DESIGNING WEARABLE ASSISTIVE COMPUTING DEVICES TO SUPPORT SOCIAL ACCEPTABILITY AND PERSONAL EXPRESSION

by

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Wearable computing devices offer numerous opportunities to support individuals with disabilities, including, but not limited to, sensory substitution and augmentation, cognitive function, telemedicine, and learning and communication. With the rise of chronic illness – largely attributed to an increased lifespan compounded by population growth – technology that can support individuals to lead independent lives will be paramount. Wearable computing devices are unique in their ability to remain with the user while on-the-go, supporting individuals in multiple and changing contexts. However, to date, many wearable assistive devices, and assistive technologies in general, remain highly stigmatizing in nature due to their distinct or medical-looking form factors and unique interaction techniques – broadcasting personal information about one's physical, sensory, or cognitive state that might otherwise go unnoticed. These socio-cultural implications can often lead to personal discomfort with using one's device in various settings – with the realistic outcome of individuals often choosing to conceal, selectively use, or abandon their assistive device altogether. Recently, there has been a two-prong shift in the adoption and treatment of assistive devices: 1) the acquisition of mainstream devices with accessibility-enabled features, and 2) devices with highly customized designs and embellishments which highlight the device as opposed to masking it. One may view this shift as a natural extension of the disability rights movement aimed at pushing back on the societal structures that create barriers for individuals with disabilities. This manuscript explores this shift to understand the attitudinal and behavioral changes with respect to customized on-body assistive

computing devices and how end users in these communities can be supported through design and Do-It-Yourself practice. It was discovered that the expressed perceptions toward novel on-body computing devices were significantly more acceptable when said computing devices were used for assistive applications. This research also uncovered the great lengths that some end users go through to customize or personalize their wearable assistive technology, in particular, hearing aids and cochlear implants, for the purposes of self-expression and to counter much of the socially-constructed discomfort that may accompany device use. Finally, we found that individuals value customization of assistive devices and that this is an important component to grant individuals agency, ownership, and pride in wearing a device commonly fraught with marginalization. The results suggest that customization can lead to increased adoption and confidence in assistive technology use and may generate greater societal acceptance and awareness toward disability as a whole.

DEDICATION

- To Mom -

Sisu.

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CHAPTER 1

INTRODUCTION

The development of smaller and increasingly powerful computing hardware permits for the design of portable and wearable assistive technologies capable of providing enhanced feature-sets to support end users. As the number of individuals with reported disabilities continues to rise (Brault, 2012), the need for robust and accessible technology becomes ever-more essential as assistive devices not only have the potential to increase user independence but can also help offset an already taxed healthcare system. In the United Stated alone, approximately 19% of the population reports living with some degree of disability, and this number rose by 2.2 million in just 5 years (from 2005-2010) (Brault, 2012). Of greater concern are the number of individuals who can benefit from assistive technology (AT) yet reject or abandon their AT device due to several nuanced reasons, such as limited functionality, cost, and stigma, to name a few.

Assistive devices in the United States average a one in three abandonment rate, with up to a 75% abandonment rate for non-life-critical devices such as hearing aids (Galvin & Scherer, 1996; Kintsch & DePaula, 2002; Scherer, 2005). These alarming statistics have been attributed to the complex relationship of the functional performance of AT coupled with the user experience or socio-cultural issues which continue to remain 'under' addressed with respect to assistive technology use (Deibel, 2013; Jacobson, 2010; Kane, Jayant, Wobbrock, & Ladner, 2009; Kintsch & DePaula, 2002; Parette & Scherer, 2004; Shinohara & Wobbrock,

2011). As smaller and more powerful computing hardware offer new accessibility possibilities, we are now at a point where we can enlist this technology to explore and address the socio-cultural considerations influencing AT abandonment that have come to light in recent years. These socio-cultural considerations encompass a number of factors that will be touched upon in this thesis, including but not limited to: societal perceptions, aesthetic dimensions, Do-It-Yourself customizations, usage scenarios, and the emotional, behavioral, and technological components that affect the social weight or stigma (Deibel, 2013; Shinohara & Wobbrock, 2011) that can be associated with AT use. While this research cannot provide an exhaustive examination of all types of assistive devices, disability presentations, and AT usage scenarios, this manuscript will specifically focus on a subset of user adopted wearable computing devices and 'expressive' (Hall & Orzada, 2013) assistive technologies in order to further understand the practices and considerations related to one's personal and social comfort of AT use.

Figure 1. Expressive AT examples: Hearing aid, image by Soichi Yokoyama, Flickr, CC-BY-NC-ND-2.0[1] (left), Star wars mod podge cast, image by Tara Faul, Flickr, CC-BY-NC-ND-2.0[2] (right).

1.1 Purpose of the Study

Over the past 15 years, we have begun to see more in-depth examinations of the social comfort of real-world assistive device usage in order to more critically understand the reasons behind how and why individuals use, appropriate, and even reject their AT devices (Jacobson, 2010; Kane et al., 2009; Kintsch & DePaula, 2002; Parette & Scherer, 2004; Shinohara & Wobbrock, 2011). As identified by the literature, socio-cultural considerations (e.g., stigma), personal values, and motivations associated with AT usage can complicate device adoption (Deibel, 2013), and we find many accounts of users concealing their devices or appropriating their AT to look less assistive in nature[1,2] (see Figure 1). Other AT users may employ mainstream technologies (e.g., iPhones) in lieu of highly specialized devices in order to limit unwanted attention (Kane et al., 2009; Shinohara & Wobbrock, 2011). As identified in Deibel (2013), additional factors that may influence device adoption include functional limitations of the device, device necessity, physical and cognitive effort, and time. If the intended benefit of the device does not outweigh the cost or

[1] https://www.flickr.com/photos/soitiki/5089584379
[2] https://www.flickr.com/photos/17939157@N00/8860308415

Given a usage *context*, the likelihood of a user with a *disability* using a specific assistive device to perform a *task* is:

$$P(\text{usage}|\text{context}) \propto \frac{\text{DeviceNecessity}(\text{context}) \times \text{TaskMotivation}(\text{context})}{\text{Time}(\text{context}) + \text{PhysicalEffort}(\text{context}) + \text{CognitiveEffort}(\text{context}) + \text{SocialWeight}(\text{context})}$$

Figure 2. Heuristic model for understanding AT adoption from (Deibel, 2013, p. 2).

potential cost (e.g., hearing aids amplify every sound in a room, making it difficult for a user to concentrate), many users may often choose to forgo use of that technology altogether (see Figure 2). These trade-offs are an important consideration with respect to both the functional and socio-cultural performance of AT and become even more complex as we design new AT devices with computational abilities.

Wearable assistive computing devices pose an interesting point of study as they will likely be accompanied by novel interaction techniques which may or may not be familiar to bystanders, potentially drawing unwanted attention to the user. Other forms of wearable assistive computing, such as digital communication devices, will mediate interaction between the user and the world (bystanders), requiring both parties to engage with and adapt to this new technology. The novelty of new devices and operation techniques may compound the social weight associated with AT use – potentially generating unique challenges and opportunities pertinent for consideration as we develop these new technologies.

To explore the socio-cultural concerns more thoroughly, this manuscript will look at instantiations of wearable technology usage for assistive applications, a head-mounted display in Study 1, and hearing aids and cochlear implants in Studies 2 and 3, to better understand how aesthetic, customized, appropriated, or mainstream technologies or objects are being used to address many of the socio-cultural aspects of AT usage. Given the complex and overlapping relationship of the perceptions and presentation of disability, AT, worn objects, and identity, the primary objective of this research is to understand: 1) if and how individuals engage

aesthetic customization to manage personal and social comfort of AT use, and 2) to understand the general impact that this practice can have both on the user and on society at large. One potential outcome is to understand the strategies and trade-offs users employ when appropriating wearable computing AT in order to devise better methodologies and/or design practices to support future AT use and development. Secondary objectives entail uncovering themes or trends that can extend to the development of other types of AT or on-body computing systems to support social comfort.

1.2 Scope of the Study

This research is aimed at understanding the perceptions toward on-body assistive computing devices and the role of design and DIY practice in managing personal and social comfort of worn AT. This research is inspired by previous work that I have done within the space of aesthetic wearable AT aimed at encouraging use of one's device and seeks to build on the opportunities offered through access to new or appropriated materials, manufacturing techniques, and technologies. My previous work includes Flutter, a smart garment that leveraged distributed sensing, computation, and actuation to explore the development of a fashion-forward, non-invasive sensory substitution device for individuals with hearing impairments (Profita, Farrow, & Correll, 2015). Follow-up work includes Lightwear, which is comprised of a series of six light-emitting, aesthetically-informed wearable accessories aimed at providing on-the-go treatment for individuals affected by Seasonal Affective Disorder (SAD) (Profita, Roseway, & Czerwinski, 2016).

Both works are representative of *research through design* explorations (though, the latter was informed through a much more rigorous application of the user-centered design process), which seek to establish aesthetic accountability[3] through the integration of "functional, formal, material, cultural and emotional concerns" (Gaver, 2014, p. 148). The strong community- and academic-interest generated by these works, coupled with the recent upsurge of aesthetic AT seen in practice, positions 'expressive' AT as an area which merits further study, particularly for the purposes of addressing factors of convenience, user preference and self-expression (Profita, Roseway, & Czerwinski, 2015; 2016), social comfort (Deibel, 2013), behavior change (e.g., adoption/abandonment/concealment) (Kane et

[3] Aesthetic accountability – "where 'aesthetic' refers to how satisfactory the composition of multiple design features are." Aesthetic accountability differs from "epistemological accountability, in which the essential requirement is to be able to explain and defend the basis of one's claimed knowledge." (Gaver, 2014, p. 147)

al., 2009; Shinohara & Wobbrock, 2011), and personal identity (Bennett, Cen, Steele, & Rosner, 2016). For the purposes of this thesis, I seek to research the concepts of personal and social comfort of AT use as enabled through aesthetic and contextual dimensions of on-body assistive computing devices.

Due to the limited extant work in this domain, this research will be primarily qualitative and exploratory in nature, with the progression of studies building on the findings and insights generated from each previous study. Additionally, the various dimensions that I plan to study in this paper can often include a complex set of criteria which may fall outside the scope of this research. For the purpose of clarity, I will define existing terms that will be referred to throughout this thesis:

1. Disability: A mismatch between the demands of society and the abilities of the individual.
2. Worn: "To carry or bear on one's body or on some member of it, for covering, warmth, ornament, etc.; to be dressed in; to be covered or decked with; to have on."[4] -Oxford English Dictionary
3. Aesthetics: "Of or relating to the perception, appreciation, or criticism of that which is beautiful."[5] -Oxford English Dictionary
4. Social Comfort: The socio-cultural factors that may influence or complicate the degree of comfort, including the physical, psychological, and social aspects, an individual feels in a given context (Deibel, 2013; Ripat & Woodgate, 2011).
5. 'Aids': Abbreviation for hearing aids.
6. Social Constructionism: "A theoretical approach which regards certain aspects of human experience and knowledge as originating within and cultivated by society or a particular social group, rather than existing inherently or naturally."[6] –Oxford English Dictionary

[4] http://www.oed.com/view/Entry/226606?rskey=iArqCA&result=2#eid
[5] http://www.oed.com/view/Entry/3237#eid9579536
[6] https://en.oxforddictionaries.com/definition/social_constructionism

1.2.1 Research Questions

The following research questions will be used to help inform design considerations that can be referenced for the future development and/or research of wearable assistive computing devices. Given that this thesis cannot evaluate an exhaustive database of AT devices and disability presentations, these research questions will focus on select forms of wearable computing AT, a head-mounted display in Study 1 and hearing aids and cochlear implants in Studies 2-3, and how the devices themselves, or, the aesthetic dimensions, context, or customization of the technology factor into personal and social comfort of AT use. The research questions are outlined below and will be revisited throughout this manuscript with each associated study:

RQ1: How do individuals' expressed perceptions of wearable computing device usage change based on the disability presentation of the wearer? (Study 1)

RQ2: What behaviors, opinions, and feelings are expressed in online communities regarding aesthetic qualities of worn assistive computing technology? (Study 2)

RQ3: What role does aesthetic customization of worn assistive computing devices play in managing personal and social comfort? (Study 3)

RQ4: What design considerations and strategies can be applied to worn assistive computing technology to support personal and social comfort? (Studies 2 & 3)

1.3 Arrangement of the Thesis

The remainder of this dissertation is structured as follows: Chapter 2 reviews related work with respect to wearable computing devices, the role of identity in worn objects, the social implications as they relate to disability and assistive devices, and the emergence of Do-It-Yourself practice for AT. Chapter 3 details the research approach and the rationale behind the devices, disability presentations, and interactive media platforms evaluated. Chapters 4, 5, 6, and 7 will expand upon the three proposed studies and study findings. Chapter 8 will discuss design recommendations to support aesthetic customization of wearable assistive computing devices. Next, a discussion of the key observations, broader implications, and study limitations will be presented in Chapter 9. Chapter 10 will discuss future work, followed by Chapter 11, which will conclude this thesis.

CHAPTER 2

REVIEW OF THE LITERATURE

This literature review will provide an overview of the multiple disciplines and theories that inform this area of research. First, we will look at the domain of wearable computing to understand the ultimate goals of this field and how it ties into AT (both functionally and socio-culturally). Next, we will consider identity formation and the personal and socially-constructed meanings attributed to objects (for the purposes of this research, specific attention will be paid to worn objects). Subsequently, we will look at the role of stigma in society, the impact that it can have on individuals with disabilities, and some of the ways that individuals are addressing stigma in the disability community to foster a new social identity (Goffman 1963). Building upon this, we will look at the role of stigma with respect to AT and the ways that individuals are using worn or collocated devices to manage personal expression and social comfort. Finally, we will look at the rising practice of Do-It-Yourself assistive technology and how this creates a sense of agency in end users.

2.1 Wearable Computing

Wearable computing can be defined as "the study or practice of inventing, designing, building, or using miniature body-borne computational and sensory devices. Wearable computers may be worn under, over, or in clothing, or may also be themselves clothes" (Mann, 2012). Existing wearable computing philosophy

emphasizes the extension of man's natural abilities. As described in (Starner, 2001, p. 44), "wearable computing pursues an interface ideal of a continuously worn, intelligent assistant that augments memory, intellect, creativity, communication, and physical senses and abilities". To date, wearable computing has been used and explored for numerous applications, including: gaming, emergency response, sports, and health monitoring, to name a few (Sazonov & Neuman, 2014). The miniaturization of sensing technology with increased computational power permits for wearable computers, often referred to as 'wearables', to be used for applications in previously unrealized and pragmatic ways. Considering that assistive technology is also designed to extend one's existing capabilities (Cook & Polgar, 2014), one clear extension of wearable computing is the computational enhancement of AT to provide increased access and support to the user. The ability to incorporate electronics into different materials now permits for the exploration of new design solutions (e.g., smart garments (Profita, Farrow, & Correll, 2015; Sazonov & Neuman, 2014) or bionic limbs[7]) that extend beyond the classic (and highly recognizable or visible) AT devices, granting us the ability to research new trade-off dimensions of AT usage that were either unfeasible or previously inaccessible.

2.1.1 Considerations for the Use of Wearable Computing and AT

Wearables can encompass several physical form factors, such as hard good accessories[8], soft goods[9] (e.g., textile-based smart clothing), or implantable devices[10]. The range of devices, applications, interaction techniques, and worn location(s) present a number of technical and contextual challenges for pragmatic use and

[7] http://bebionic.com/the_hand
[8] https://jawbone.com/up
[9] http://aiqsmartclothing.com/
[10] http://www.nhlbi.nih.gov/health/health-topics/topics/pace/

adoption. Technical challenges and issues that persist to this day include power use, heat dissipation, networking, privacy (Starner, 2001), size, attachment (Gemperle, Kasabach, Stivoric, Bauer, & Martin, 1998), comfort, washability, weather, and processing power (Sazonov & Neuman, 2014). Functionally, there is significant overlap with the technical challenges of assistive devices. Size, or 'fit', attachment, and comfort of AT (Cook & Polgar, 2014) are critical for the user and one's changing needs. Digital devices must be designed for ease of use and need also factor in requirements such as failure, privacy (Kane et al., 2009), and exposure to the elements (Kintsch & DePaula, 2002). Other factors for AT design entail developing for simplicity, context, durability, customization, user preferences, and (potentially) with multiple stakeholders in mind (Kintsch & DePaula, 2002).

More nuanced issues of wearables situate themselves within cultural and social contexts and hinge on the temporal expectations, attitudes, and norms within a particular society (Dunne, Profita, & Zeagler, 2014a). Given the reciprocal relationship that wearable computing seeks to achieve with its user (Mann, 2012), both technical and contextual considerations are paramount for societal adoption and acceptance of the technology. Additionally, while AT use often occurs on the individual level, it is subject to a much larger socio-cultural environment (Ripat & Woodgate, 2011). However, the socio-cultural considerations factored into AT design, display, and use continue to remain a relatively underexplored research area (Bennett, Cen, Steele, & Rosner, 2016; Bispo & Branco, 2009; Jacobson, 2010; Kane et al., 2009; Kent & Smith, 2006; Pape, Kim, & Weiner, 2002; Parette & Scherer, 2004; Profita, Roseway, et al., 2016, 2015; Pullin, 2009; Ripat & Woodgate, 2011; Shinohara & Wobbrock, 2011) of which this thesis will seek to contribute to. The following two sections will reflect on the meaning of objects in a social context to understand the potential impact of social aspects on worn or collocated items.

2.1.2 Identity and the Meaning of Personal Objects

In "The Presentation of Self in Everyday Life", Goffman discusses how individuals present themselves to others as an act of desired impression management (Goffman, 1959). This 'presented' identity is constructed through one's objects, context, conduct, and appearance which communicate personal information about the user, thus becoming the continual focus of external judgment and impression formulation. Worn objects and physical characteristics are particularly subject to this judgment, as their conspicuousness makes them highly noticeable to, if not the first thing noticed by, others. Bystanders use this information to formulate opinions and expectations about others in order to "navigate relationships" (Shinohara & Wobbrock, 2011, p. 706) and also to operate within socially-accepted norms. As a result, individuals are likely to pursue identity constructions that solicit group acceptance (Goffman, 1959).

