staff). Tim asks the man: "Excuse me, what gate is this one?". Standing next to an open seating space that is enclosed by retail stores, and with nothing to indicate Tim's visual impairment, the staff member responds confused: "This isn't a gate." Rephrasing his question Tim asks: "Alright, where's A18?" and receives instructions to "Hang on straight and it should just be there". This confirms Tim is going in the right direction. Thus, asking the staff for help, and building on that person's visual abilities and potential expertise of the airport, aids his understanding of the space.

As Tim keeps walking through the airport, he explains how the patterned floor makes it difficult for him to distinguish people: "People might just think I'm rude and that I'm walking at them, but I'm not just walking at them, I'm just a bit confused trying to work out what's floor and what's person, at the moment." At each step Tim carefully attends to the movements of other people to identify and avoid accidentally walking into them. Again absent of a signifier of his visual impairment, like a cane, all the work that Tim puts into this process remains invisible to others, putting him at risk of being perceived as 'rude' if walking to close to them.

Soon, Tim stops and again uses his phone to read signs. One sign points to gates A13 and A14; another shows an information icon. Neither offers Tim the information he is looking for. As a high-table comes into his view, Tim takes a left turn and walks towards what he assumes to be a help desk. Moving closer, he finds silhouettes of people working on laptops instead, and also finds himself in a cul-de-sac. Having misjudged the situation, he turns around and expresses slight frustration: "This turns out to be a bit of a nightmare". Returning to the main path, the next sign points to gate A18 as straight ahead. Finally arrived, Tim admits: "It took 20 minutes longer than it should have, but there you go". Thus, while Tim is able to reach his destination, it shows how having to constantly collect and check for information, that is not vision centric, is effortful and time-consuming.

This suggests that, despite frustrating, continuous access to relevant information resources can assist in the formation and validation of assumptions about the surroundings, and thus, a person's ability to act upon these more confidently.

Collective Triangulation: Social Cues & Dialogue

In the above example, Tim's consultation with the (sighted) staff member helps to inform his understanding of the terminal. Our second example shows how Jerry and Amy, who are both blind, locate a seat to have coffee together. It foregrounds how different methods of dialogue – social and material interactions – become integrated into sense-making processes and aid an understanding of the physical space:

With a cup of coffee and a cane in either hand, Jerry and Amy step outside a coffee shop. Jointly they walk towards what they assume is an area with tables and chairs. Side by side, they tentatively move forward. Using her cane as a pointer, Amy asks: "Is there chairs in front of us?". Jerry

confirms visually: "Yeah there is, but I don't know if there's people or not." Continuing her path, Amy's cane now hits a chair. Tapping against its metal legs, she affirms: "That's a chair!". Still trying to make out whether there are people, Jerry takes slow steps, adding playful commentary to his every move: "Oh wait, wait. I'm edging ever so closer, bit by bit". Amy giggles. Now sat down she counters proudly: "I've got a chair, don't know about you guys." Sensing the edge of the table, Jerry confesses: "I still can't make out people.". Putting his coffee down, he turns his head around once more to scan the surroundings. He concludes: "I think this seems like a reasonable place", and takes a seat.

This example of collective triangulation brings awareness to different methods of communication that are part of Jerry and Amy's sense-making processes. It captures a rich interplay of material cues, such as Amy's tapping against the chair, with joint movements and conversation. By verbally sharing individual assumptions gained during their step-by-step discovery of the space, the couple build up a fuller picture of the surroundings for, and through, each other. This shows how social interactions, which are often disregarded in assistive technology design for people with VI, can support information gathering and triangulation, and extend their understanding of a space, and others in it.

Ability as Socially Performed & Collectively Negotiated

All our participants present and describe themselves as very able people. To negotiate their abilities and maintain a sense of independence however can be an effortful process. This is shown in the airport example with Tim, where he is, amongst others, carefully attending to people's movements to identify them against the patterned floor. In doing this, he displays his competence and ability to navigate the space. In this section, we illustrate how such demonstrations of ability do not only offer a functional process for achieving a particular task, such as locating a gate or empty seat, but are bound up with concerns of how a person's behavior is perceived by others or intervenes in a social context. We describe three examples of different participants performing their abilities in the presence of others, and how this is moderated by their perceptions of 'social norms'. At first, we present two examples of different meal times with Tim; then, we detail a sight-seeing activity Jerry participated in with his friends.

Wanting to 'fit in' to a World Made for Sighted People

For Tim, coming to terms with his continuing sight loss presents perhaps his biggest struggle. He describes himself as very able, wanting to do things by himself, and having 'sort of always tried to fit in'. To realize that one may not be able to do certain activities anymore is a common issue for many people with VI and often means a perceived loss of independence. Describing his struggles, Tim says: "I think I'm sort of starting to lose independence, but I'm really not, I'm clinging onto it as tightly as I can. I think one day I will have to sort of just like suppress all these stereotypes myself and start thinking about having to use either a cane or dog, even if it is just for the symbol. (...) There is a lot of people out

there, a lot less disabled than me, who are a lot less able than me. And I just like being able, I like trying my best getting around." For Tim, to be able and be perceived as able by others presents a constant issue of concern. His personal perceptions of 'social norms' and desires to conform to those, mean that, throughout our time together, he often tries to keep his disability hidden. The next example shows how this influences how he negotiates his abilities, and justifies the choices he makes in the presence of others.

--- Example 1: Tim Accounting for his Choices to Others

On our first morning in Rio, we have breakfast in the hotel. The breakfast room is not very well lit, making it appear as 'obscenely dark' to Tim, who's pupils do not dilate easily. Making his way tentatively towards the buffet, Tim picks up a plate and notices the warmth radiating from a stand with hot food containers. Opening the lid of a container to his right, he describes: "This is literally a massive issue now, 'cause this could be anything to me. It smells like bacon. I don't feel like eating any red meat today." He picks up a text label to one side of the next container. Unaware he is holding it upside down, he remarks: "I know this is sort of quite big [the letters], personally, I cannot make that out. I can't even see which way this is meant to go to be honest. Could be in any language; it's a bit hard work at times."

In principle, Tim could use his phone to enlarge the text to work out the various foods on offer. Yet, gathering such information comes at a cost. Pragmatically, in this context, it would take time and effort to 'zoom in' on all items. Socially, Tim may also not want to be perceived by others as different as he inspects the buffet with his phone. Lifting the lid of the next hot food container, Tim notices: "Ah, tomatoes [He takes two]. So at this point, I literally just, every time I open these [the containers] I just smell what's in there mainly. I could be completely wrong. Gonna try and be quite healthy today." As he reaches the last container, Tim is surprised: "That smells sweet, is that a waffle? Alright, ok. I'm not going to be healthy today, I changed my mind." Using tongs, he reaches for a waffle: "Depth-perception don't fail me now." In this last comment, we begin to see how perceptions of ability are always present as a concern, and as something that is at stake for Tim. In this moment, he shows awareness of the limitations of the vision he has and is keen to not embarrass himself picking up the waffle.

Back at the table, Tim reflects on how his food choice appears to the research team: "I know it's just a really strange combination of tomatoes and waffle". While his food choice could be regarded as a consequence of the sequential order of the buffet that may have suggested these items, Tim feels obligated to justify his actions by expressing their liking. On this morning, and likely emphasized in front of the camera, Tim is maintaining an impression of being able that aligns his behavior more closely with his perception of the norm. Later in the week, as Tim continued to discover the richness of the buffet, he admits that struggles to see in this space and his initial unfamiliarity with the buffet meant he did not want

to spend too much time looking around, which led to his seemingly odd choice of tomato and waffles.

The above shows how, despite the availability of his phone and thereby functionality to extend his understanding of the space, Tim does not employ this technology. Here, uses of the phone in negotiations of ability are at odds with desires to be perceived as competent, independently able, and what he construes as 'normal'. Our second example extends these observations to show not only how a person's negotiations of ability may be perceived by themselves and others, but also, how these actions, in turn, shape the social context in which they are situated. We show how certain mechanisms might be avoided so as not to disrupt the rhythm of a group.

--- Example 2: Not Wanting to Disrupt the Group Rhythm Leaving Copacabana beach, Tim leads the way in locating a place for lunch. He stops at the first beach bar and jokes to Sally: "Here we are, that will do. I can smell chips. That smells quite nice." Moving towards a large food menu board (Figure 1 left), he briefly takes a look at the menu, then turns back to Sally and the research team: "That's like tiny writing.", and suggests going in. Sat down, everyone starts browsing the food menus on the table. While Tim did not take his phone out to read the large food board earlier, both he and Sally are now using the camera zoom on their phones to magnify the various pages of the menu (Figure 1 right).