2.1.3 Clothing, Aesthetics, and Social Aspects

As previously noted, clothing and displayed objects may be subject to external judgment (Goffman, 1959), ultimately influencing the choices we make regarding the items we display. To more thoroughly review the factors at play, and why this may serve as an important connection for future wearable computing and AT development, this section will look at the role of social aspects and aesthetic dimensions in clothing (and other worn items) expression. We note the significance of this connection as wearable devices (Dunne et al., 2014a), like assistive devices (Shinohara & Wobbrock, 2011), have commonly been developed and evaluated with respect to functional criteria and less so with respect to socio-cultural implications.

Inherent in worn items is not only what is meaningful to the user, but what is expressed to others. Over the years, as clothing was able to fulfill more functional

requirements, it became increasingly likely to see variations of clothing that expressed personal characteristics, societal trends, and values (Dunne et al., 2014a). In effect, we can begin to draw parallels with Maslow's Hierarchy of Needs[11] - as functional requirements are met, individuals seek fulfillment on other levels. As a result, we can look to the existing evolution of aesthetic elements of clothing (or other worn objects) and the visual interpretation of these elements to potentially inform the design of wearable computing and AT devices to address personal and social comfort. To briefly touch upon important socio-cultural characteristics of worn items, aesthetics, and identity, the following section will turn to the "Social Interpretation of Aesthetics" (Dunne et al., 2014a, p. 26).

DeLong's (1998) conceptualization of the visual processing and expressivity of the aesthetic properties of clothing is represented by the 'apparel-body-construct', where the visual properties of both clothing and the body come together to encode meaning and identity. This meaning is also constructed through the perceptions of groups or 'bystanders', which may result in either an agreed upon societal acceptance or judgment of dress. Bell (1976) describes 'codes' and 'appropriateness' of dress as being dictated by society and context. As a result – what is permissible for one setting or group (e.g., older adults) may not translate for another setting or group (e.g., children) and may have an associated social weight and call unwanted attention to the user. For dedicated AT devices or newer forms of wearables, limited device selection means that individuals have less choice regarding the devices that they end up using (and thus, are at greater risk for being subject to the associated meaning encoded in that device). The constructed meaning may differ drastically with the values or desired self-presentation of the user and can negatively impact the user and the actual *use* of the device.

[11] http://www.simplypsychology.org/maslow.html

2.2 Stigma and Disability

Goffman's definition of stigma is perhaps the most widely accepted conceptualization of stigma (Goffman, 1963). Goffman discusses stigma with respect to "social identity" (p. 2), outlining a discrediting outcome as the result of the relationship between an attribute (an existing state) and a stereotype (a socially-derived response to that state). Goffman positions stigma as an attribute that is "deeply discrediting" (p. 3), as not all attributes are stereotypically negative. Over the years, a proliferation of work has elaborated on Goffman's conceptualization of stigma to include dimensions and frameworks of stigma that are individually, socially, and contextually constructed, as reviewed in (Crocker, Major, & Steele, C., 1998). Link and Phelan (2001) popularized their conceptualization of stigma by framing stigma as a complex relationship between the individual, socially-defined experiences, cognitive processes, power structures, and the consequential outcomes involved. Up until Link and Phelan, stigma had been predominantly framed as an individualistic experience (Fine & Asch, 1988; Oliver, 1990), discounting society's role in 'affixing' stigma to others (Link & Phelan, 2001; Sayce, 1998).

With respect to disability presentation, stigma results from the socially-constructed meaning encoded in the 'attributes' of the disability along with the devices and/or assistive objects used to aid the individual (Ripat & Woodgate, 2011). As a result, both the disability and the device can create separatist 'us' versus 'them' attitudes and, according to Shinohara and Wobbrock (2011), such devices can pose "social barriers to access" (p. 706) to the very situations that these devices were developed to overcome. An interesting dimension appears in the case of "invisible" disabilities (Shinohara & Wobbrock, 2011, p. 708), as AT introduces a visible component to a disability that otherwise might go unnoticed. Stigma can also result from social interactions with individuals with disabilities (Elliott, Ziegler, Altman,

& Scott, 1982) and, coincidentally, may extend to those interactions that the AT has been developed to mediate. In effect, AT development should take into account these additional layers of stigma that they may introduce.

As described in (Herman & Miall, 1990), extant literature has primarily focused on the negative outcomes of stigma associated with disability presentation. In Charlton's book, "Nothing About Us Without Us" (2004), the author discusses the levels of oppression and injustice experienced globally by individuals with disabilities and goes on to detail the ways that these individuals resist oppression to support disability rights, empowerment, and inclusivity. This shift is also documented by scholarly efforts in disability studies focused on addressing social and legislative problems experienced by individuals with disabilities (Mankoff, Hayes, & Kasnitz, 2010). Over the years, efforts towards empowerment have been reflected in a number of movements (e.g., the disability rights movement (Mankoff, Hayes, & Kasnitz, 2010) and disability arts (Barnes & Mercer, 2001)) that have arisen as a mechanism to address, manage, change, raise awareness about, and even challenge stigma related to disability. This has also largely been facilitated by a shift from the medical model of disability to the social model, reshaping the way individuals think about disability by moving "the location of the disability out of the person and into social structures" (Cook & Polgar, 2014, p. 10).

The concept of disability culture emerged in the 1970s as a means of embracing individual differences to foster a new social identity focused on empowerment and disability awareness (Barnes & Mercer, 2001). The result is the participation of individuals with disabilities in the arts, media, policy, and legislation. This is a demonstration, at large, of how communities can channel negative experiences into more positive ones. Such initiatives are occurring on

smaller-scale levels as well. For instance, Gimpgirl.com[12] is a current example of how one blog is reclaiming the negative terminology associated with disability to overturn the associated sense of 'pity.' Correspondingly, Sara Hendren, a former design graduate student from Harvard University, sought to replace existing handicapped signage with imagery that is more active[13]. Such activity showcases personal endeavors and design interventions, respectively, aimed at changing perceptions toward disability and/or AT use.

2.3 Assistive Technology and Stigma

Assistive technology is defined by the United States legislation in The Assistive Technology Act of 1998 (amended: 2004) 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" (Cook & Polgar, 2014, p. 2). Many assistive devices are worn or collocated in nature due to the need for the item(s) to be readily accessible and to move with the user to provide continuous support. This positions AT users as perhaps one of the more experienced user groups of wearable and collocated devices, and, as a result, extremely well-qualified to give feedback and input regarding the design of useful and meaningful wearable AT systems for everyday life.

Ripat & Woodgate (2011) look at the role of culture and disability in identity formation of AT users. Often times, the device becomes an extension of the user and part of their identity construction. However, the impact that AT can have on identity in relation to socio-cultural norms can often dictate adoption or abandonment of the device, despite its functional performance (Pape et al., 2002;

[12] http://www.gimpgirl.com/
[13] http://www.npr.org/2013/07/07/189523504/new-handicapped-sign-rolls-into-new-york-city

Ripat & Woodgate, 2011): "When AT does not promote a positive self-identity or hold an acceptable socio-cultural meaning, individuals may choose not to use one, choose to use a more socially accepted AT device…or use specific strategies to obscure AT use such as concealing it…" (Ripat & Woodgate, 2011, p. 90).

Within the past 10 years, we have begun to see a greater focus in the literature on researching the stigmatizing elements of AT devices (e.g., aesthetics, gender, age, and social acceptability) (Parette & Scherer, 2004) and the ways in which individuals manage stigma (Jacobson, 2010; Kane et al., 2009; Shinohara & Wobbrock, 2011) of specific AT devices. These management techniques include device modifications (Jacobson, 2010), device avoidance, using mainstream devices, highlighting the device (Shinohara & Wobbrock, 2011), hiding the device (Kent & Smith, 2006), and using devices mainly in private settings (Kane et al., 2009). From the work of (Bispo & Branco, 2009; Kent & Smith, 2006), the theme of 'normality' has arisen, and other related works have emphasized the role that design can play in overturning many of the 'prejudices' related to disability and AT use (Bispo & Branco, 2009; Pullin, 2009; Shinohara & Wobbrock, 2011). Shinohara and Wobbrock (2011) put forth the recommendation of "design for social acceptance" (p. 712), while Bispo and Branco (2009) sought to design symbols and imagery that broke away from the standard signifiers of 'disability'. While these recommendations have been presented, there remains very little work in the research domain which critically examines these aesthetic dimensions with respect to worn AT computing devices (Profita, Roseway, et al., 2015, 2016; Williams, Roseway, O'Dowd, Czerwinski, & Morris, 2015). The following section will provide a brief overview of design research explorations specifically related to aesthetic wearable AT computing solutions.

One of my earliest works, 'Flutter' (a fashion-forward smart garment for sensory substitution) is an exploratory piece that sought to capture how advances in low-profile robotic hardware and technology/textile integration could facilitate

aesthetic assistive devices aimed at overturning many of the negative societal perceptions of AT (Profita, Farrow, et al., 2015). Follow-up work included 'Lightwear', a series of light therapy wearables designed for the treatment of Seasonal Affective Disorder. These prototypes were specifically developed to explore how fashion-driven wearables could rectify issues of treatment inconvenience, non-compliance, and social weight (Profita, Roseway, et al., 2016, 2015). Other related works include 'SWARM', a fashion-driven actuated scarf aimed at mediating affect for individuals with difficulty recognizing and regulating emotions (Williams et al., 2015) and the work of Bonanni et al. (2006), which explored the use of scarf-embedded haptics for touch therapy. From these works, we can glean the dual-purpose nature of fashionable or textile-based wearable computing AT.

Other research has looked at the stigma related to fashion-based dressing by blind women, revealing a high level of situational-stress and lack of technologies in aiding the dressing process (Burton, 2011). The findings aligned similarly with that of stigma management for AT devices (e.g., avoidance), as one participant minimized the use of jewelry as it was one more item to try and coordinate. With respect to clothes, individuals reflected a similar desire to fit in (or, not stand out any more than they already do). Thus, for these visually impaired women, clothing and fashion were also seen as a way to manage social acceptance. In a follow-up study, Burton et al. (2012) explored the use of VizWiz, a mobile phone application capable of providing answers to visual questions for crowdsourced fashion advice. A much more recent initiative is MIT's Open Style Lab[14], which started hosting summer workshops aimed at applying fashion and user-centered design to AT. As a portion of this research will be specifically geared toward aesthetic customization of

[14] http://www.openstylelab.com/

HAs, CIs, and other listening devices, the following section will provide an overview of stigma as it relates to AT for hearing loss.

2.3.1 Hearing Aids and Stigma

In the U.S. alone, only 20% of hearing impaired individuals capable of benefitting from amplification actually use hearing devices[15]. Existing research has shown stigma associated with HA use to be a critical component of decreased hearing aid uptake (David & Werner, 2016; Jenstad & Moon, 2011; Wallhagen, 2010). Wallhagen (2010) interviewed older adults and found three dimensions of stigma: alterations in self-perception, ageism, and vanity. For these end users, stigma affected almost all aspects of their HA-related decision-making processes, including: initial acceptance, seeking treatment, HA selection, and selective AT use. Stigma appeared to be generated by device conspicuousness and its inherently negative qualities (e.g., connoting one as old, less able, or deficient). As a result, individuals often rationalized non-use, selective use, or deemphasized the severity of their hearing loss. As stigma inherently exists as a social construct dictated by the behaviors and judgments of others (Major & O'Brien, 2005), end users likely suppress AT use in order to avoid stigma-inducing experiences. A survey of HA-related stigma research showed stigma to be the primary reason for HA non-use in 1/3rd of the 21 works surveyed (David & Werner, 2016). In many of these studies, size, visibility, and cosmetics were the primary reason and focus of these stigma-inducing occurrences (Blood, 1997; Cienkowski & Pimentel, 2001; Johnson et al., 2005; Johnson, Danhauer, & Edwards, 1982; Kochkin, 1993, 2012). Despite the significance of cosmetics on participants attitudes toward HAs, few works to date have looked at the impact of aesthetics (aside from size) on HA use (Ellington &

[15] https://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=95

Lim, 2013). Furthermore, existing stigma research for CIs is predominantly focused on the ethical dimensions of implantation and its impact on Deaf culture (Grodin & Lane, 1997; Hyde & Power, 2005; Sparrow, 2005). This manuscript will explore different dimensions of expressive HAs and CIs to understand if and how end users employ aesthetic customization to manage personal and social comfort of AT use. Though extant research on expressive AT for hearing loss remains limited, the following section details examples of other forms of aesthetic AT that have emerged.

2.4 Expressive Assistive Technology

While the work in the research domain remains relatively limited, in practice the concepts of creating socially acceptable, expressive, and fashion-driven AT have begun to receive more widespread attention. Eyeglasses are a notable AT device that have morphed into a widely adopted fashion accessory, ultimately challenging their association with disability (Pullin, 2009). The Alternative Limb Project[16], Prosthetic Ink[17], and Hayleigh's Cherished Charms[18] are examples of consumer-driven endeavors in the beautification of AT that have gained increasing momentum over the past 5 years.

Canes and walking sticks[19] come in a range of available configurations, colors, and designs. e-NABLE ("Enabling The Future," 2015) and DIYAbility ("DIYAbility," 2016) are maker-focused initiatives for inclusion and AT development. Another notable illustration of expressive worn AT includes the personal decoration of one's device. We see this in a number of items, including the decorating of casts, wheelchairs, eye patches, and crutches. Other items that offer

[16] http://www.thealternativelimbproject.com/
[17] https://www.prostheticink.com/
[18] http://www.hayleighscherishedcharms.com/
[19] http://www.fashionablecanes.com/

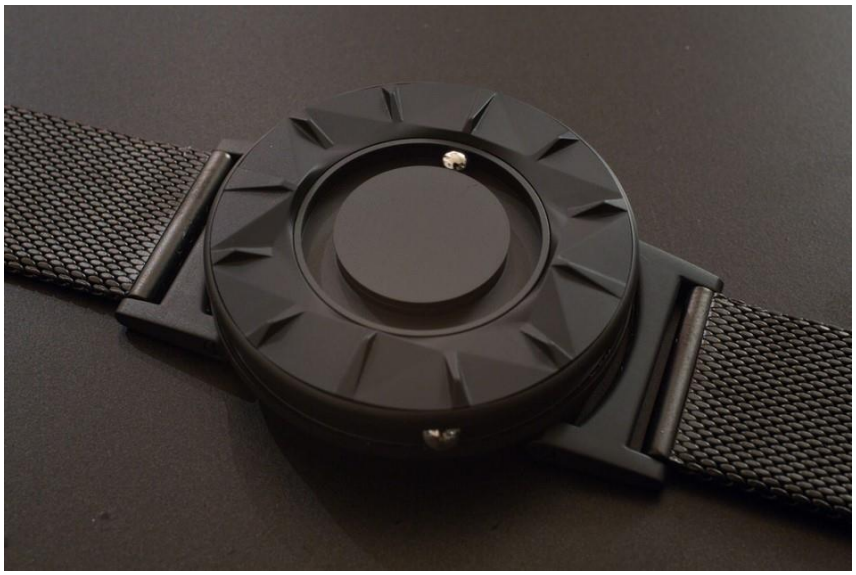

Figure 3. Eone Bradley Watch, image by Scott Schiller, Flickr, CC-BY-2.0[21] (right).

more subdued designs may appeal to users by encapsulating more of a mainstream or 'sleek' appearance, including items such as Apple's iPhone[20] or the Eone Bradley Timepiece[21] (see Figure 3) for the blind. The following section will discuss the emergence of Do-It-Yourself (DIY) AT practice in greater detail.

2.5 Do-It-Yourself Practice in Assistive Technology

The growing engagement in DIY AT modification in the disability community reflects a change in the accessibility of tools, resources, and information available for individuals to develop or modify their own artifacts. Furthermore, it may be the result of the expansion of local 'fab labs' (Gershenfeld, 2007) and hackerspaces which have made it possible for individuals to access 3D printers, laser cutters, and electronic kits. Prior work has shown that the process of engaging in the design or modification of one's own AT instills a sense of personal agency and investment in the design process, giving users greater ownership of their devices (Hurst & Tobias,

[20] http://www.apple.com/iphone/
[21] https://www.flickr.com/photos/schill/31523291325

2011) and also enabling end users to engage in design practices independent of major manufacturers and exorbitant associated costs.

DIY AT projects are most commonly shared on Thingiverse (Buehler et al., 2015), personal websites (Hurst & Tobias, 2011), and other communities that advocate for people with disabilities to use DIY technology ("DIYAbility," 2016, "Enabling The Future," 2015). In addition to these sharing and community activities, we see a growing trend with DIY AT practices and materials, particularly for supporting communication needs (Hamidi, Baljko, Kunic, & Feraday, 2014), accessible media and learning aids (Buehler, Kane, & Hurst, 2014; Stangl, Kim, & Yeh, 2014), and for creating prosthetic limbs (Buehler et al., 2015; Hofmann, Harris, Hudson, & Mankoff, 2016). Prior work has shown that many DIY AT devices are created by people with disabilities or on behalf of loved ones or friends, and that "these designers frequently have no formal training or expertise in the creation of assistive technology" (Buehler et al., 2015, p. 525). While existing DIY assistive technology has focused on primarily functional enhancements, Bennett et al. (2016) have studied the use of fabrication tools in creating prosthetic limbs and found that these technologies often encouraged end users to explore aesthetic and personally meaningful designs. The recent prevalence of DIY modification and aesthetic AT enhancement merits further exploration for a deeper understanding of how existing craft materials and DIY techniques can be used to create AT artifacts that reflect pride, user empowerment, and personal expression.

CHAPTER 3

RESEARCH APPROACH

This manuscript is predominantly concerned with the societal perceptions of on-body assistive computing devices and the customization activities that AT end users engage in to manage personal and social comfort of AT use. As worn assistive computing devices often mediate interactions and expectations between the end user and the world, understanding the challenges and characteristics related to device use can generate design considerations aimed at holistically supporting the user. The following section will briefly discuss the decision to focus on wearable computing devices for this research.

There are a plethora of new computing technologies being released into the marketplace that advertise increased accessibility features to support a more inclusive user base. However, we do not yet know how these devices will be received, either by the public or by the end user. The implications are manifold. Accessibility-enabled mainstream technologies, though perhaps more preferred amongst disabled persons due to their ubiquity or increased technical support, may also require novel interaction techniques that can potentially garner unwanted attention. Opposingly, dedicated AT may be more stigmatizing and therefore less popular, but it also functions to communicate important social cues about one's abilities to others in their immediate environment. Of even greater contention in this day and age is the prospect of privacy violations enabled through digital technologies and social media. Though built-in device features, such as cameras or microphones, may be extremely advantageous for individuals with disabilities, they

pose separate and unique concerns if used in non-assistive capacities. All of these issues, and more, are at the forefront of wearable computing assistive devices, and, though they may offer a number of unprecedented opportunities to support users of AT, can also ultimately challenge adoption, use, and acceptance of said technology.

The following research was conducted to further understand the societal response and associated challenges inherent in wearable assistive computing use and how we can learn strategies from existing practitioners in AT communities to manage potential misconceptions or social discomfort. The following section will detail the research approach, namely, the rationale behind the devices, disability presentations, and social media platforms selected for evaluation.

Study 1 was conducted in order to understand if expressed perceptions of a head-mounted display change based on the disability representation of the user. The goal is to ascertain whether societal attitudes toward wearable computer use fluctuate based on the assistive application of the device. A head-mounted display, Google Glass[22], was chosen as it was developed for mainstream use and later promoted for its accessibility features. In this study, the end user was represented with a visual impairment. This disability was selected as the physical appearance of the end user could be easily manipulated (i.e., represented with or without a white cane) to evaluate attitudinal changes of the device as they related to perceived disability status.

Study 1 revealed that the assistive nature of wearable computer use did significantly impact the expressed perceptions of device appropriateness. While Google Glass was a mainstream device available on the consumer market, it was not widely adopted within the disability community, limiting the ability to evaluate real-world AT stigma management techniques as they may relate to this device.

[22] https://www.google.com/glass/start/

Thus, in order to gain insights into existing stigma management techniques and practices as they relate to on-body assistive computing devices, the focus of this research shifted to the Deaf and Hard of Hearing (DHH) community – and more specifically, users of hearing aids, cochlear implants, and other listening devices. This community was selected for numerous reasons: 1) hearing aids, and later, cochlear implants, are arguably the oldest existing form of wearable computing used in an assistive capacity, making it an ideal candidate for study (with the exception of the pacemaker, which, for the purposes of this research, is exempt from qualifying as a traditional wearable computing device due to the fact that it is an implantable technology – thus, operating under a different set of societal norms), 2) digital hearing aids have remained in active use since the 1950s (and cochlear implants since the 1970s), making them ideal forms of AT in which to understand utilitarian and socio-cultural trade-offs as the technology has evolved over time, 3) this technology mediates communication and impacts perceptions of end users, 4) the DHH population is one of the largest disability communities (360 million individuals with hearing loss world-wide[23]), and yet, positive interventions for management of the socio-cultural concerns that impact HA and CI use remain vastly under-researched, and 5) we have begun to see, in practice, design-related stigma management strategies employed by end users of hearing aids, cochlear implants, and other listening devices.

Understanding the stigma management techniques and practices inherent in this community can not only shed insight on how to implement design strategies essential to the development of future wearable computing AT but can also enhance our understanding of how we can further support these specific practices of DHH AT users.

[23] http://www.who.int/pbd/deafness/estimates/en/

CHAPTER 4

STUDY 1: THE AT EFFECT

Prior research has demonstrated that individuals with disabilities may opt to conceal or limit AT use or use accessibility-enabled mainstream devices in order to engage with the world "just like everyone else" (Shinohara & Wobbrock, 2011). This is at odds with the fact that universally recognized forms of AT can establish environmental cues regarding how to interact with the end user (e.g., recognizing that an individual using a white cane may require more time to cross the street). This is especially challenging with the advent of new device form factors that offer multimodal forms of assistance, yet whose assistive capacity is not universally recognized. To better understand how perceptions towards wearable computing devices and disability interact, Study 1 addresses the following research question:

> **How do individuals' expressed perceptions of wearable computing device usage change based on the disability presentation of the wearer?**

This study evaluated third-party attitudes towards a head-mounted display used for assistance[24]. The objective of this study was to explore if disclosing increasing amounts of information about a mainstream device's assistive application generated higher overall acceptance ratings of the device. Here, the term 'mainstream' is used to indicate a device designed for general consumption. This research has helped establish that individuals view technology favorably when used specifically for assistive purposes, and that scrutiny may in fact be more inherently tied to the lack of understanding about the device and its intent.

[24] Portions of this chapter are adapted from (Profita, Albaghli, Findlater, Jaeger, & Kane, 2016)

4.1 Participants

For this study, 1281 participants (613 female, 663 male, 5 undisclosed) between the ages of 18 and 78 (M =35.24, SD =11.34*)* were recruited using Amazon's Mechanical Turk Marketplace[25]. Given that cultural attitudes and norms may vary across countries, recruitment was limited to the United States (as determined by SurveyGizmo's IP-based geo-location) in order to gather a consistent set of cultural responses. Workers that had either a 90% approval rating or a Mechanical Turk Master Worker status (a qualification granted by Amazon for excellence in performance) were recruited. The survey was administered via SurveyGizmo[26] and participants were each compensated $1.00 USD upon survey completion (mean completion time: 6.33 minutes, SD = 5.05). All responses were filtered to remove incomplete and ineligible (outside the United States) data points.

4.2 Method

Participants were tasked with completing an online survey. This study was comprised of four experiments in total, each with 2-4 conditions (see Table 1), for a total of 13 conditions. Participants were assigned to one of the 13 conditions, resulting in approximately 100 participants per condition (some conditions had slightly more or slightly fewer than 100 responses due to random assignment and filtering).

[25] https://www.mturk.com
[26] https://www.surveygizmo.com/

Experiment 1: Effects of Perceived Disability	
Condition	**Textual Description**
Visible Disability (E1-V, N=90)	"The following video shows a person at a bus stop using a wearable computing device."
No Visible Disability (E1-NV, N=101)	"The following video shows a person at a bus stop using a wearable computing device."
Experiment 2: Disclosure of Disability Status	
Condition	**Textual Description**
No Information (E2-No, N=120)	"The following video shows a person at a bus stop using a wearable computing device."
General Disability (E2-Dis, N=89)	"The following video shows a person with a disability at a bus stop using a wearable computing device."
Blindness (E2-Blind, N=89)	"The following video shows a person who is blind at a bus stop using a wearable computing device."
Experiment 3: Disclosure of Assistive Purpose of the Device	
Condition	**Textual Description**
No Use Description (E3-NU, N=88)	"The following video shows a person who is blind at a bus stop using a wearable computing device."
General Assistance (E3-Gen, N=92)	"The following video shows a person who is blind at a bus stop using a wearable computing device for assistance."
Personal Use (E3-Mail, N=100)	"The following video shows a person who is blind at a bus stop using a wearable computing device to listen to an audio version of her email."
Assistive Use (E3-Bus, N=111)	"The following video shows a person who is blind at a bus stop using a wearable computing device to listen to an audio version of the bus schedule."
Experiment 4: Disclosure of Video Recording	
Condition	**Textual Description**
Camera Only (E4-Cam, N=115)	"The following video shows a person who is blind at a bus stop using a wearable computing device that contains a video camera."
Camera Recording (E4-Rec, N=95)	"The following video shows a person who is blind at a bus stop using a wearable computing device that is recording images using a video camera."
Personal Use (E4-Photo, N=102)	"The following video shows a person who is blind at a bus stop using a wearable computing device that is recording images using a video camera for a personal photo album."
Assistive Use (E4-Sign, N=89)	"The following video shows a person who is blind at a bus stop using a wearable computing device that is recording images using a video camera in order to recognize street signs."

Table 1. Text descriptions used in the study. In Experiment 1, participants were randomly assigned to Video 1 or Video 2. In Experiments 2-4, all participants were shown Video 1.

Figure 4. Two video scenarios used for the study. Participants judged the social acceptability of an actress using a head-mounted display in public. Information about the actress's disability was varied by manipulating the video description and the actress's appearance. Actress wearing Google Glass (left). Actress wearing Google Glass with eye shades (right).

4.2.1 Video Scenarios

Two videos depicting identical interaction sequences were used in this study (see Figure 4). Each video was 50 seconds in length and portrayed an actress walking to a bus stop (distance view), standing at the bus stop (distance view), and interacting with a Google Glass head-mounted display (close-up view). In Video 1, the actress was shown wearing eye shades and using a white cane to indicate a potential disability (see Figure 5), while Video 2 depicted the actress wearing Glass with no additional accessories.

Each video was edited using a series of still images showing the actress walking toward the bus stop at a distance view, followed by a close-up video of the actress interacting with the head-mounted display. The Glass interaction sequence (conducted with the user's right hand) was designed to depict a realistic interaction scenario that one might use when interacting with the Glass device. The interaction

Figure 5. In Video 1, the actress walks to a bus stop using a white cane and dark sunglasses to indicate that she has a disability. Video 2 presented an identical interaction scenario sans the white cane and sunglasses.

sequence consisted of a 24-second operational succession of taps and swipes outlined in Table 2:

Tap Sequence
Tap, Forward Swipe, Forward Swipe, Forward Swipe, Forward Swipe, Tap, Pause, Tap, Back Swipe, Forward Swipe, Back Swipe, Forward Swipe, Down Swipe, Tap.

Table 2. Head-mounted display interaction sequence used in video scenario.

The actress was represented as having a visual impairment due to the general societal understanding and awareness of this disability and associated AT accessories, and in order to manipulate the actress's visual appearance for the video (white cane vs. no white cane). The bus stop setting was chosen as a recognizable and plausible public space with which participants might observe bystanders interacting with different forms of technology. This public environment was presented in order for participants to more realistically envision themselves as observers to this interaction scenario.

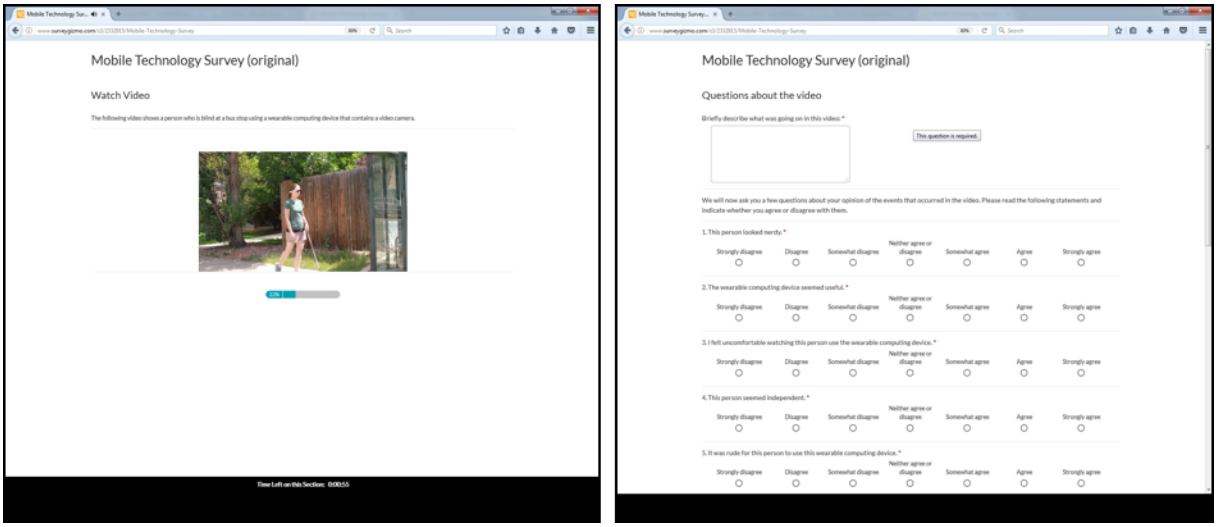

Figure 6. Survey screenshots.

Participants in Experiment 1 were randomly assigned to either the 'Visible Disability' condition (Video 1) or the 'No Visible Disability' condition (Video 2). All participants in Experiments 2-4 viewed Video 1 only (as this video could plausibly depict either a disabled or non-disabled individual) with text descriptions altered based on the condition to which they were assigned (see Table 1, Experiments 2-4).

4.2.2 The Survey

The survey was divided into four sections: video presentation, video scenario evaluation, demographic questionnaire, and open response on device appropriateness. To prevent participants from changing their responses, the back button was disabled in SurveyGizmo's browser. The survey was displayed on a white background to minimize the presence of distracting content (see Figure 6).

Section 1: Video Presentation. Participants were first prompted to watch the video, which was presented along with explanatory text based on assigned condition (see Table 1). The "Next" button was disabled until the entire video had elapsed to prevent participants from prematurely progressing to the next page.

Section 2: Video Scenario Evaluation. Upon completing the video, participants proceeded to Section 2 where they were asked to provide an open-response description pertaining to the content in the video. This was used as a quality control measure to ensure that participants watched the video and to ascertain whether or not participants noticed the disability representation of the actress.

Participants were then asked a series of 13 questions (see Table 3) to gauge their impressions toward the actress's interaction with the device, the actress specifically, and the device itself. Questions were administered in a random order, and participants were asked to rate each question on a 7-point Likert scale from Strongly Disagree to Strongly Agree. These questions were derived from prior work conducted on the social acceptability of mobile and wearable computing devices (Profita et al., 2013; Rico & Brewster, 2009, 2010).

Statements about the interaction

1. It looked awkward when this person was using the wearable computing device. *(Awkward)*
2. It looked normal when this person was using the wearable computing device. *(Normal)*
3. It was appropriate for this person to use the wearable computing device in this setting. *(Appropriate)*
4. It was rude for this person to use this wearable computing device. *(Rude)*
5. I felt uncomfortable watching this person use the wearable computing device. *(Uncomfortable)*
6. I would be distracted by this person if I were at the bus stop with them. *(Distracting)*

Statements about the user

7. This person seemed independent. *(Independent)*
8. This person needed help. *(Need Help)*
9. This person needed the wearable computing device. *(Need Device)*
10. This person looked cool. *(Cool)*
11. This person looked nerdy. *(Nerdy)*

Statements about the device

12. The wearable computing device seemed useful. *(Useful)*
13. The wearable computing device seemed unnecessary. *(Unnecessary)*

Table 3. Survey questions used for device evaluation.

Section 3: Demographic Questionnaire. Following the evaluation of the video scenario, participants were asked to provide basic demographic information as well their familiarity and sentiment towards the head-mounted display used in this study. For this portion of the survey, questions were asked in a fixed order as presented in Table 4 (response options presented in parentheses here for clarity):

1. Were you previously familiar with the wearable computing device shown in this video? *(Yes, No)*
2. If so, have you used it before? *(Yes, No)*
3. How interested are you in using the wearable device? *(Strongly Uninterested, Uninterested, Somewhat Uninterested, Neither Interested or Uninterested, Somewhat Interested, Interested, Strongly Interested)*
4. What is your opinion on the wearable computing device?
5. What is your gender? *(Male, Female, Other, Prefer not to answer)*
6. How old are you?
7. Please enter the name of the city and state which you live in.
8. What is your level of education? *(Some high school, High school graduate, Some college, College graduate, Graduate or professional degree)*

Table 4. Demographic questions.

Section 4: Effects of disability on device appropriateness. Of particular interest for this study was to understand if, how, and why the actress's disability status may have impacted participants' expressed perceptions of device use. This section was devised in order to cross-reference qualitative responses with the experimental results. Participants were first prompted with the following statement: *"We are interested in understanding to what extent it is acceptable to use a wearable computing device in public, and whether this acceptability changes if the wearer has a disability."*

Participants were first asked: *"In the video you watched, did the person have a disability?"* with options *Yes, No, and Not Sure*. Participants were then asked: "*In general, does your opinion of the social acceptability of using a device like this change if the wearer has a disability?"* with the options *Strong Negative Influence, Negative Influence, No Influence, Positive Influence, and Strong Positive Influence.*

Finally, participants were prompted to an answer an open-ended response question, *"Please explain how this information would influence your opinion."*

4.2.3 Experiments

Four experiments were conducted to disambiguate how changing the video (in Experiment 1) and the text descriptions (in Experiments 2-4) influenced participants' expressed perceptions about the user, the wearable computing device, and the user's interaction with the device. Please refer to Table 1 for the text descriptions presented in each condition.

The four experiments were designed to assess attitudinal differences based on the actress's perceived disability status (Experiment 1), disability information *explicitly disclosed* about the actress's disability status (Experiment 2), or the assistive application of the device (Experiments 3-4). For Experiments 2 through 4, only Video 1 was used (Google Glass with sunglasses and a white cane) in order to provide a controlled testing scenario for a more reliable comparison of the varying levels of disclosed information. Each experiment is described in further detail below:

Experiment 1: Effects of Perceived Disability. This experiment was used to assess whether participants perceived the actress's disability status based solely on the inclusion/exclusion of AT accessories (sunglasses and white cane) used in the video. Participants were presented with the same descriptive information, *"The following video shows a person at a bus stop using a wearable computing device.",* and were assigned to either Video 1 (Google Glass with sunglasses and a white cane) in the '*Visible Disability'* condition or Video 2 (Google Glass only) in the '*No Visible Disability'* condition.

Experiment 2: Disclosure of Disability Status. This experiment was used to assess whether explicitly disclosing information about one's disability status affected participants' perceptions about the user, the device, and device use. Participants in each condition were shown the same video (Video 1: Google Glass with sunglasses and a white cane) but received either no information about the actress's disability status (*No Information* condition), were told that the actress had a disability (*General Disability* condition), or were informed that the actress was blind (*Blindness* condition). This experiment was also designed to explore if providing more information about the end user's disability (i.e., blind versus has a disability) specifically increased the acceptability of device use.