Ostensibly, Tim has the same technology available for the 'task of reading a food menu', yet he chooses to use it in one instance and not the other. We believe it's differences in the social dynamics in each context that moderate his choice. In social contexts, timing and the flow of social activities matter. For Tim, to read all the small print on the food board would take a long time to accomplish, risking inconvenience to others, who would have to wait. Thus, although in possession of technology that could help, Tim may choose not to use it to avoid potentially disrupting the group. Further, to be using his phone to enlarge the food board could again be perceived as unusual behavior and risk marking him out as 'less able'. Yet, when the group is at the table, the social situation shifts. With everyone engaged in reading the menu, Tim's effort to read it is now aligned with the group. While 'using a phone to read' may be perceived as unusual, here, this may be socially more acceptable than not reading the menu at all, whilst others do.

This example shows how fluid shifts in configurations of the context can alter perceptions of what is considered socially acceptable behavior; and how concerns for maintaining the flows and rhythms of a social group shape how sense-making strategies, including technology use, are applied.

Being More Accepting of one's Condition & 'Rolling with it' A desire to be perceived as able is also present in the interactions we observe of Jerry and his friends, even though they seem less concerned with how their regular use of touch is perceived by others.





Figure 1. Left: Tim approaching large food bard; Right: Tim using his phone to enlarge the text for reading the table menu.

Since rapidly losing his sight at age 19, Jerry has come to terms with his changed experience of the world - he often speaks of 'just rolling with it'. He has a very active social life as a player and coach of Goalball, and is involved with the blind community, which has enabled him to meet with other VI people and form close friendships. Partner Amy and friend Pia describe how, growing up with support from the blind community, has encouraged acceptance of their own sight loss, and has meant that they now feel more at ease with it. The next example describes how the friends engage in a sight-seeing activity. It shows how their greater comfort with VI, even in the presence of other people, opens up the capacity to apply alternative mechanisms for experiencing and interacting with the world. Specifically, we show how touch and social exchanges feature strongly in their negotiations of ability, and how their collective engagement in sense-making is much enjoyed.

--- Example 3: Experiencing the World Differently "Together" Arriving at the iconic Christ de Redeemer (Figure 2 left) on a cloudy morning, Jerry points towards the statue: "Is that a christo? I can vaguely make out the shape, it's like a 'blob'." He remembers seeing it on TV when he was younger. For Amy, the light is too bright to make out any shape. Jerry suggests: "I can show you what he's like if you want [Taking the statue's pose], he's like this, I think." Using her hands to feel his body shape along the stretched out arms (Figure 2 right), Amy jokes: "Yeah, so it does look like he's been crucified"; Jerry clarifies: "But it doesn't look like he is in pain or anything. He looks like he's just chilling". While a touching of Jerry's body to depict the pose may be considered unusual behavior, it does not appear awkward but rather a taken for granted way for them to interact with each other.

Touch also featured in their explorations of the physical space. Discovering two bronze figure heads with their hands (Figure 3, left), Amy and Pia speculate about the looks of the people who commissioned and created the statue. Despite the many other tourists around, both appear very comfortable and enjoy exploring these figures through touch. Standing to either side of them, they ask us to take a photo, and hand us their canes so these do not feature in it. In this moment, they show concern about the capture of their canes, not wanting to unnecessarily draw attention to these mobility aids, and associated perceptions; and instead seek to foreground their sight-seeing discoveries and experiences.



Figure 2. Christ statue & Jerry posing for Amy as Christ.

Leaving the attraction, the friends discover a souvenir shop and closely gather around a stall with tote bags. Pulling the top bag towards him, Aaron, who has most sight, starts reading out its repeated writing: "I heart Rio. I heart Rio. I heart Rio". Jerry jokes: "Who is Rio?"; and Amy teases: "Read that one more time." The bags spark interest from the girls. Each picks one up. Pia wonders about the color of the bag in her hand. Turning to Aaron she asks: "What kind of blue is this?" to which he clarifies how the bag is not blue, but red: "Coca Cola red, with Coca Cola white on". Excitedly, Amy adds: "Oh! You like red!". Pia is thrilled about her find, and purchases it later. This shows how the friends build an understanding of the bags through jointly attending to material and social exchanges. Benefiting from Aaron's sight, or Jerry's memory of the statue, they complement and add to each other's sense-making abilities, and thereby achieve a richer picture of their surroundings. This suggests 'vision' as something that is enacted together.

The friends linger in the store for a while. They are particularly excited about small replica statues of the Christ made from its original stone, and take turns and their time in carefully feeling them (Figure 3, right). Continuing their discoveries, they weigh, tap and explore the different textures of bottle openers and candle holders. Jerry identifies a box with what he assumes are magnets. From the sound created by finger taps against the flat object wrapped in foil, he confirms to Amy: "See this one here, this is a magnet" and places it in her hands. Touching its even, cold surface, Amy notes how she can't feel what it says. Jerry hands her another, this time a 'feel-y' magnet – as he describes it. Through the foil she explores its tactile surface and makes out a heart shape at first, and then the letter 'I'. Excitedly she shares: "Uh! This one is 'I heart Rio' and the 'I' is the Christ I think. That's cool. I like that!". Meanwhile, Jerry has found another magnet. As he starts describing it to Amy, she quickly interrupts: "Wait, wait, no, no, let me guess!", eagerly wanting to figure it out herself.

In the abstract, one could construe the lengthy process involved in identifying different store items as a 'burdensome task'. Yet, it becomes clear from these observations how the joint discovery and passing of objects between the friends does not only assist their sense-making; it presents a pleasurable activity, something that they enjoy and want to make time for, and that is a significant part of their sight-seeing experience.





Figure 3. Touching of bronze heads & small statue replica.

This instance of the four friends engaged in sight-seeing highlights the different ways for encountering and experiencing a setting. While the behaviors recounted are potential markers of 'being different', touch offers a way of richly sensing the world, and thus, a powerful mechanism in their negotiations of ability. Further, amongst this group of friends who all have VI, this behavior is generally perceived as common, and thus considered as socially accepted. This echoes research by [20] and foregrounds how differences in audience – a community of predominantly VI members rather than sighted people – can moderate what behavior is considered appropriate. Finally, our example shows how the friends build up and extend their understanding of the surroundings through each other; and how this collective assistance extends beyond the functional, in that it interweaves with the social relations and experiences of the activity.

Negotiating Assistance From Others

As already alluded to in previous sections, we often observed how participants sought assistance from others, and how receiving help can be valuable and assist in negotiations of ability. In this final section, we draw further attention to how common (mis)perceptions of the abilities of people with VI, mostly by strangers, can affect whether provided assistance feels 'helpful' or 'disempowering'. Further, we provide accounts of how giving and receiving assistance does not need to be an explicit act or intervention, but can be quite implicit and gentle, and closely entangled with a person's social relationships and experiences.

(Mis)Perceptions of Abilities: What is Helpful Assistance? In the following, we depict three short instances that our participants told us about and that nicely capture common misperceptions by others, mostly strangers, of what kind of assistance to provide to people with VI; and how these instances of negotiations of assistance have been perceived.

We begin with an example provided by Jerry and his friends. They describe a two-hour journey, requiring four changes, to travel between their hotel in Rio and the Paralympic Park. Framing their experiences positively, they rave about the warmly offered and friendly help they received on their travels. Pia recounts: "We met such nice people everywhere. Like, when we come off the metro or we are just walking down the street, we would have to wait 10 seconds, not even that, and someone would be at the side, 'oh do you need help? where do you want to go?". However, there is also a downside to the assistance they receive. Describing their

search for the right bus, Pia shares: "And I think they thought they needed to take us all the way to the hotel. The bus is there, just show us.". Aaron adds: "Yeah, we nearly missed one bus, because they were being too nice.". While the friends are very appreciative of the pro-active, frequent and friendly offers of help, they encounter familiar difficulties in receiving appropriate assistance. In the situation they retell, they describe how people 'take over' for them, responding to an idea of their inabilities (e.g., to find the hotel, identify the bus, board transport, etc.). Diminished or disregarded are how they use their environments and sense-making practices to become able, and thus how help might be targeted at this.