Experiment 3: Disclosure of Assistive Purpose of the Device. In certain situations, knowing that a device is being used in an assistive capacity may make bystanders more sympathetic to, or aware of how to engage with, the user. For this experiment, participants in each condition were shown the same video (Video 1) and initial text description: *"The following video shows a person who is blind at a bus stop using a wearable computing device."* For each condition, this explanatory text was amended with either no information about the assistive application of the device (*No Use Description* condition*),* the fact that the device was being used for an assistive purpose (*General Assistance* condition), the fact that the device was being used to check email (*Personal Use* condition), or the fact that the device was being used for a specific assistive purpose - to access an audio version of the bus schedule (*Assistive Use* condition). The specificity of the actress's disability (blindness) was initially disclosed in order to provide a baseline understanding of why the actress might be using the device for these different use cases.

Experiment 4: Disclosure of Video Recording. Public use of wearable computing and mobile devices has raised numerous concerns over the past few

years due to the potential threat of unwarranted video and photo capture. Recording devices, however, can offer a number of benefits for accessibility purposes which may be at odds with the pervading privacy concerns. In this experiment, participants were assigned to one of four conditions in which they were told that a blind person was using a wearable computing device which had a camera (*Camera Only* condition), told that the blind person was currently recording with the camera (*Camera Recording* condition), informed that the camera was being used to record a personal photo album (*Personal Use* condition), or informed that the camera was being used to recognize street signs (*Assistive Use* condition).

4.3 Results

Over 1300 responses were collected and filtered, leaving a total of 1281 complete questionnaire responses analyzed for this study. Data were analyzed using IBM SPSS Statistics version 22 on Mac OS X. For Likert-scale responses, Experiment 1 used the Mann-Whitney U test and Experiments 2-4 used the nonparametric Kruskal-Wallis test. Table 5 presents mean ratings for each of the 13 scales across the 13 study conditions, and Table 6 presents the significant main effects from each of the four experiments. Pairwise comparisons were made using the Mann-Whitney U test with Dunn-Bonferroni correction (Dunn, 1961) and are presented in Table 7. For the purposes of readability, only significant results are included in this section. The qualitative analysis focused on obtaining participants' reasons and opinions toward the social acceptability of device use. Open-ended responses were analyzed using qualitative open and axial coding (Corbin & Strauss, 2015). Two authors from the initial research study (Profita, Albaghli, Findlater, Jaeger, & Kane, 2016) reviewed approximately half of the data together to develop

	E1-V	E1-NV	E2-No	E2-Dis	E2-Blind	E3-NU	E3-Gen	E3-Mail	E3-Bus	E4-Cam	E4-Rec	E4-Photo	E4-Sign
Awkward	4.3 (1.8)	4.8 (1.6)	4.3 (1.8)	3.1 (1.8)	3.6 (1.8)	3.6 (1.7)	3.4 (1.8)	3.0 (1.7)	3.0 (1.6)	3.4 (1.8)	3.3 (1.9)	3.9 (1.8)	3.1 (1.7)
Normal	3.6 (1.7)	3.1 (1.5)	3.7 (1.7)	4.5 (1.8)	4.5 (1.6)	4.4 (1.7)	4.4 (1.4)	4.5 (1.6)	4.8 (1.6)	4.4 (1.6)	4.2 (1.8)	4.2 (1.7)	4.6 (1.6)
Appropriate	5.2 (1.5)	4.7 (1.5)	5.1 (1.4)	5.7 (1.4)	5.7 (1.3)	5.6 (1.4)	5.7 (1.1)	6.2 (1.0)	6.1 (0.9)	5.5 (1.2)	5.5 (1.6)	4.8 (1.6)	6.1 (1.1)
Rude	2.0 (1.3)	2.4 (1.3)	2.2 (1.4)	1.6 (1.1)	1.5 (0.7)	1.7 (1.0)	1.6 (0.9)	1.4 (0.7)	1.4 (0.7)	1.7 (1.1)	1.8 (1.2)	2.1 (1.2)	1.3 (0.6)
Uncomfortable	2.6 (1.8)	3.1 (1.7)	2.7 (1.7)	2.2 (1.7)	2.5 (1.7)	2.4 (1.6)	2.2 (1.4)	2.2 (1.5)	2.1 (1.4)	2.3 (1.5)	2.4 (1.6)	2.5 (1.5)	2.2 (1.5)
Distracting	3.8 (1.9)	4.6 (1.8)	4.1 (1.9)	3.1 (1.8)	3.4 (1.9)	3.2 (1.7)	3.3 (1.8)	3.2 (1.8)	2.9 (1.7)	3.7 (1.8)	3.6 (1.9)	3.8 (1.8)	3.3 (1.9)
Independent	5.5 (1.4)	5.2 (1.3)	5.7 (1.1)	6.1 (1.0)	6.1 (1.0)	6.0 (1.0)	5.8 (0.8)	6.2 (0.9)	6.1 (0.8)	6.1 (0.7)	6.1 (0.8)	5.8 (1.0)	6.2 (1.0)
Need Help	3.1 (1.7)	2.6 (1.3)	3.4 (1.7)	3.1 (1.6)	3.2 (1.3)	2.8 (1.5)	3.5 (1.6)	2.6 (1.7)	3.1 (1.6)	3.2 (1.5)	3.1 (1.6)	2.8 (1.3)	3.1 (1.6)
Need Device	4.4 (1.7)	3.1 (1.3)	4.6 (1.6)	5.0 (1.4)	4.9 (1.4)	4.8 (1.5)	5.0 (1.4)	5.3 (1.4)	5.6 (1.2)	4.6 (1.3)	4.4 (1.5)	4.0 (1.6)	5.4 (1.4)
Cool	3.6 (1.6)	3.1 (1.5)	3.7 (1.6)	4.4 (1.4)	4.3 (1.4)	4.1 (1.4)	4.5 (1.1)	4.4 (1.4)	4.5 (1.4)	4.3 (1.4)	4.5 (1.6)	4.2 (1.4)	4.5 (1.3)
Nerdy	3.6 (1.9)	4.5 (1.7)	3.5 (1.8)	2.6 (1.6)	2.7 (1.5)	2.9 (1.5)	2.8 (1.6)	2.8 (1.6)	2.7 (1.7)	2.7 (1.5)	2.6 (1.5)	2.8 (1.6)	2.5 (1.4)
Useful	5.1 (1.4)	4.5 (1.5)	5.2 (1.5)	5.6 (1.3)	5.3 (1.4)	5.3 (1.4)	5.2 (1.5)	6.4 (0.8)	6.2 (1.0)	5.2 (1.3)	5.0 (1.6)	4.7 (1.5)	5.7 (1.2)
Unnecessary	3.8 (1.8)	4.6 (1.6)	3.6 (1.8)	3.0 (1.7)	3.0 (1.6)	3.1 (1.7)	3.1 (1.7)	2.5 (1.4)	2.2 (1.3)	3.4 (1.6)	3.7 (1.7)	4.0 (1.6)	2.6 (1.5)

Table 5. Mean values and standard deviations for Likert-scale questions.

	E1 (U)	E1 (p<)	E1 (r)	E2 (X^2)	E2 (p<)	E3 (X^2)	E3 (p<)	E4 (X^2)	E4 (p<)
Awkward	5357	0.03	0.16	21.664	0.0001	8.042	0.045	11.648	0.009
Normal	3737.5	0.031	0.16	13.744	0.001	3.301	0.348	2.911	0.405
Appropriate	3538.5	0.007	0.20	18.75	0.0001	15.623	0.001	37.523	0.0001
Rude	5506	0.008	0.19	21.864	0.0001	7.433	0.059	30.809	0.0001
Uncomfortable	5427	0.017	0.17	12.749	0.002	3.686	0.297	4.699	0.195
Distracting	5634	0.004	0.21	14.664	0.001	3.61	0.307	4.612	0.202
Independent	3720.5	0.023	0.16	16.08	0.0001	15.572	0.001	8.292	0.04
Need Help	3868.5	0.063	0.13	1.574	0.455	20.56	0.0001	3.96	0.266
Need Device	2433.5	0.0001	0.41	2.556	0.279	17.406	0.001	45.201	0.0001
Cool	3815.5	0.052	0.14	11.734	0.003	5.171	0.16	3.505	0.32
Nerdy	5736	0.002	0.23	16.047	0.0001	2.026	0.567	1.924	0.588
Useful	3543	0.007	0.19	5.612	0.06	61.874	0.0001	21.711	0.0001
Unnecessary	5646	0.003	0.21	8.73	0.013	23.495	0.0001	36.078	0.0001

Table 6. Test scores and p-values for the 4 experiments. For Experiment 1, effect size is included, calculated as Z/sqrt(N). Shaded cells indicate attributes with a significant main effect (p<.05) for that experiment.

the coding scheme. The two authors each coded the 1281 explanations separately then resolved disagreements. Please see section 4.3.5 for details about coded themes and inter-rater reliability using Cohen's kappa (Cohen, 1960).

4.3.1 Experiment 1: Effects of Perceived Disability

Experiment 1 revealed that the perceived change in the actress's disability status (based on the visual indicator of AT accessories) had a direct impact on the reported social acceptability of wearable computer use.

E2: Disclosure of Disability Status
General Disability vs. No Information: General Disability was less awkward‡, more normal‡, more appropriate‡, less rude‡, less uncomfortable‡, less distracting‡, more independent‡, more cool‡, less nerdy‡, less unnecessary†
Blindness vs. No Information: Blindness was less awkward†, more normal‡, more appropriate‡, less rude‡, less distracting†, more independent‡, more cool†, less nerdy‡, less unnecessary†
E3: Disclosure of Assistive Purpose
Assistive Use vs. General Assistance: Assistive Use was more appropriate†, more independent†, needed device more‡, more useful‡, less unnecessary‡
Assistive Use vs. No Use Description: Assistive Use was more useful‡, less unnecessary‡, needed device more‡
Personal Use vs. General Assistance: Personal Use was more appropriate†, more independent‡, needed help less‡, more useful‡
Personal Use vs. No Use Description: Personal Use was more appropriate†, more useful‡
E4: Disclosure of Video Recording
Assistive Use vs. Camera Only: Assistive Use was more appropriate‡, less rude‡, needed device more‡, less unnecessary‡
Assistive Use vs. Camera Recording: Assistive Use was more appropriate†, less rude†, needed device more‡, more useful†, less unnecessary‡
Assistive Use vs. Personal Use: Assistive Use was less awkward‡, more appropriate‡, less rude‡, more independent†, needed device more‡, more useful‡, less unnecessary‡
Camera Recording vs. Personal Use: Camera Recording was more appropriate‡, less rude†
Camera Only vs. Personal Use: Camera Only was more appropriate†, needed device more†, less unnecessary†

Table 7. Significant pairwise comparisons from Experiments 2 through 4. † denotes significance at p<.05; ‡ p<.01.

Overall Effect of Disability on Social Acceptability. A Mann-Whitney U test was used to compare the 13 scale questions across the two video conditions. There was a main effect on 11 of the 13 scales (see Figure 7). Participants who viewed Video 1 (*Visible Disability* condition) rated the interaction less awkward, more normal, less rude, more appropriate, less uncomfortable, and less distracting; rated the actress less nerdy, more independent, and thought she needed the device more; and rated the device more useful and less unnecessary (see Table 6 for p-values and effect sizes).

Manipulation of Actress's Disability. To determine the effectiveness of the video manipulation and to assess whether participant responses correlated directly with participant's awareness of the actress's disability (as opposed to some

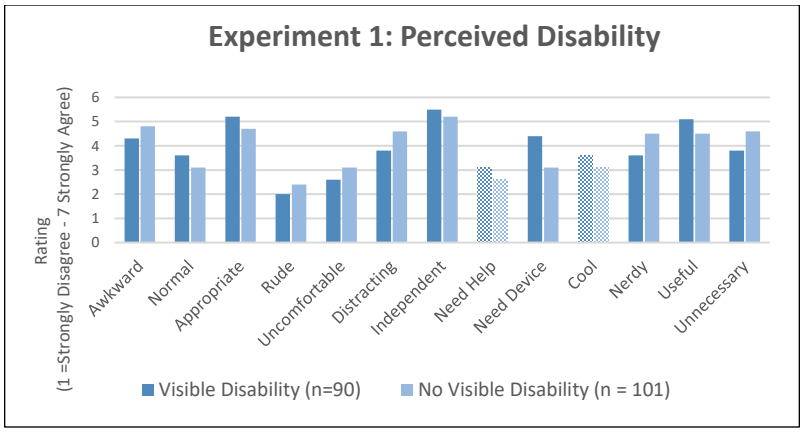

Figure 7. E1 graph of perceived disability ratings on 13 scale questions. Significant effects (solid) were seen on 11 of 13 (all but *Need Help* and *Cool*) dimensions.

other random factor), a qualifying question was placed at the end of the survey: *"In the video you watched, did the person have a disability?"* with response options: *Yes, No, and Not Sure.*

Of the 101 participants assigned to the '*No Visible Disability*' condition (Google Glass only), 62 (61.4%) indicated that the actress was not disabled, 39 (38.6%) responded 'Not Sure', and no participants reported the actress as having a disability. For those participants who viewed the *'Visible Disability'* condition (Google Glass with sunglasses and a white cane), 60 of 90 participants (66.7%) indicated that the actress had a disability, 24 (26.7%) were unsure, and 6 (6.7%) said the actress was not disabled. A Chi-square test demonstrates the response difference as statistically significant between the two video conditions: X^2 (2, N = 191) = 109.42, $p < .01$. The qualifying question (free text) responses were also analyzed to gauge the perceived disability status of the actress. Of the 90 participants who viewed Video 1 (*Visible Disability* condition), 38 (42.2%) mentioned blindness, 5 (5.5%) mentioned a cane or walking stick, and the remaining 47 did not mention either of those things.

To further understand if awareness of the actress's disability directly impacted social acceptability of device use, a Kruskal-Wallis test was conducted on

Yes vs. Not Sure: Yes was less awkward†, more normal‡, more appropriate‡, less rude‡, less uncomfortable‡, more independent‡, needed device more‡, more useful‡, less unnecessary‡
Yes vs. No: Yes was more normal†, more appropriate‡, less rude‡, less distracting†, less uncomfortable‡, more independent‡, less nerdy†, needed device more‡, needed help more†, more useful‡, less unnecessary‡
Not Sure vs. No: Not Sure needed device more†

Table 8. In Experiment 1, participants' awareness of the actress's disability affected their assessment of the interaction. Participants considered the interaction more positively when they believed the actress had a disability. † denotes significance at p<.05; ‡ p<.01.

all 191 participants assigned to Experiment 1 to determine whether the participants' disability determination (*Yes, No, or Not Sure*) affected their ratings on the 13 social acceptability dimensions (see Table 3). Overall, the findings revealed that those who considered the actress to have a disability rated the actress, the device, and device interaction more favorably on 11 dimensions than those who did not and more favorably on 9 dimensions than those who were unsure of the actress's disability status (see Table 8).

Misconceptions About AT Use. Review of participant commentary revealed that confusion existed as to why someone with a visual impairment might use a device with a screen:

> *"The only thing I thought was weird is that for Google Glass, you need to be able to see; it looked like the lady had vision issues so it looked kind of incompatible. But maybe she only had partial blindness and so google glass helps her in some way."*

This quote demonstrates the misconceptions surrounding disability and AT use and is consistent with prior studies of mobile technology use by persons with disabilities (Kane et al., 2009; Shinohara & Wobbrock, 2011). Such perceptions may be met with greater confusion for individuals with 'invisible' disabilities as their disability is likely to go unrecognized altogether. This ambiguity sheds light on

realistic outcomes that persons with disabilities might be required to navigate with respect to accessible computing device use.

4.3.2 Experiment 2: Disclosure of Disability Status

Experiment 2 was conducted to understand if altering the amount of information disclosed about the actress's disability changed participants' judgments about device use. This experiment differed from Experiment 1 in that participants were directly informed of the actress's disability through explanatory text. The goal of this experiment was to see if explicitly conveying the actress's disability (versus the visual cues of a video) impacted participants' perceptions and whether or not those attitudes were further influenced by knowing additional details about the specific type of disability (e.g., learning that the actress was blind?).

As seen in Figure 8, when the actress was described as either blind or disabled, in comparison with no disability description, participants considered device interaction significantly less awkward, more normal, more appropriate, less

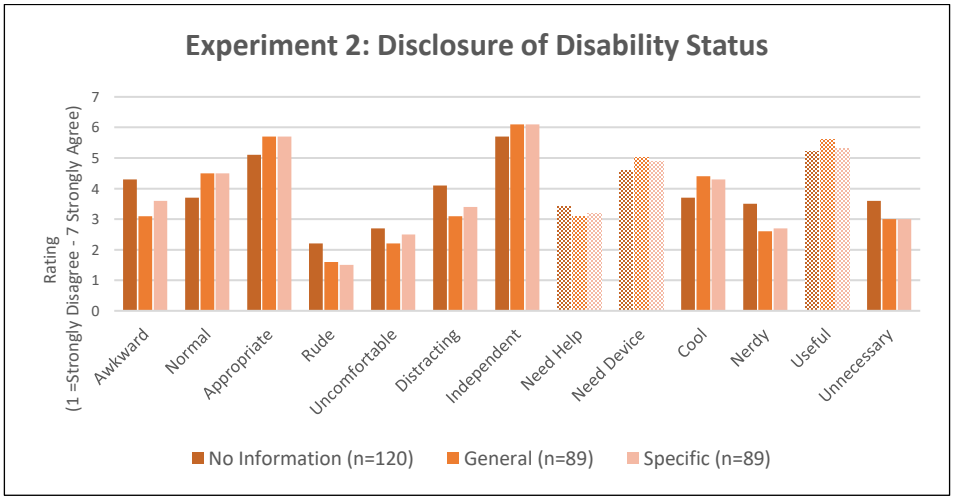

Figure 8. E2 graph of disclosed disability status ratings on 13 scale questions. Significant effects (solid) were seen on 10 of 13 (all but *Need Help, Need Device,* and *Useful*) dimensions.

rude, less uncomfortable, and less distracting; considered the actress more independent, more cool, and less nerdy; and considered the device less unnecessary (please see Table 7 for further details on significant pairwise comparisons).