Misconceptions of what people with VI may or may not be capable of, are even more pronounced in other stories. Pia and Amy for instance describe how others can respond on recognising their VI, by slowing down and increasing the volume of their speech, or often treating them as if they can not walk far, and need transport. This reflects views of VI that regard it as a 'uniform category of disability', appearing indistinct from impaired cognition, hearing or mobility. That this can feel humiliating is particularly apparent in an example Sally recounts from the airport: "They told me they'd gonna put me in a wheel chair, it was a bit degrading, I'm not going to lie, but you know, I could just not be bothered arguing with them in the end and just got into the chair and was like, 'Ok, that's what I gonna do', because they said they wouldn't give me assistance otherwise, they just did not understand." Sally's example powerfully illustrates how assisting people with a disability in crude and uniform ways risks disregarding existing skills and reinforcing stigmas; Sally (especially as a professional athletic sprinter) is more than capable of walking herself. Jerry underscores the need to break misconceptions of VI (dis)ability with his incredulous explanation: "I can do everything but see!".

In our last example, Pia raises an illustrative example to highlight how 'help' can be well intended but at the same time introduce further difficulties: "Or this thing when people hold doors open thinking they are helping you, but they don't say anything. You know there's a door there, you gonna try to open it and it's already open. 'Say something!'." Our participants also often spoke of their frustrations with peoples' inability to articulate and explain a situation; the default is to 'grab' and 'pull' a person in an effort to assist them. Here, we begin to see how situations could be improved with an attention to the collective sense-making between people. The challenge would seem to be that of not removing or reducing one's agency in or on the world, but enabling it, by providing meaningful contextual details such as: 'saying something'!

Jointly, these examples point to a need for more education and empathy about what it means to have a sensory impairment; as well as design opportunities to support the provision of social assistance by developing better communications.

Assistance as Belonging to & Being with Others

Finally, we highlight how providing assistance can be more implicit and gentle, and entangled with a person's social relationships and experiences. To illustrate this, we draw and extend on two previous examples from Jerry and Amy.

First, we revisit how the couple located free seats for coffee. Their assisting of each other in making sense of the surroundings has little resemblance to a 'functional operation of giving help'. Instead, their joint discovery of the space is more attuned in the way they move together step-by-step and respond to any difficulties or potential awkwardness in navigating the space with humor. In this instance, their mutual assistance appears as gentle and as something they are both comfortable and familiar with, and that has become an unremarkable part of their ways of *being together*. Their support for each other does not interrupt what they are doing, but is part of the activity, and their experience of it.

Similarly, when Jerry emulates the pose of the Christ statue for Amy, with his body, it does not only assist her understanding of the attraction, it presents an act of care, expressing a sensitivity to her ways of sense-making. Here, the assistance is again a reflection of their relationship; intertwined with a sense of connection to, and care for each other. It suggests that these kinds of social configurations of support present a desirable *inter-dependency* that can positively foster social experiences.

DISCUSSION: DESIGN TO EXTEND CAPABILITIES

Our findings reveal a nuanced, socially complex picture of how people with various types of VI fluidly and continuously negotiate their abilities to build up an understanding of, and partake in, different contexts. They show how, through social and material interactions with the world, participants extend their abilities. Next, we identify and discuss opportunities for technology to take a meaningful part in ability negotiations, with particular emphasis on how these can be embedded into the social interactions and lives of people with VI.

Triangulation: Afford Relevant Information Resources

Our examples demonstrate how participants skillfully gather information in the world to enable this sense-making process outside of normal vision. Further to Williams et al. [58], who describe some of the skills that blind people involve in detecting environmental cues through cane use, we detail a host of sensory strategies – feeling, smelling, listening to sounds created by, or magnifying material things. We demonstrate how these sense-making strategies and their interplay are central to negotiations of ability. Moreover, the examples show uses of many additional information sources: past experiences, social interactions, and technology uses.

Our findings illustrate how our participants triangulate these information sources, creating elaborate juxtapositions to formulate and test assumptions about their environment. Yet, we also described moments where sense-making processes broke down. This includes Tim wandering in the wrong direction at the airport and his semi-intentional breakfast

choice of tomatoes and waffle, or the four friends searching for the right bus to their hotel. These examples suggest that providing additional information could assist their awareness of the surroundings, and thereby extend their ability to travel more effectively, or to make more desirable food choices.

Examining how ability is negotiated in these contexts challenges existing approaches in the AT design space that continue to seek to either replicate a sense like vision [i.e. 61], or assist the individual to circumvent visual problems [i.e. 14, 25, 32, 38]. In line with Shinohara and Wobbrock [49], we argue that the focus of AT design should not be on technology becoming the 'primary source' of information, nor should it be the 'primary solution' to a 'sensory problem'. Instead, we pose that technology can be re-imagined as supporting triangulation processes through the provision of relevant information about the environment.

Refocus Technology to Assist Sense-making (not Vision) — Our examples illustrate a myriad of sense-making strategies that are employed by VI people to construct their abilities; and through this extend their capabilities. As highlighted by Williams et al. [58], any additional information provided must complement on-going sense-making processes, not disrupt them. Whilst a shift in orientation from replicating vision to sense-making presents a starting point in this direction, our findings have also pointed to considerations of the personal and social context as a key driver in how ability becomes negotiated. We unpack this in more detail next.

Adapt Information to the Person – In principle, technology use can ease many practical accessibility challenges involved in gathering contextual information to aid triangulation and sense-making. For example, computer vision can support the recognition of signs, objects, peoples' faces, or the layout of a space [14, 28, 46]. Yet, the challenge remains how to identify from all potentially available information about an environment what is relevant to the person's in-situ ability negotiations; and present it without significant disruption [cf. 58]. While previous research on ability-based design [59] highlights the need for systems to adapt to their user, the examples presented often describe singular notions of a person's needs and mechanisms for systems to adapt to a user's behavior and to be customizable to their physical and cognitive abilities. Yet, to develop adaptive systems for more complex, real-world situations suggests a widening of focus from 'modeling a user' or 'specific task' towards a much closer consideration of, and more nuanced system response to, the context-dependency of a person's (information) needs.

Adapt Information to the Social Context – Our findings illustrate how the strategies that become employed in negotiations of ability can vary depending on the social context in which interactions are situated. Tim's decision to use a phone to magnify text in one setting and not another is an especially useful example of this. Here, we find how desires to convey an image of ability to others, to display socially appropriate behaviors, and to fit into the context of a restaurant are key

drivers in his ability negotiations. This resonates with previous works [2, 20, 44, 49, 50] that emphasize how AT use is shaped by how device interactions become perceived by others. While this existing work has led to a notion of social accessibility for a given technology, our findings show how notions of social acceptability of AT are *continuously shifting* in different situations and for different people. This suggests for AT design to be more sensitive to how systems integrate with on-going (social) interactions. This could be improved through a stronger focus on more subtle ways to support information access in-situ and designing information notifications that are responsive to what people are doing, where.

Social Bridges: Support Assistance by People

Our findings illustrate a myriad of ways in which participants sought and received assistance from others, both explicitly and implicitly. Tim, for example, explicitly approaches an airport staff member to help direct him to his gate. More implicit provisions of assistance in ability negotiations are apparent in the interactions we observed of the four friends. Their attuned processes of physical and verbal exchanges allow them to build on each other's senses and assumptions about the world. Taking the souvenir shopping as an example, we show how such collective negotiations of ability enable them to gain a fuller sense of the shop items with, and through, each other; and how this extends their ability e.g., to make more desired purchases. The giving and receiving of help in these implicit processes of assistance exhibits a sensitivity that does not interrupt, but rather fosters a pleasure in their sight-seeing experiences. Our examples show how both these processes of seeking and receiving support from others, explicitly and more implicitly in on-going interactions, can assist in information gathering and triangulation; and as such present an important resource for ability negotiations.

This is somewhat echoed in assistive crowdsourcing systems such as VizWizii [5, 15], a service that allows people with VI to pose questions about a visual problem (captured through a photo) either to Mechanical Turkiii or peoples' wider social network on Facebook [8] (also see ethnographic work of coconstructed accessibility in the home [9] and at work [10]). However, outside routine environments in which access to information can be pre-configured or better planned for, the reaching out to other people for help becomes a different challenge for technology to support. We illustrate this in particular in the examples of Tim at the airport or the friends at the bus stop, where the identification of helpers in less constrained and more opportunistic. Recognizing the importance of other people in constituting a sense of a setting and what is happening, we suggest that technology should not try and replace human assistance, but instead enable people with VI to better identify and interact with others in-situ.