As in Experiment 1, the results revealed that device interaction was rated more positively if participants' considered the actress to have a disability. There, however, was little evidence that additional disclosure about the actress's disability status (e.g., blind) altered participants' assessments (see Table 5, E2-Dis vs. E2-Blind). This may be because participants automatically inferred the actress's specific disability (blindness) based on the visual cues presented in the video.

4.3.3 Experiment 3: Disclosure of Assistive Purpose of the Device

In some instances, knowing if a device is being used for assistance (versus a superfluous activity) can generate greater bystander patience and awareness about how to interact with the end user. For example, it is common for those with a visual impairment to use a white cane to signify to others that they may require more time executing certain activities (e.g., crossing a street). Experiment 3 focused on understanding whether conveying greater context about device use positively influenced participant decisions. This was of particular interest given that Experiment 2 showed little evidence that disclosing additional information about participants' judgments about device use hold if the device was being used explicitly for accessibility purposes (checking a bus route) versus more personal activities (checking email).

As seen in Figure 9, significant effects were seen across 7 of the 13 dimensions. As reflected in the mean scores presented in Table 5, participants rated device interaction more positively when provided with more detail about how the device was being used (versus when no specific use case was described).

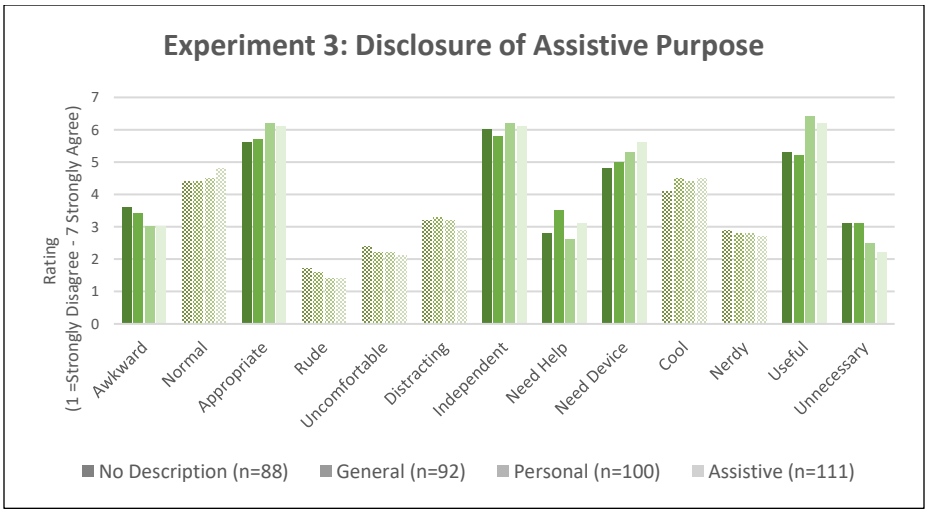

Figure 9. E3 graph of assistive purpose ratings on 13 scale questions. Significant effects (solid) were seen on 7 of 13 dimensions.

Significant pairwise comparisons are shown in Table 7. There was a significant effect of experimental condition on awkwardness ($p<.05$) but no significant pairwise interactions after post-hoc correction. Unlike Experiment 2, the results indicated that the device was viewed significantly more positively when the specific assistive or personal use case was known (in comparison to the *No Use Description or General Assistance use cases).* There were no significant effects between the *Assistive Use* and *Personal Use* conditions.

4.3.4 Experiment 4: Disclosure of Video Recording

Numerous related works have looked at the assistive potential of worn cameras (Afinogenov et al., 2016; Hayden, 2014; Hernandez & Picard, 2014; Hodges et al., 2006; Marcu, Dey, & Kiesler, 2012; Voss et al., 2016; Xu et al., 2016; Zhao, Szpiro, & Azenkot, 2015). However, the power of video capture as an accessibility feature is at odds with the growing privacy concerns surrounding this technology.

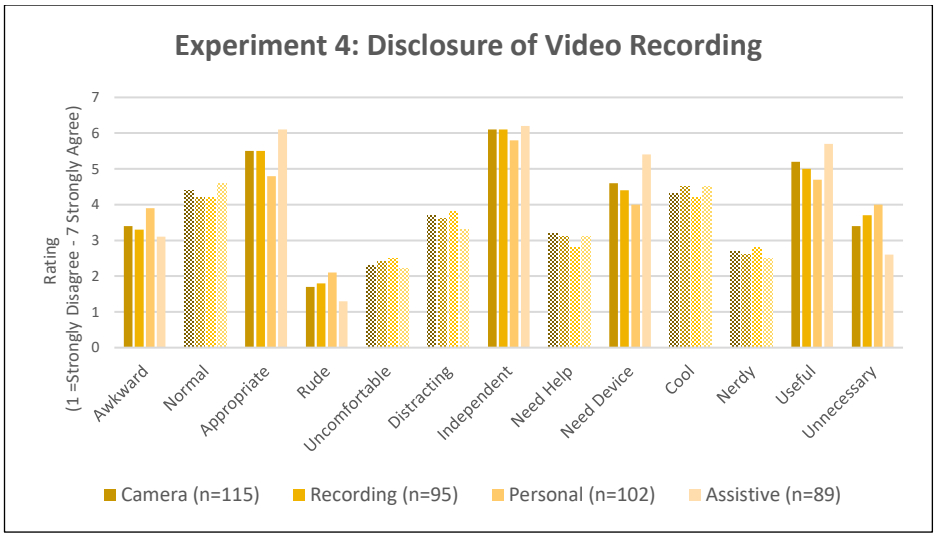

Figure 10. E4 graph of video recording ratings on 13 scale questions. Significant effects (solid) were seen on 7 of 13 dimensions.

Experiment 4 was designed to evaluate whether the assistive context of device use alters participants' perceptions of video recording devices. Similar to Experiment 3, there was particular interest to see if disclosing incremental amounts of contextual information about device use (assistive versus personal versus non-assistive) influenced participants' impressions. Figure 10 shows the significant main effects across 7 of the 13 scale questions.

Participants rated (mean scores) the assistive scenario (versus the non-assistive *Camera Only* condition) more positively across 12 of the 13 dimensions yet indicated that they thought the actress needed the device more. Interestingly, device use was rated as significantly less appropriate when described as being used for a personal purpose (*"using a video camera for a personal photo album")* versus the other three use cases (*Camera Only, Camera Recording, Assistive*). Though it was conjectured that providing more information about the recording device would alleviate bystanders concerns about misuse, the findings indicate that this is not so. Disclosing more information about device use primarily appeared to positively affect judgments within the context of assistance – highlighting the pervading controversial attitudes toward public video recording in general. No significant

differences were found about device acceptability between the recording (*Camera Recording*) and non-recording (*Camera Only*) scenarios.

4.3.5 Qualitative Evaluation

To expand on the experimental findings, participants were asked directly to indicate whether they thought it was more or less acceptable for an individual with a disability to use a wearable computing device. For ease of analysis, findings were analyzed across all experiments.

Participants were asked, *"In general, does your opinion of the social acceptability of using a device like this change if the wearer has a disability?"* Of the 1281 respondents, 524 (40.9%) indicated that this information would have a positive influence, 242 (18.9%) stated that it would have a strong positive influence, and 500 participants (39%) indicated that the disability status of the user would have no influence on their overall opinion of device acceptability. Only eight participants (0.8%) responded that this information would have a negative influence on their judgment, while seven participants (0.5%) indicated this information as having a strong negative influence on their opinions.

Participants were then asked to expound on how this information would influence their opinion. Qualitative coding was performed on the open-response commentary to identify major themes and patterns with respect to the social acceptability of device use.

Using the device was more acceptable for a person with a disability because it helped them (654, 51%, κ=0.75). Participants primarily commented on the potential advantages of wearable computing devices for accessibility. Some

participants indicated device necessity as positively influencing bystander impressions:

> *"I would be less likely to form a negative opinion of a disabled person wearing such a device, because I would likely believe that it was helpful or necessary for them. A non-disabled person using such a device in public is more likely to seem obnoxious."*

Others cited independence as one of the major factors behind device appropriateness: "*I think that disabled persons should be helped to be more independent and to function in society as best they can. So it would be totally socially acceptable to me that the young blind lady would use this device to help her get around and do things that she needs to do in an independent fashion."* Some participants even posited how such a device could revolutionize activities of daily-living:

> *"as a former physical therapy tech, I can see the need for this device for use with people with disabilities. It would open doors for them that they didn't have before. Maps, directions, traffic warnings of when to cross streets."*

Due to this participant's occupation, they may likely have an increased understanding of the potential of such a device for accessibility purposes. In addition to those who viewed the device as strictly necessary or helpful, other participants expressed extreme enthusiasm for the possibilities of such AT, positioning the device "cool".

Using the device was less acceptable for a person without a disability because it was not needed (118, 9.2%, κ=0.61). Comparatively, the second largest theme documents participants' changing attitudes toward those who may use such a device in public without a legitimate need. For non-assistive applications, participants positioned this device as an overpriced toy - *"for many*

people, not disabled, it's just another toy for the well-to-do" - designed to show off or isolate themselves from social interactions:

> *"I thought it was helping her in some way. That it was something allowing her to maneuver safely. So I immediately thought that she needed it or it was useful. If someone without a disability is wearing it, I wouldn't think they needed it at all. I would see them more negatively, like arrogant, in the way, distracting, rude, and show-offy."*

Concerns about recording (34, 2.7%, κ=0.68). Recurring concerns around video recording surfaced as a theme. A number of participants explicitly discussed the trade-offs between the benefits of the technology versus the potential cost to privacy:

> *"It really depends how the device is used. If the device is helping a visually disabled person navigate the surroundings, then I think it's OK. If that same person was using the device to just record everything, then it's probably not OK."*

In some cases, the fact that the user might be disabled made this less of a concern:

> *"You figure a handicapped person isn't going to use a device to secretly record you and put it on Youtube, you figure they have more of a need to have special devices."*

Though, the findings from Experiment 4 demonstrate the complexity of the reasoning behind this statement. On the other hand, one participant suggested that limited user awareness could pose a greater risk to privacy:

> *"It could be negative in this case because the blind person does not know what she is recording. She didn't appear to be filming her family, so why would she want video of people she didn't know?"*

Using a HMD would not be beneficial to a blind person because the interface is primarily visual (33, 2.6%, κ=0.76). As previously reported, some participants expressed confusions as to why an individual with a vision impairment would use a head-mounted display. This ambiguity resulted in a number of

misconceptions about the user (if the actress was truly visually impaired) and the capabilities of the device (assuming it only provided visual feedback):

> *"The wearable device is purely visual and the person was blind, so it made no sense."*

In fact, the majority of individuals with a vision impairment still have some vision intact, indicating the lack of societal awareness surrounding this disability[27].

Comparisons to other forms of AT (28, 2.2%, κ=0.82). Participants also justified the acceptability of a wearable computing device based on existing policies related to accessibility and use of other types of assistive technologies:

> *"I think if it is something that helps the person, than [sic] it should be more accepted. Think of a seeing eye dog in a grocery store or restaurant. It is frowned upon for many people but accepted for people with disabilities, as it should be."*

Interestingly, this comparison extended to general differences in societal standards surrounding disability:

> *"Some people find it disrespectful to wear sunglasses in all settings (such as indoors). The user's blindness excuses her from such expectations."*

Using the device could cause problems for a person with a disability due to a lack of situational awareness (8, 0.6%, κ=0.62). Some participants expressed concerns about the possible dangers that may accompany device use. One reason for this negative opinion was to suggest that a person with a disability might be especially vulnerable to distractions from technology:

> *"I think if person already has [a disability] they need less distraction and [a] wearable computing device in public can be more harmful."*

[27] http://www.afb.org/info/living-with-vision-loss/for-job-seekers/for-employers/visual-impairment-and-your-current-workforce/learning-about-blindness/12345

4.4 Discussion

In general, public HMD use was deemed more socially acceptable when the user was considered to have a disability or used the device for an assistive application. As seen in Experiments 1 and 2, this interaction was consistent independent of whether or not the disability was inferred or explicitly mentioned, respectively. However, opinions toward device use were rated less positively for a non-disabled user. As expressed by some participants, one may not always be able to reliably identify if an individual has a disability based on appearance alone. While directly disclosing the use of the AT resulted in more positive ratings, realistically this is less likely to occur in real life – posing an inherent challenge surrounding the expectations of wearable computing AT use. Though it's unrealistic to assume that all AT users will explicitly divulge device use to bystanders to generate greater social acceptance, there may be opportunities to integrate or combine AT symbolism into the device to communicate the assistive context of use. The inclusion of cosmetic features that an end user can toggle on and off as needed can provide a user with increased control of how to communicate relevant information to the outside world.

The findings from Experiment 2 revealed that knowing more information about a user's disability status did not significantly affect bystander attitudes, indicating that perhaps conveying only the most basic of information is all that is needed to adequately influence societal attitudes about AT use. We see this (varying levels of information) effectively implemented in some existing forms of AT. For example, in the United States one may inquire as to whether a service animal performs an assistive function but may not directly ask the user what the specific function is. The findings, however, may have been influenced by the specific disability depicted in this study, as it may have been easier for participants to

directly assume the type of disability without being explicitly told. Thus, future work may benefit from looking at disclosing incremental levels of information about less conspicuous disabilities or individuals with multiple disabilities.

In addition to uncovering the impact of disability status on device acceptability, the findings revealed that providing additional information about the device's context of use positively influenced perceptions. The exception to this was the description of video recording for personal use. Based on the findings, it is difficult to know whether these negative ratings were generated from the current privacy concerns surrounding wearable cameras, the fact that participants considered this type of use superfluous given that the actress was blind (and therefore might not need a photo album), or a combination of the two.

Aside from the *Personal Use* video recording condition, participants tended to rate both the actress and device interaction more positively when the device was being used for an assistive application. This overall positive tendency led to some counter-intuitive trends in the ratings and also puts forth unique implications for the social acceptability of public wearable computer use. For example, open response commentary revealed that participants considered the device to be more "normal" when they believed that the actress was disabled. This is unexpected as we can presume that, in general, it's less common to see someone with a disability versus someone without a disability. This outcome may be due to several reasons: it may be that participants considered it normal for a person with a disability to use AT in public, or individuals may still harbor polarizing attitudes toward head-mounted display use, or participants may simply have a more positive impression of the actress overall when she is identified as disabled because of some halo effect (Thorndike, 1920). Likewise, the Likert-scale ratings revealed that participants rated the actress as significantly more "independent" when she was described as being disabled: this may be because the concept of independence is particularly

salient when considering a person with a disability and may have been further influenced by the fact that the disabled actress was represented in the video scenario as navigating the world in an independent fashion. Or, participants may have viewed the presence of the HMD in particular as enabling an independent lifestyle. While this study was restricted to one type of disability representation and one type of wearable computing device, exploring the motivations for these judgments with respect to other types of disabilities or computing technologies presents an exciting opportunity for future work.

4.4.1 Implications for Wearable Computing Design and Policy

While these findings cannot generalize across all disabilities, assistive technologies, or on-body computing devices, awareness of the relationship between disclosure and device acceptance has implications for considering how we design both assistive and non-assistive wearable computing devices and how to set proper policy for using such devices in public settings.

Prior research has documented the concerns surrounding conspicuous AT use (Kane et al., 2009; Shinohara & Wobbrock, 2011) often resulting in persons with disabilities choosing mainstream devices, in part due to a desire to blend in (Kane et al., 2009). This sentiment is somewhat at odds with the results of this study as bystanders appeared to be more positive about the actress when they were aware that she was using AT. Thus, are devices that look more assistive in nature more socially acceptable? Perhaps some AT does a better job of mediating societal response. For example, service dogs can often be identified by their distinctive harness, and it is less likely that someone will be questioned about a dog that appears to be a service dog. This may also be, in part, due to greater societal awareness of these AT symbols. Implementing more universal disability imagery

that can be disclosed at the discretion of the user may prove beneficial for navigating societal boundaries and expectations with respect to AT use.

While this study revealed that bystanders had a more positive attitude about a device when informed that it was being used for an assistive purpose, disclosing information about one's disability may directly conflict with the user's desire for privacy. In order to balance accommodation and user privacy, some of our participants noted that people with disabilities may need special privileges for using technology just as they currently have special privileges when bringing service animals into public places. As this study highlighted that not all participants knew why the device was being used, enabling individuals with disabilities to use new forms of AT in public while maintaining their privacy may involve a combination of social norms and policies, design changes to the AT itself, or software modifications (e.g., forcing devices to stop recording in public spaces or using privacy-preserving algorithms, such as blurring bystander faces when capturing images in public).

CHAPTER 5

STUDY 2: AESTHETIC MODIFICATION OF HEARING AIDS AND COCHLEAR IMPLANTS IN AN ONLINE COMMUNITY

Study 1 demonstrated that societal attitudes of a wearable computing device may change based on the assistive context of device use. However, this remains at odds with the empirical evidence suggesting a lack of desire (at times) for individuals with disabilities to wear or use assistive devices that can highlight their disability (Kane et al., 2009; Shinohara & Wobbrock, 2011). This is perhaps due to the fact that mainstream devices such as Google Glass or smart phones were not developed solely as an assistive device and therefore are not ascribed the same societal meaning as a dedicated assistive device such as a hearing aid or a white cane. Consequently, individuals who depend on a dedicated assistive device for activities of daily living may not have the same level of control in how the device (and what it conveys about the user) is presented to the world. In light of these considerations, we have begun to see a recent shift toward Do-It-Yourself (DIY) modification of assistive technology (AT) for the purposes of self-expression and to instill a sense of pride in users. To better understand how individuals with disabilities, as well their friends, family members, and caregivers, customize their AT to achieve aesthetic goals and personal empowerment, I studied an online community dedicated to sharing aesthetic modifications of hearing aids (HAs) and cochlear implants (CIs)[28]. This study answers the second research question:

> **What behaviors, opinions, and feelings are expressed in online communities regarding aesthetic qualities of worn assistive computing technology?**

[28] Portions of this chapter are adapted from (Profita, Stangl, Matuszewska, Sky, & Kane, 2016)

This study revealed not only how individuals are customizing their assistive devices but shed light on the community at large and its role in supporting DIY and customization practice AT practice.