Aid Awareness of People in the Vicinity – Enabling people with VI to be more aware of people nearby can enable opportunities to engage with others and choice about who to approach for assistance. The literature suggests that people

have strong preferences about who they might ask for assistance, with many carefully considering the social costs that arise in asking for favors i.e. of friends or colleagues [10, 61]. Our examples too suggest that asking for assistance from those whose job it is to offer assistance, e.g. transportation staff, is often preferred. However, we also show differences in the kinds of support that is given. This is most apparent in help between friends, whose more intimate knowledge of each other means that their help is of a different kind and quality. Thus, the aim should not only be for AT design to create mere awareness of others in the vicinity, but to also be mindful of, and consider creating opportunities for, a VI person's personal preferences in identifying who might be most suited to offer them the kind of assistance they want.

Support Formation of Common Ground with Helpers – Our findings also describe some of difficulties that participants experienced in receiving the kind of information or help they desired from people. This was apparent in their sharing of stories of others 'grabbing' or 'pulling' them in efforts to assist, or where helpful conversations were difficult to establish. For VI people, establishing a conversation (i.e. what question to ask) can be more complicated since much of the information in their surroundings that could assist in formulating certain questions and grounding a conversation may be outside their immediate awareness. Difficulties to establish common ground are also reported in AT research for navigation [e.g. 20, 48, 58, 54] that reference how sighted helpers' struggle to verbally articulate information about the surroundings in a non-visual, unambiguous, and yet helpful manner. Our findings suggest that creating a greater shared understanding of other peoples' actions can act as a starting point to address such challenges. For example, identifying someone as 'approaching' can give opportunity for a person with VI to verbally manage an interaction before action is taken. To assist in creating common ground when vision is not a shared sense is still underexplored in the AT space, and warrants more research.

Aid Collective Sense-Making - Lastly, we attend to how our examples of collective negotiations of ability assisted in participants' understandings of their surroundings, and was also bound up with pleasurable experiences for our participants. In the AT literature, the provision of assistance is frequently considered as an explicit and pragmatic act of help and as often a burden to the helper. Less often, we find considerations of how the provision of assistance can also be an opportunity to connect with another person through joint interactions and shared experiences. In our findings this was perhaps most pronounced in the examples from Jerry and Amy, who appear to have developed a genuine sensitivity between each other. The ways they have learnt to move and in a sense 'see together' presents a form of inter-dependency that not only helps extend their abilities, it is linked to a sense of belonging and enjoyment. This binding of assistance with relationships is also described by Branham and Kane [9] in the co-creation of an accessible home, something that can be both a burden and an aid to intimacy. Contrary to a previously strong focus on *independence* in the contexts of AT design and disability, we suggest that designers think about how their technology can help enable collective sense-making experiences, and how it sits within these important social relationships and avoids the risk of interfering with them.

Limitations

We chose to conduct our ethnographic research as part of the 2016 Paralympic games in Rio rather than peoples' ordinary lives. This meant that participants came to explore both everyday scenarios such as restaurant visits or shopping as well as new settings and activities such as sight-seeing, which may appear less frequently in daily life. Yet, having to navigate a foreign country can add to challenges in sense-making. and thus, pronounce such processes and help foreground key insights into how abilities are negotiated. For example, while difficulties recognizing bank notes and monetary amounts occur in daily life, this was emphasized in Rio, where the currency was unfamiliar and requested payments were often verbalized in Portuguese. Further, we have to acknowledge that during the Paralympics, official helpers were present at key transportation points or sporting venues, proactively approaching our participants to offer help upon seeing their canes. Generally, participants valued the more relaxed attitude other people showed towards their VI, which differed from their experiences at home and aided their readiness to seek help. Finally, our research focused on the experiences of a few individuals with varying types of VI. This provided rich and detailed examples, surfacing some of the complexity and nuance involved in different ability negotiations, but naturally presents data limited in their generality.

CONCLUSION

Our research took an orientation to disability that regards it as something that is not fixed or manifested alone through the body, but created through a person's social and material interactions with the world. We explored, through rich video ethnography, how athletes and spectators with VI negotiated their abilities in various contexts during the Rio Paralympics. Our findings presented in-depth examples that show how our participants triangulated information resources to understand their environments, posing this as a way to focus design in this space. We showed how providing additional information to on-going sense-making should not solely be considered as a mechanistic process, but as one that is deeply embedded in the social context in which interactions occur. We drew out how negotiating ability is shaped by perceived social norms, social opportunities for connection, and not least, assistance from other people, who can act as a vital information resource. Discussing these insights, we identified opportunities for technology design to become a meaningful part in processes of ability negotiation, and, through this, to assist in extending the abilities of people with vision impairments.

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