5.1 The Online Community

For this study, I looked to a growing online Facebook (FB) community actively engaging in DIY modification of hearing aids (HAs) and cochlear implants (CIs). Online communities for disability support have been an emerging area of study (Bigham, Ladner, & Borodin, 2011; Cavender, Otero, Bigham, & Ladner, 2010) as they can provide a means for individuals to build connections and a support network when they may otherwise lack a physical equivalent.

An initial review of online communities in the fall of 2015 revealed this Facebook group to be the only highly active online presence of members engaged in DIY customization of HAs and CIs. Upon initial consultation with the University of Colorado Boulder's International Review Board (IRB), I reached out to the Facebook community's group administrators to establish myself and fellow authors as researchers in order to operate with complete transparency. We received FB administrator and IRB approval to conduct this research. To respect the privacy of group members and to adhere to IRB guidelines, data analysis and reporting are limited to trends observed from community activity. For specific quotes and images, I obtained consent directly from individual group members.

5.2 Method

Data collected for analysis included FB posts made from September 1, 2015 – December 31, 2015, resulting in a total of 365 posts. This timeframe was selected in order to capture DIY customization activity revolving around multiple seasons and holidays. At the time of data capture, this FB community had 10 administrators and 4,830 community members.

Data was saved as an immutable html snapshot to prevent the possibility of new or deleted postings altering the raw dataset throughout the period of data analysis. While this FB community also hosted a discussion page and marketplace, data analysis was restricted to the group's main wall (designated for sharing HA and CI customizations) as I was primarily interested in analyzing customization activity. Identifiable community member information was removed and replaced by unique IDs for members, posts, and comment threads. The FB data were parsed by photo, post, comment, and comment replies. For this study, only photos and initial posts were analyzed as comment threads appeared to be primarily brief reactions to posts. The parsed data-set and anonymized FB html page were used to conduct open-coding of the 365 posts.

5.2.1 Data Analysis

An open-coding approach based on Corbin & Strauss's (Corbin & Strauss, 2015) methodology was used for analyzing the 365 data points (Facebook posts) from the group's main wall. The first stage of analysis entailed reviewing the data to uncover underlying themes and patterns. For this stage, a fellow researcher and I reviewed the first 50 data points to develop a coding manual. These codes were generated independently, and a third co-author was consulted to reconcile inconsistencies. The same two initial co-authors used the generated coding manual

to independently code an additional 40 data points to check for consistency. The finalized coding manual contained 11 codes and definitions (see Table 9) denoting the general types of post activities with respect to community involvement, customization themes, customization methods, resources and trade-offs, personal experiences, and the identity of the designer (e.g., if the customization was made for oneself or for another person). The remaining data was coded independently by two co-authors according to the coding definitions. All posts were coded twice, once referring to the text descriptions that accompanied the posts and once referring to the image itself (as it was noted that some FB group members did not provide the appropriate alternative text with images – a requirement of the FB group enforced by the group's administrators). Posts containing multiple themes were coded for each theme. Inter-rater reliability, the probability of random agreement, and Cohen's kappa (Cohen, 1960) for each category can be found in Table 9.

Code	Definition	Inter-rater Reliability	Prob. Rdm Agreement	κ
Community Participation	Community building, appreciative comments, comments on group etiquette.	98.36%	71.44%	0.94
Questions	Questions about potential customizations (e.g., materials, suitability of specific devices for customizing).	98.63%	61.63%	0.96
Resource Sharing	Posts sharing DIY materials, supplies, or deals that one has decided to share with the group.	98.08%	86.06%	0.86
Social Factors	References about perceptions, pride, shame, attitudes about using one's AT.	98.63%	70.55%	0.95
Shared Excitement	General excitement and anticipation to participate in DIY customization.	98.08%	72.33%	0.93
Design Aesthetics	Customizations that reflect themes: holidays, sports teams, clothing/nail coordination, seasons, life events, etc.	95.07%	51.59%	0.90
Sharing a Customization	General sharing of a customization or related post.	90.41%	52.45%	0.80
Tech Issues and DIY Trade-offs	General lessons learned, impromptu modifications, appropriations, or technical issues or challenges with devices or customizations.	96.71%	67.00%	0.90
Stories and Experiences	Sharing one's AT or customization experience.	96.16%	62.53%	0.90
Post for Self	Member is posting on behalf of themselves.	98.08%	61.89%	0.95
Post for Another	Member is customizing on behalf of another.	96.71%	55.85%	0.92

Table 9. Categories of analyzed posts, including code name, code definition, and inter-rater reliability (reported using Cohen's Kappa, κ). Categories are not mutually exclusive.

A second stage of analysis was conducted following the initial open-coding analysis. Once all posts were coded according to the 11 major themes, each theme category was analyzed separately by two co-authors to identify the specific types of community questions being asked, the particular customization methods, themes, materials used, and the types of challenges and trade-offs that emerged.

5.3 Results

A number of insights were generated regarding the types of AT customization activity that emerged as well as how the FB group acts as a support mechanism for this growing online community. It should be noted that the type of AT customizations observed in this FB group often highlight or showcase one's device conspicuously, which appears to be in direct contrast to the industry standard which trends toward discretion through the offering of predominantly neutral-colored (flesh and hair tone) devices (see Appendix A) with increasingly smaller footprints[29]. The following section presents themes and trends with respect to: 1) who participates in AT customization of HAs and CIs, 2) the types of posts community members made (revealing community interactions), 3) the ways in which individuals customize their AT, 4) customization design themes, and 5) the challenges and trade-offs that arose from AT customization.

5.3.1 The AT Customization Community

One-hundred ninety-one individual group members contributed to the 365 analyzed posts. Of these 191 community members, 133 posted only one time, 27

[29] http://www.npr.org/sections/health-shots/2013/04/08/176225511/listen-up-to-smarter-smaller-hearing-aids

posted two times, and 31 individuals posted three or more times (*M=1.9, SD=2.6*). In posts, group members often referred to AT customization as 'blinging' or 'pimping'. While an exact gender ratio of participating FB members could not be derived, a script was used to collect the gender of any poster who included their gender in their public FB profile. Of the 191 individual posters, 150 disclosed their gender (143 female, 7 male). This skew towards female participation aligns with prior research documenting decision-making within fashion-oriented online communities (Said, Burton, Hurst, & Kane, 2014) and is of interest for this study to better understand who, in particular, this customization activity supports.

While an exact breakdown of the age distribution for the dataset could not be determined, there was evidence that AT customization spanned multiple age groups, from children to elderly individuals, but trended towards young adult. In lieu of age-related data, the researchers recorded how many posts appeared to be of designs made for oneself, and how many designs appeared to be made for another person (e.g., a parent customizing a device for their child). 94 (25.8%) of the 365 posts were documented as a design customization that an individual clearly made for themselves (κ=0.95), while 177 (48.5%) posts were made depicting customizations clearly created for somebody else (κ=0.92):

> *"My 1st proper attempt at pimping my granddaughters [sic] CI'S. ..processors covered with purple craft tape and purple and silver sticky rhinestones...coils have purple and silver rhinestones right coil has a blue one in the middle the left coil has a pink one background is the arm of my red sofa..."*

In line with this quote, it was observed that many posts related to parents or caregivers posting on behalf of children. Though an extensive analysis of the third-parties was not conducted, a keyword search revealed that 22 of 365 posts (6%) contained the word "son" and 45 posts (12.3%) contained the word "daughter". The

higher prevalence of documented female versus male children is consistent with the overall gender representation of this community.

Other posts were shared on behalf of another person even if they (the poster) did not directly create the customization:

> *"The girly amazes me everyday. Today she had to wear her spare (unpimped) aids as one of her others was playing up.En route to college by taxi she messaged to say she would try to pimp her aids with some craft tape.Completely blind"*

Here, the act of posting on someone else's behalf may be viewed as a celebration of this activity and desire to share such a story with others. The fact that the subject of the post also has a visual impairment challenges notions that individuals who are blind do not care about the appearance of personal objects *and* demonstrates the importance of this activity in establishing user agency.

5.3.2 Types of Posts

The 365 posts were analyzed to understand what types of content members posted about to the community. It was observed that posts generally fell into one of five categories: 1) sharing customization content, 2) asking questions, 3) sharing advice, resources, and tips, 4) sharing life experiences, and 5) administrator curation. Often, posts fell into more than one category (e.g., sharing a customization and sharing an experience). The types of posts are discussed in order from most frequently occurring to least frequently occurring.

Sharing Customization Content. Sharing a customization was the predominant activity posted to the main wall, representing 330 of 365 posts (90.4% of posts, $\kappa = 0.80$). This typically involved a member posting one or more images with alternative text describing a particular customization made to a hearing aid,

cochlear implant, or other type of AT (though less frequent). The types of customizations made as well as the design themes that emerged will be analyzed in greater details in sections 5.3.3 and 5.3.4, respectively. Sharing a customization might also involve asking questions, sharing resources, and sharing experiences, as described below.

Asking Questions. Since many designs involved repurposing craft materials, FB group members often asked questions about where to acquire materials or supplies (see Table 10 for a breakdown of the types of questions asked). Asking questions was the second most common posting activity, with 102 of 365 posts (27.9% of posts, $\kappa = 0.96$) falling into this category. Members would also solicit feedback on their work, ask for examples of specific techniques, or request recommendations on less common designs. One member asked:

"hy all..This is my photowork. i like an art and photography. I want to pimp my hearing aids, but i'm tomboy. And i'm not like a feminine. so, who can anyone help me how to make in accordance with my background tomboyish? Please.. and thank you more [sic]".

Description of Question Types	**#**
Questions about supplies: e.g., design techniques, where to get specific materials, tools for fitting decorations to HAs, and HA cleaning supplies, as well as if specific types of supplies will work.	36
Questions/concerns about functionality: how to avoid damaging HA, making design robust to wear and tear, customizability of new HA models, removing sticky residue from previous designs.	19
Questions about how to use specific supplies or techniques: applying nail stickers or Washi tape.	14
Posts requesting group feedback: e.g., asking the FB group to help them choose between options.	14
Requests for examples and ideas: requesting gender specific ideas, handmade supplies, or examples of particular design themes.	11
Questions about deafness-related issues: how CIs will affect one's life, how to handle increasing deafness, how to negotiate challenges with equipment, who to contact in case of lost HAs, and where to get emergency referrals.	6
Requesting help: asking others in the group to customize their HAs.	2

Table 10. Categories of questions posed by FB group members.

Sharing Advice, Resources, and Tips. Oftentimes, as group members share their customizations, they include information about the quality of products, where they obtained materials, or the best techniques implemented. Of the 365 posts analyzed, there were 25 total instances (6.8% of posts, (κ=0.86) of resource sharing (see Figure 11); 6 instances of people sharing items on sale; 14 posts about where to obtain resources; 3 instances of posters providing material/technique reviews, feedback, or commentary; one instance of a person sharing information about a news media event about device customization; and one instance of a person sharing a tutorial about their design process.

Figure 11. Low-cost nail foil material posted to the community.

Sharing Life Experiences. Group members also posted details about their lives to the FB group. The level of detail varied greatly, but in many cases the anecdotes provided a sense of context to one's modification activity. These posts comprised 25 of 365 posts (6.8% of posts, κ=0.90). A number of posts included

anecdotes about the challenges of wearing HAs or CIs, expressing optimism about the prospect of customizing their AT to combat some of these challenges:

> *"Thank you for accepting me! I have had a hearing aid for almost a year now and am very conscious of it and hate having it on show. Now I have seen this page I can't wait to get pimping my aid and showing it off! Thank you!! X".*

In this example, the member expressed gratitude for finding the FB group. Consistent with this finding are other posts that conveyed appreciation for the FB group due to the fact that individuals had not previously been exposed to the option to modify their AT and were searching for people experiencing similar circumstances. Others expressed interest in customizing their devices to counter the dullness of plain HAs:

> *"Hi all thanks for letting me join! My son got aids today but is a bit upset at how dull they are so I showed him some pics I found online on pimped hearing aids he LOVES them my question is where do I get the stuff for them and how do I do it I'm so confused any help appreciated."*

As in this last example, we see that the prospect of pimping can lend to changing attitudes toward device use and may combat some of the emotional discomfort of wearing an HA. Multiple posts also describe circumstances where HAs have been lost or destroyed (e.g., chewed by a pet), as well as moments when members found ingenious ways to modify their AT to suit their needs.

Members also shared stories about modifying HAs to be representative of one's self, for example, how to find an appropriate aesthetic for being older in age, or finding resources to coincide with characteristics about the individual (e.g., trying to find decoration options for boys). Throughout the posts there is a general sense of excitement, positivity, and pride toward AT customization. Members report on instances when they received positive feedback about their HA from a stranger or acquaintances and expressed their excitement to show off their work to others:

"I wore Jamberry Jams today and my students loved the designs. I half joked "I'll bling your hearing aids and processors" and all six BOYS jumped at the idea. Here are a few of my creations."

Administration and Community Interactions. Ten FB group administrators were proactive in maintaining a strong sense of community. Their posts (and their presence) was aimed at reinforcing group etiquette through continual postings of the rules and responsibilities to the group (e.g., reminding members to provide alternative text descriptions to make the content accessible for members with visual impairments). There were 11 posts related to administration and community interactions (3% of posts, κ=0.97). In addition to maintaining community etiquette (e.g., no soliciting), administrators and members engaged in activities to strengthen the community at large, such as holding Halloween-themed customization contests. Administrators also polled the group to list where they were from or to post information in appreciation of local teachers. Other community building practices included providing useful information regarding proper and safe customization practices so as not to obstruct the functionality of the device and asking new members to read the rules and responsibilities (after which they would 'like' the page in recognition).

Figure 12. Examples of HA customizations: a) Commercially-procured HA with a purple ear base and a shimmering emerald ear mold, b) HAs with My Little Pony tube riders (third-party accessories), and c) DIY blue and silver glitter-decorated HAs with coordinated nails.

5.3.3 Types of AT Customization

Three distinct levels or, types, of customizations were observed: 1) the procurement of commercial devices, cases, and ear molds, 2) purchased third-party accessories, and 3) personal modifications using DIY materials (see Figure 12).

Commercially-Procured Customizations. Some users elect to purchase commercial HAs and CIs offered in different color options from manufacturers. While the number of options continues to remain limited (see Appendix A), more and more companies are offering color options, especially for children HA and CI users. Some cochlear implant companies also offer a number of mix-and-match case options for end users[30] (see Appendix B). Other individuals change the appearance of their device by opting for device covers[31] or colored ear hooks[32]. Customized ear molds are another popular item offered in a variety of colors and ornamentation options, such as glitter and gems embedded in the mold (see Figure 12a).

[30] http://www.medel.com/us/sonnet
[31] http://www.okmedical.com.mt/SubCategories/Nucleus-5-Coil-Sound-Processor-Covers/156
[32] https://www.phonak.com/us/en/hearing-aids/phonak-sky-v.html

Third-Party Add-On Accessories. It is common for members to acquire specialty accessories or charms from third-party companies to stylize their HA or CI. A number of these companies can be found on Etsy.com[33], Facebook product pages, or have personal product websites for customers to place orders. Third-party accessories include charms, clips, protective skins, colored tubes, and stickers, and range from purely ornamental to those offering dual functional benefits.

Charms. Charms encompass accessories that are purely decorative in nature. One popular company, Tubetastic Pimps[34], offers charms including "dangles" and items commonly referred to as "tube riders" which are outfitted with an aperture permitting for the charm to be attached to the HA tube (see Figure 12b). From the cartoon character themes and playful nature of tube riders, we can infer that these charms are typically geared towards a younger market and come in a variety of character options to appeal to both girls and boys. Hayleigh's Cherished Charms[35] and Hearrings[36] are examples of two other companies that have developed accessories resembling earrings or other ear-worn jewelry. These charms are often designed to fit onto the HA/CI tube, ear mold, or dangle from the device. They come in multiple styles to appeal to different users and include charms that align with holiday or seasonal themes.

Retainer Clips. Clips with lanyards are used to tether one's device to either their hair, shirt collar, or ear in order to prevent the device from being easily knocked off or displaced. This is especially common with active children or with parents of newborns who worry about the child unintentionally grabbing hold of their (the parent's) device. The Hear Clip[37] offers stylized chains that can be

[33] https://www.etsy.com/
[34] http://www.tubetasticpimps.co.uk/
[35] http://www.hayleighscherishedcharms.com/
[36] http://www.hearrings.co.uk/
[37] http://www.thehearclip.com/

attached to a device and then mounted to one's hair or ear – resulting in a device that is both fashionable and functional. This company's products appear to be geared toward teenage and adult users as they specialize in ear-worn jewelry such as ear linkages or ear cuffs. Other clips sporting cartoon characters can be found on Etsy and Tubetastic Pimps, which appear to be designed for a younger audience.

Protective Skins. Ear Gear[38] offers fabric-based covers designed to fit snuggly over the device for protection from the elements. Some Ear Gear pieces come with accompanying retainer clips and are designed to pursue both functional and ornamental properties in order to appeal to the combined interests of users who wish to express their individuality while simultaneously safeguarding the device.

Colored Tubes. Some third-party companies[39] also offer HA tubes in an assortment of colors for users to mix and match with the body of the device.

Stickers. In some instances, individuals note that they received manufacturer stickers for their HA or CI from their audiologist. Pre-made stickers are also available through third-party companies[40,41] and come in multiple design options to meet the specifications of particular HA and CI models.

DIY Modifications and Materials. The final, and perhaps most popular, type of customization entailed using DIY materials and resources to stylize their or their loved one's AT. Members used a variety of craft materials which could be acquired online or from local stores. Many of the items coincide with materials that might be used for scrapbooking or other craft-like hobbies. Detailed in Table 11 is an overview of the materials (compiled from alternative text descriptions) used for customization, with the most popular resources listed in order of frequency.

[38] https://www.gearforears.com/
[39] http://www.tubetasticpimps.co.uk/product-category/coloured-tubing/
[40] http://www.tubetasticpimps.co.uk/product-category/stickertasticpimps/
[41] a) http://www.skinit.com/, b) http://www.medel.com/us/skins/

Material	#	Description
Nail Foils/Stickers/ Wraps	61	Popular to FB members. Brands with easily removable adhesives were used so as not to harm the HA or CI with nail polish remover.
Generic stickers	31	Generic stickers that did not include either nail foils or gem stickers.
Duct tape	28	A type of easily removable tape.
Tubetastic Pimps/Riders	27	Commercial accessories and charms that affix to the tubes of a HA.
Washi Tape	23	A form of Japanese-style craft tape.
Glitter/Glitter Tape/Foils	21	Glitter or tape products with glitter (Not including glitter ear molds).
Charms	19	Add-on charm-like accessories.
Diamantes	19	Brand name adhesive gems.
Gems and Rhinestones	11	Gems with adhesive backings.

Table 11. Materials used for HA/CI DIY modification.

Other DIY materials less commonly mentioned include: nail polish, beads, pearls, googly eyes, elastic, felt, pipe cleaners, chains, fabric, hair clips, hair bands, foam, glue, thread, H\holly water decals, unspecified tape, baubles, a buckle, a nail file, a sharpie, buttons, string, tapefetti, nail varnish, and scissors.

Figure 13. Customization designs with different colors, patterns, and textures. Clockwise from top left: two bronze HAs with stickers of fox heads, one HA with a pink flower sticker, a beige CI with dangling anklet, a CI with adhesive gems on processor and coil, two beige HAs with holographic stickers.

5.3.4 Customization Themes and Designs

Participants produced a range of designs, from non-descript decorative enhancements, such as colors and patterns, to thematic enhancements, (e.g., a holiday or season), to designs coordinated with other worn items. Themes are presented based on the frequency with which they appeared.

Colors, Patterns, and Textures. The majority of customized devices were adorned with various colors, patterns, shapes, and designs that had no specific symbolic representation beyond shape, pattern, or generic images (see Figure 13). Some were designed with minimalistic decorations including small stickers such as flowers, patterns, or happy faces placed on bare HAs or CIs. More advanced designs consisted of intricate patterns or layers of Washi tape, nail foils, or diamantes (adhesive gems) that extended around the entire bodice of the HA or CI.

Figure 14. Holiday-themed customizations: two CIs with Santa heads on the coils (left), two HAs with red foil, Christmas tree cutouts, and red and silver adhesive gems (right).

Celebrating Seasons and Holidays. A substantial amount of customized designs contained symbols, patterns, or color schemes that relate to seasons and holidays (see Figure 14). In total, there were 59 holiday-themed customizations: 41 posts referencing Christmas, 17 referencing Halloween, and one referencing Remembrance Day. Additionally, there were three references to winter, two references to autumn, and one reference to summer. At times, users would also refer to their designs as "wintery" or "autumn" - reflecting the season, however, the design might depict characteristics that coincided with both a holiday and a season, such as snowmen or snowflakes. During major holidays, it was common for other thematic embellishments to appear. Plastic spider decorations were a common decoration for Halloween, and many Christmas designs emerged with images or charms of Santa stockings, Santa Claus, reindeer, or candy canes.

In October, the group administrators advertised a Halloween-themed design contest, which may have inspired members to create and post new designs. Some Halloween designs were decorated to coordinate with one's costume. Christmas was another popular holiday theme for designs, with the hashtag #christmaspimps used 26 times. The cause of the high volume of activity around these holiday months is difficult to conclusively discern; if the increase in activity was due to the fact that people wanted to participate in these holiday themes *more*, or, if designs trended toward these themes because more seasonal materials were available.

Figure 15. Character-themed customizations. Clockwise from top left: two HAs with My Little Pony tube riders, two CIs with Elmo and Cookie Monster faces on the coils, two CIs with Olaf stickers and an Olaf-themed retainer clip, two HAs with Lego character tube riders, and two HAs with minion stickers.

Showing Favorite Characters. There were 36 instances of designs featuring specific cartoon characters (see Figure 15). These encompassed characters from books, movies, and TV, including Buzz Lightyear and Lotso Bear (Toy Story), Cookie Monster and Elmo (Sesame Street), Darth Vader (Star Wars), Elsa and Olaf (Frozen), Stewie (Family Guy), Disney's Cars, Minions, Peppa Pig, Lego characters, Minnie Mouse, Hello Kitty, My Little Pony, Ninja Turtles, and Sonic the Hedgehog.

Matching Clothing, Nails, or Other Devices. A common occurrence entailed individuals matching their HA or CI to other items that were either part of one's wardrobe and personal expression, or part of a suite of AT devices used by the individual. Recurring coordination appears with matching the design to one's nails (fives instances), clothing (two instances), or Halloween costume (one instance). Additionally, it was common for users to decorate their nails using the same nail foils appropriated for HA/CI customization (see Figure 16a). There were seven instances of individuals decorating complementary listening devices, such as a

Figure 16. (a) Two HAs and matching nails, (b) HA with rosary appropriated for church attendance, and (c) RONDO with Green Bay Packers sports decoration.

ComPilot audio streaming device, and three of these seven individuals had decorated these audio accessories to match their HAs. Other customized items included: crutches, a hand splint, earbuds, and a battery keychain caddy designed to match one's HAs. Users with two or more devices at times decorated their devices with matching designs (see Figure 12c) or complementary designs (see Figure 12b).

Celebrating Life Milestones. It was common for members to modify their devices in celebration of a life event. There were eight instances of life event customizations, including: preparing for the first day of school or work (three instances), weddings (two instances), church attendance (one instance – see Figure 16b), participation in a parade (one instance), and one instance of preparing for Children in Need, a BBC UK charity for children with disabilities. In some cases, customization was extended to other items, as with one member who decorated a birthday cake with an image of their child's CI. Such activity depicts the ways in which device customization is integrated into personal milestones.

Showing Team Affiliations. There were three instances of group members customizing their HA or CI with decals or color schemes associated with sports teams, including the Green Bay Packers (see Figure 16c), Seattle Seahawks, and a Rugby ball sticker representing a South African team.

Figure 17. Demonstration of a practice customization on a stuffed animal.

5.3.5 Customization Challenges and Trade-offs

Challenges and design trade-offs appeared to exist primarily for those engaging in DIY customizations due to the ad-hoc nature of this practice. DIY customizations ranged from very simplistic to extremely elaborate. It was observed that new members (as self-reported by the poster) created more basic designs, quite possibly due to limited experience. During the time period analyzed, there were 16 instances of new designers. In many cases, the new members requested advice on what to do or the best resources to use. Some members took to practicing customizations on other items first (see Figure 17):

> *"So I hope y'all don't think I am crazy, but my daughter was implanted this past Monday and I have been practicing pimping the CI that came along with our Cochlear koala! Glad I took some time to practice because I don't know that I have the fine motor skills for this and semi-botched it! I think I had better continue practicing before we get her real ones next week".*

Considering Device Form Factor. In many cases members appeared to make decisions on what materials to use based on the affordances of the device (e.g., some areas might need to be left blank, such as hinged battery doors, microphones,

volume and control switches, or FM boots). Members often include the type and brand of device so that others with the same device could benefit from the information shared. Challenges outside of the users' control included extremely small devices (or in-the-ear/in-the-canal HAs) or insurance changes, resulting in different or limited HA or CI style options from the manufacturer:

> *"Hi everyone.. I'm 22 and have these BTE aids... I want to jazz them up a bit.. I've seen kids with coloured plastic bits (not stickers) all pink/blue/orange etc... I'd really like them but I know I probably can't get them from my ENT and Audiology as an adult! Has anyone got suggestions of where I can get them or the coloured moulds from? Thanks "*

Considering Material Qualities. At times, decorating decisions are based on the affordances of the materials as well. For example, sticker stiffness, proper cutting utensils, ease of cutting, if materials would leave residue on the device, and difficulty of material removal, as well as issues with the material texture, flimsiness, or the adhesive itself.

Adapting to Limited Materials and Time. When individuals cannot find the exact type of stickers, nail foils, or other resources they want to use, they often opt to move forward with what they had on-hand. Group members also resort to "redoing" the design if they do not like the end product or if the initial design had been done hastily. Some of the more elaborate physical changes left users questioning whether or not it might interfere with overall device functionality or comfort of the device. Participants also considered the factor of time when making design trade-offs, such as intricacy of the design (e.g., matching patterns up) and how long a design might take to implement.

5.4 Discussion

This study documents HA and CI customization as a rich and creative activity occurring within this online DHH community. This analysis revealed that decorative customization is rooted in a variety of motivational factors and is executed by (and for) individuals of different age ranges, gender, and varying levels of DIY expertise. Furthermore, it was found that this online community provides a platform which benefits members looking for a network of individuals with shared experiences and to support and empower those who wish to customize their AT. This section will discuss underlying motivational factors for customization, the role of online communities for DIY practice, and how to support these growing communities of AT decoration and customization.

5.4.1 Motivations for Customization

The FB posts were analyzed to better understand why individuals engaged in this activity. While this analysis could not provide an in-depth account of all motivational factors (due to the nature of the data), review of the posts revealed three major reasons for AT customization. First, members were often driven by the desire to find a solution that would encourage a loved one to embrace their AT. There were a substantial number of parents soliciting suggestions for their children, each often facing unique challenges such as a child with a newly fitted device, designs for males, or designs that teenagers could appreciate.

The second major theme revolved around practitioners often wanting to instill a sense of pride and empowerment about wearing one's device. This often encompassed members using their device as a medium for self-expression. As a result, individuals decorated their devices to align with their personal likes and interests. As previously noted, the act of decorating AT serves to highlight the

device as opposed to concealing it. Thus, intentionally drawing greater attention to one's AT can be seen as a mechanism for showcasing pride in one's device and disability. Furthermore, this research reveals that individuals went to great lengths (and time) to decorate their devices, demonstrating that customization instills an increased sense of agency and control in end users (e.g., a blind community member who personally decorated their AT). Even more telling is the fact that individuals seemed to have very little hesitation decorating these expensive devices. For example, cochlear implant surgery is a $50,000 to $100,000 procedure[42]. And, while maintaining device integrity was viewed as an extremely important aspect promoted by the group moderators, the fact that individuals still partook in an activity that *could* potentially compromise a device demonstrates the significance of expressive freedom in device use. Another key question was to understand if customization was driven solely by the lack of available aesthetic options. If manufacturers offered more aesthetically pleasing options would DIY customization end? The data suggests that this is extremely unlikely, as members appeared to appreciate the flexibility of personal customization (creating multiple designs fairly frequently), indicating that end users derive some intrinsic value from the act of DIY customization.

Finally, it appeared that the mere presence of this online community acted as a facilitator of growing HA and CI customization. It is likely that the existence of this community served as an essential resource for individuals who had been looking for a solution to aesthetically modify their AT. Belonging to a community that understands the needs of other HA and CI users appeared to have a profound effect on members, as many relayed their personal stories of wishing that such a

[42] http://www.nvrc.org/wp-content/uploads/2011/07/Insurance-Coverage-for-your-Cochlear-Implant1.pdf

support had been available when they were growing up so that they too could have been more comfortable with their AT.

As gathered from this analysis, these motivations establish a space to understand how we can begin to better support individuals who wish to engage in expressive DIY AT customization. While this research was restricted to just one online community using a specific type of AT, insights learned from this research can perhaps serve as a stepping stone to understand how to support AT users in different disability communities. While this research did not seek to directly answer the motivational underpinnings behind AT customization, we can glean from the data that pride, empowerment, and community-building are strong factors for fostering AT customization. Future work would benefit from in-depth interviews with end users to gather deeper insights outside the scope of this study.

5.4.2 DIY AT Practice and Online Communities

There is a growing body of work looking at how online communities can support DIY practice for AT customization (Bennett et al., 2016; Buehler et al., 2015). However, the majority of existing work in this space focuses on the ability for DIY practice to meet functional needs, such as less expensive or unique solutions. This community, however, was specifically focused on aesthetic enhancements and successfully supports thousands of members who choose to engage in this self-expressive activity.

While different AT communities may require different needs to support self-expression, this section will briefly touch upon key elements that appeared to make this community so successful. First, the ubiquity and features (e.g., ability to create a closed group) of Facebook offered a familiar, safe, and accessible platform capable of reaching a wide audience. This FB group, and the Internet at large, permits for

individuals from different geographical regions to connect with others engaging in this activity and to explore new materials and techniques that can be appropriated for DIY AT.

Second, this form of DIY AT practice appears to address an unmet need that affects a very large population. In fact, some of the concerns and questions expressed by members appeared to be spurred by the limited supply of materials developed solely for HA or CI stylizing. And finally, the barrier to entry for this activity is relatively low. Individuals can appropriate inexpensive and readily available scrapbooking tools and materials to implement their designs and can also share their designs with ease (e.g., can share images of changes to the appearance versus having to share CAD models). This is an interesting point and deviates from other online DIY AT communities such as e-NABLE, which requires knowledge of CAD modeling and access to CAD software and 3D printers. As such, those in the e-NABLE community often rely on an intermediary (expert) to create the designs, while members of this FB community could often execute the designs on their own. One can then ascertain that AT users who require changes to the physical structure (versus pure device appearance) of the device may need greater infrastructure and expertise for customization support. In either case, the role of the Internet appears to be indispensable in facilitating these activities at scale.

Given the nature of this activity, topics of self-expression and identity appeared to be central to many of the discussions that took place, differing from other community forums which primarily focused on economical or practical issues. Many of the conversations also appeared to express genuine enthusiasm with this activity and at the prospect of wearing their new designs, indicating that expressive DIY customization generated positive associations with device use. The presence of the online community may be viewed as contributing to the positive environment surrounding AT use as well. There was a general theme of inclusivity promoted by

members and administrators within this group, and the visual nature of posts also appeared to support community members who spoke different languages. It is also important to note the significance of the administrators and their role in actively maintaining the objectives of this supportive online community.

5.4.3 How to Support Device Customization

The analysis showed that those engaging in expressive DIY AT included individuals from different age ranges, genders, and levels of customization experience. However, it was clear that customization, and more specifically, decorative customization, trended toward a gendered activity, as many of the posts reflected gender- and age-targeted colors, patterns, and characters. While decorating worn objects may traditionally align with activities pursued by women and girls, making AT more acceptable to men may require another approach, such as producing more options related to favorite characters or sports teams.

It was also observed that members cared not just about the device appearance but also considered the process of customization as an act of self-expression. Customization was often implemented more than once, and many individuals experimented with different designs, color options, and materials. This suggests that supporting flexibility in design would enable individuals to pursue creative solutions to meet their changing needs. While members turned to appropriated materials due to the lack of available manufacturer solutions, the creation of templates, materials, and adhesives designed specifically for HAs and CIs may work well in eliminating much of the concern and uncertainty some members expressed about appropriated materials. While there was one follow-up comment with a sticker template provided by an audiologist, it was observed that these templates were not commonly used or widely circulated, indicating that

perhaps they are a) not widely available, b) not preferred by individuals as they want to choose their own patterns and designs outside of template options, c) might be restricted to just certain brands of HAs or CIs, or d) the adhesives functionally do not work very well. As one member indicated on this comment thread, the pre-designed template stickers[43] do not stick very well, suggesting functional limitations behind the product. Providing online digital templates that one could personally design online and then print out at home (or have sent to them with better quality adhesives) might be a useful and valued option.

Furthermore, the trend of matching one's HA or CI to one's nails, outfits, and environment provides a rich design space. A complement to existing practices could be the development or appropriation of a smart phone application that allows one to take pictures of their surroundings, impose the image onto a sticker customized to a specific HA or CI brand, and send it to the user. It was also common to see members requesting ideas for a particular brand of hearing aid. Creating a resource page that catalogs examples of designs by theme or manufacturer make and model may be a helpful addition, allowing individuals to access decorations or modifications specific to their HA or CI needs.

[43] http://1.bp.blogspot.com/-FruBGc1xNXk/UUzn6MzOUtI/AAAAAAAAAFU/u4kDW_SVvk4/s1600/Phonak.jpg

CHAPTER 6

STUDY 3: SOCIO-CULTURAL FACTORS OF AESTHETIC MODIFICATION OF HEARING AIDS AND COCHLEAR IMPLANTS

Study 2 demonstrates how the practice and coordination of aesthetic customization for hearing aids and cochlear implants are co-constructed in an online community, documenting a categorical overview of the types of aesthetic customizations generated, the strategies and resources users employed, as well as the represented user population engaging in this activity. To build on these findings, Study 3 will investigate the role of aesthetic customization in managing personal and social aspects of AT use. While Study 2 was restricted to the analysis of observational data (shared posts without the ability for follow-up by the researcher), this study will pursue interviews with practitioners of aesthetically-customized and DIY AT aimed at answering the following research question:

> **What role does aesthetic customization of worn assistive computing devices play in managing personal and social comfort?**

Prior work on assistive devices for upper limb loss has demonstrated that AT use is closely intertwined with identity production, experimentation, and presentation of self (Bennett et al., 2016). In a similar vein, this study will explore the personal aspects of aesthetic AT customization and what purpose this activity serves for those who choose to engage in this modification practice.

6.1 Participants

Ten individuals (9 female) were recruited for this study. Participants ranged in age from 17-62 *(M: 39.9, St. Dev: 14.77)* and were comprised of seven individuals who implemented HA and CI customizations for personal use (end users) and three individuals who created HA and CI customizations for somebody else (caregivers). The three caregivers were comprised of two parents and one teacher, ranged in age from 26-40, and were all female. Four end users (3 female, ages 17-62) also pursued entrepreneurial initiatives, turning their custom-made designs into patented third-party accessories (developers). All four developers were end users of their personal accessory line, and one was a certified audiologist with a self-run audiology practice. Please see Table 12 for a demographic breakdown of participants.

	Participant	**Age**	**Sex**	**Origin**	**Vocation**	**Disability**	**Listening AT**	**Customization**
1	Caregiver (Parent of HA user)	40	F	UK	Unemployed	NA - Child has bilateral high tone deafness	NA. Child used HAs, radio aid	Commercial, DIY
2	End User	52	F	USA	Federal Government Librarian	Late onset, right ear profoundly deaf, left ear mild to moderate hearing loss	Advanced Bionics - Bilateral CIs	3rd-party accessories
3	Caregiver (Parent of HA user)	26	F	UK	Self-Employed Cleaner	NA - Child has late onset bilaterial hearing loss	NA. Child used Phonak Sky Q HAs	Commercial, DIY, 3rd-party accessories
4	End User	50	F	UK	Teacher	Bilateral Mid frequency sensorineural hearing loss	Digital HAs ReSound Danalogic iFIT 71 es	DIY
5	End User, Developer	40	F	UK	Audiologist	Bilateral congenital sensorineural hearing loss	Bilateral BTEs and CICs, Loop systems	Makes/wears 3rd-party accessories
6	End User, Developer	54	F	USA	Tech Writer	Bilateral hearing loss	HAs	Makes/wears 3rd-party accessories
7	End User, Developer	62	M	USA	Retired	Lost hearing in right ear after surgery	BAHA	Makes/wears 3rd-party accessories
8	End User, Developer	17	F	USA	Student	Severe to profound bilateral hearing loss	Bilateral Oticon Safari HAs	Makes/wears 3rd-party accessories
9	End User	23	F	UK	DHH Teacher	Severe Sensori-Neural Hearing Loss in both ears	Bilateral Phonak Compilot and 2 Phonak Nios S HAs	Commercial, DIY
10	Caregiver of HA/CI Users	35	F	USA	DHH Teacher	NA	NA	DIY

Table 12. Study 3 participant demographic breakdown.

6.2 Method

The researcher engaged in semi-structured interviews with the participants. Single-session interviews lasting between one and two hours were conducted via phone (2 participants), video conference (4 participants), or over a chat service (4 participants) such as Facebook Messenger (as deemed appropriate by the University's IRB review). The chat service was offered as a communication medium in lieu of an ASL interpreter, and all communication options were chosen to support long-distance interviews. Five participants were from the United States, and five were from the United Kingdom. Real-time interviews were documented through detailed note-taking and through audio recordings which were transcribed for analysis. One audio recording was lost due to a technical malfunction. Participants received no compensation for participation.

6.2.1 Analysis

The researcher employed affinity diagramming to extract underlying themes and patterns from the data as they relate to personal and socio-cultural considerations of aesthetically-customized AT use. These themes identify trends with respect to practitioner-specific activities and motivational accounts related to the personal meaning and general outcomes of aesthetic AT customization. The major thematic categories presented in Table 13 reveal the many ways that individuals leverage aesthetic customization to manage personal and social comfort, including: exercising agency, showcasing pride and self-expression, engaging in advocacy, managing communication expectations, empowering AT use in others, and generating excitement and community bonding.

For clarification purposes, activities specific to end users and caregivers were analyzed independently from activities specific to developers as these practices were

Theme	Definition
Exercising Agency	Customization (DIY practice in particular) was viewed as a mechanism to exercise control, flexibility, and independence in both the act of customizing and in how individuals chose to represent themselves.
Showcasing Self-Expression, Confidence, & Pride	An expressed notion of confidence and the desire to showcase one's personality through their customized AT.
Engaging in Advocacy	Using customized AT to generate increased recognition and societal awareness, challenge expectations, change views, normalize AT, and promote positive associations about AT use.
Managing Communication Expectations	Leveraging conspicuous physical attributes of the AT to set realistic expectations about how to interact with the user.
Empowering AT Use in Others	Leveraging customization to empower others to use and accept their AT.
Generating Excitement & Community Bonding	A general sense of excitement related to AT use and pursuant actions that foster community building and community relations.

Table 13. Study 3 analysis themes.

viewed as requiring a different set of logistical processes, resources, and barriers to implementation. Thus, findings specific to the developers will be presented in the following chapter. For readability, end users and caregivers will be collectively referred to as 'practitioners' unless data is reported specific to one of the two groups.

6.3 Results

The following section will discuss the personal and social considerations as they relate to aesthetic customization of hearing aids, cochlear implants, and other listening devices. While this analysis specifically focused on the socio-cultural aspects of device use, a general overview of how participants got started in this practice, why they have chosen to engage in this activity, and the challenges and trade-offs of aesthetic customization will be presented at the start of this section to provide a greater contextual foundation for the core analysis.

6.3.1 Getting Started in AT Customization

It was evident that no participant started out with the direct intent of decorating their AT device. In fact, the majority of practitioners happened upon HA and CI aesthetic customization either by accident (3 participants), through word of

mouth (3 participants), out of a lack of existing accessory options on the market (4 participants), or a combination of these reasons. Here, the presence of the Internet is noted as playing an instrumental role in *discovery* of HA and CI customization. The Internet and specific customization-related sites were cited as being key resources for getting started in this space, and participants often returned to these sites for continued community support, procuring materials, exchanging ideas or stories, and to discuss and learn DIY best practices. This serendipitous learning of HA/CI customization is consistent across all practitioners (caregivers and end users) and suggests that aesthetic AT customization remains widely unknown and unadvertised to members in the DHH community. The role of the Web in fostering AT aesthetic customization aligns with more modern DIY communities that leverage online resources for knowledge dissemination (Kuznetsov & Paulos, 2010).

6.3.2 Engaging in the DIY AT Modification Process

Practitioners discussed their customization process and the techniques, materials, and customization trade-offs employed.

Techniques. Planning, collaborating, and strategizing about the best way to implement a design were common occurrences amongst practitioners. One end user who enjoyed personal device decoration (versus purchased accessories) expressed that she already had purchased materials and planned her next design for a holiday-themed customization. Another participant found DIY decoration to be extremely engaging, planning designs not only to match other accessories, such as a necklace, but often appropriating materials and techniques from other sources (e.g., a fabric hearing aid cover adapted from a sewing pattern for a Christmas tree ornament). She conveyed an eagerness to decorate, especially when she had

something new in mind. This end user would often *plan* to create a template or detailed documentation of her design explorations that she would later share on her personal blog for other interested end users.

While decoration was often a solo activity for end users, caregivers emphasized the collaborative nature of their DIY customizations. As relayed by the caregivers, the children ('caregivees') whom they created the customization for were always closely involved in the decoration process – choosing the particular materials and aesthetic properties that the caregivers would later physically implement.

"Yes I don't think she would allow me to do them without her input, she's too independent." –P3, F

Here, we see that this DIY activity is enabled by a co-collaborator. The ability to choose the design enables 'caregivees' to directly take part in this activity of personal expression, and the caregiver role is instrumental to facilitating said expression. To support this collaborative activity, all caregivers indicated that they keep a supply of materials on-hand for whenever inspiration strikes. Caregivers (and 'caregivees' alike) appeared less eager for the child to implement the designs, citing the precision involved and the potential damage to the device as justification.

Practitioners also discussed strategies in their approach to DIY customization. Modification strategies often revolved around ways to minimize device obstruction, appropriating materials in useful ways, and pursuing time-saving solutions. One caregiver would practice decorations on replica hearing aids to ensure that the materials would not leave behind any harmful residue. The same caregiver devised an extremely efficient decoration process, allowing her to create designs in under three minutes in order to meet the demands of customizing devices for multiple students. Oftentimes, learning which techniques and materials to use emerged from trial-and-error, as one caregiver recounted a story of accidentally

taping over one student's battery air vents, causing the batteries to overheat. Two other participants emphasized how early DIY designs were rather simple in nature (likely due to the learning curve required for this practice).

Materials. Practitioners used many materials that had already been vetted by other HA/CI DIYers (e.g., Duct tape, nail foils, and Washi tape) – sourcing items from craft shops, art stores, and eBay[44]. Decorative Duct tape was credited by two participants as the most versatile craft material as it was low cost, easily sourced, could stay adhered for multiple weeks, and left no residue. Participants also appropriated components from other objects, such as beaded jewelry, and gravitated towards items that could be easily sourced and used.

Customization Trade-offs. The top customization trade-offs routinely revolved around cost, time, and ease of execution. Participants often opted for low-cost DIY solutions instead of more costly third-party accessories, despite DIY customization being more time consuming. One practitioner stressed that her enjoyment implementing designs was curtailed by the time commitment – thus, despite this end user's excitement to explore new styles, she naturally tried to make her customizations long-lasting due to the tedium of the intricate designs she produced. This same end user admitted to the high caliber with which she held her designs, indicating that if a design is badly executed she'll immediately redo it.

It was evident that practitioners were constrained by the difficulty of working with certain materials. One participant enthusiastically conveyed her desire to have unique and interesting HA case designs yet primarily made hearing aid accessories out of jewelry as operating pliers to combine components was easier than the dexterity required to manipulate fine pieces of tape and other small decorative

[44] http://www.ebay.com/

embellishments. For another end user, the simplicity of Skinits allowed her to express herself while leaving her more time to pursue other interests, *"I don't have to do anything extra, I apply them and they are good to go".*

The final and perhaps most topically relevant insight revolved around the discussion of functional versus aesthetic trade-offs. For one end user, conspicuous aesthetic expression played an extremely important role for raising HA societal awareness. This practitioner used both behind-the-ear (BTE) and completely-in-canal (CIC) hearing aids, and though her CICs functionally performed better, she often opted for wearing BTEs because they permitted for decorative attachments.

6.3.3 Creating Personal Meaning and Social Comfort

This study was noteworthy in understanding the motivational factors behind customizing one's AT and the role that aesthetic customization plays to manage personal and social comfort (RQ3). It was found that practitioners engaged in DIY and aesthetic AT customization to exercise agency, showcase pride, confidence, and self-expression, engage in advocacy, manage communication expectations, empower others to use their device, and to instill excitement and generate community bonding. The following section will discuss these themes in greater detail. Accounts of practitioners' experiences (anonymized using pseudonyms) will be presented in the form of participant quotes and abridged stories consistent with (Bennett et al., 2016; Scherer, 2005) in order to illustrate how creative solutions are born out of complex narratives.

Exercising Agency. Perhaps one of the most widely noted advantages of aesthetically modifying one's AT was the ownership, flexibility, control, and power of choice that it granted practitioners and users. This section will first present the

story of Rachel, a mother who leveraged DIY craft to give her daughter the hearing aids she had been dreaming of.

> *Rachel is a stay at home parent who has been decorating her daughter's hearing aids for three years. Her daughter is 13 years old and has worn two hearing aids for high-tone deafness since age 6. As a citizen of the UK, Rachel's daughter received her hearing aids for free through the country's National Health Service[45] (NHS). However, due to the NHS's restriction on administering patterned hearing aids, Rachel's daughter was denied the giraffe print hearing aids that she direly wanted. Rachel circumvented this restriction by using DIY materials to personally decorate the aids based on her daughter's stylistic preference.*

It is common for AT users to face insurance restrictions for device upgrades and non-critical feature enhancements. Rather than accepting defeat, Rachel engaged DIY craft to produce stylized HAs that reflected her daughter's personality. She continues to leverage DIY methods for new designs, granting her the flexibility to change her daughter's customization with each newly arising mood and interest.

While some customizations were born out of disallowance, other customizations were viewed as an opportunity to express creative license. One end user considered customization as an ability to channel her inner artist, opting to make designs out of materials and techniques that other HA users could then easily implement. This end user refused to purchase commercial or third-party accessories, alluding to the sense of ownership enabled through DIY craft.

Others preferred DIY craft (to commercial or third-party accessories) for the level of control it offered participants. One caregiver revealed her account of purchasing Ear Gear, a soft-cover accessory designed to protect HAs and CIs from the elements, which ultimately distorted the sound quality of her daughter's hearing aids. For this parent, personally decorating her daughter's device was a way to ensure that "*all [the] bits that need to be uncovered are left uncovered."* This reliance on the self (and the online community network) depicts a clear detachment

[45] http://www.nhs.uk/pages/home.aspx

from proprietary restrictions, allowing participants to reclaim a sense of agency with respect to their devices.

Finally, one of the main reasons that aesthetic customization was viewed so positively was the power of choice bestowed on users. Six of the ten practitioners explicitly mentioned the importance of one's ability to choose how to represent themselves as an important factor for AT use: "*I think it [decoration] empowers them [chidren]…it definitely is empowering that they have a choice and they're able to choose for themselves, and they're able to change that for their personality."* One end user described the ability to choose as reclaiming a sense of power over something that initially had power over you. Others likened the power of choice to that of consumer products, indicating that increased user options normalized perceptions of the device: "*the fact that it's decorated…it's more acceptable and society is accepting it more because it can be decorated and that it's a choice.*" Thus, the ability to choose was considered a key component for empowering users and enabling AT expression and greater societal acceptance.

Showcasing Self-Expression, Confidence, and Pride. For many, decorating one's device was not only a way to show the world that they had accepted their AT, but that they were also proud to show off this side of their personality. We look to the story of Jeannie, a cochlear implant user with a passion for music:

> *Jeannie was diagnosed with bilateral hearing loss in 3rd grade and wore hearing aids until the age of 35 before transitioning to two cochlear implants. She recalled the isolation she felt growing up as the only child with hearing loss in her town, lending to self-conscious behavior such as covering her hearing aids with her hair. It took until she was in college to gain an assertiveness about her disability, choosing to attend a DHH University to learn "how the other side lives." She recalled the difficulty of navigating both the hearing and deaf communities, as she was both deaf and a musician, a self-proclaimed rarity in the DHH community. When Jeannie lost the remaining portion of her hearing she contemplated relinquishing AT altogether before finally deciding to undergo cochlear implant surgery. For Jeannie, deciding to embrace CIs gave Jeannie her "life back" as she acknowledged that she was a deaf individual who chose to live*

> *in a "hearing world." Jeannie now decorates her CIs with musical note Skinit stickers to express her love of music, even though she knows that "some people might find it ironic." She claimed to finally be at a stage in life where she felt peace with her hearing loss, wearing her hair "anyway I want."*

Jeannie's story demonstrates the fluidity of her presentation of self, with her CIs serving as a platform to express other unique passions. Jeannie realized that her self-conscious behavior wasn't doing her *"any favors",* first experimenting with Deafness[46] and then finally utilizing AT and aesthetic modification to reclaim (and showcase) the aspects of her life that were important to her. Jeannie's story is consistent with other end users who leveraged AT customization to not only express themselves but to also channel other personal interests.

> *Nadeen discovered that she had bilateral mid-frequency hearing loss at the age of 43, noting the embarrassment and difficulty it took for her to confront and accept the fact that she needed hearing aids. Nadeen is a design instructor at a local University, detailing how her accidental discovery of Do-It-Yourself AT filled a void that allowed her to embrace her aids. For Nadeen, customization became a personal pet project, not only exploring ideas and appropriating materials to create new and intricate designs but also ultimately creating a blog post about each new design journey that allowed her to share ideas and connect with others like her. Hearing aids served as the muse for her artistic explorations, creating photoshopped visual media and storylines riddled with comic relief to document her experiences with hearing loss. Nadeen expressed that her artistic pursuits not only lightened up the mood about her "predicament", but also that she spent so much time teaching that customization granted her a space to pursue design as a pastime. Now, Nadeen says that she feels naked if her aids remain undecorated.*

Like Jeannie, customized AT served a dual (non-functional) purpose. It allowed Nadeen to express herself and also channel her avocation (i.e., design) as part of this expressive process (see Figure 18). In fact, a theme of artistic and *"techy"* inclinations was noted across five of the ten practitioners, suggesting that they might have a natural affinity for partaking in DIY activities. For example, Constance, an audiologist, recounted her childhood of making hearing aid 'hacks':

[46] "Using capital D 'Deaf' to indicate a cultural identity and lower case 'deaf' to refer to those whose level of hearing does not allow them to live easily in a spoken-language-oriented society." (Sparrow, 2005, p. 135)

Figure 18. Artistic blog posts with hearing aids as the subject. Space-themed HA rocket costumes (left), handmade mouse HA covers attempting to 'cute-ify' one's aids (right).

> *"I was quite a witted kid…I did what was called craft design technology, which is like woodworking, metalworking in school yea, and, um, I used to make stuff to do with hearing aids all the time…I was a bit obsessed with it."–P5, F*

AT customization was also likened to normative consumerist behavior and how the act of personalizing a device makes it truly yours:

> *"You want to be excited about it…and personalizing it and making it yours, putting your personal mark. Because the first thing that most of us do when we buy a cell phone is we pick out our case, and our case really makes it ours. So without…decorating it, designing it, it's a piece of technology…it's a phone. But once we go and we pick out that case or we pick out whatever it is it makes it ours and it makes it part of us, and…it kind of shows our personality too." -P10, F*

These accounts demonstrate the close-knit relationship that users have with their AT as agents of self-expression. Participants also talked about their AT use with respect to identity, as four of the seven end users and all children (as conveyed by caregivers) considered their AT a part of who they were. Throughout the interview process, it was evident that for some individuals device acceptance was facilitated by aesthetic customization. For example, one participant, Ashley, had rejected her HAs throughout her teenage years due to chronic bullying. Her recent 're-adoption' of her hearing aids was closely tied to the ability to customize her AT: "*I thought well if I'm going to wear them i [sic] don't want to hide the fact anymore, I want to be proud of them, it's who I am as a person I shouldn't have to hide the fact I*

need hearing aids." Here, customization (and its associated conspicuousness) was seen as a direct way to broadcast one's confidence in their device by wearing it *"loud and proud"*. Rather than *telling* the world, 'I accept my hearing aids', customization acts implicitly by allowing users to *show* the world this newfound acceptance. Though Ashley previously rejected her HAs, customization inspired her to reintegrate her AT into her life and instilled an added sense of confidence and pride.

For others, customization was the 'window dressing' for those who had already subsumed disability as an indelible part of who they were. This was closely linked to an unwavering sense of pride, and individuals celebrated their disability identity[47] through vibrant customizations which highlighted the device. As Marie conveyed about her daughter: "*She is very proud of having hearing aids…She introduces herself by saying 'hi [sic] I'm Sally and I'm Deaf' usually followed by showing her aids. She loves to spot people out shopping as well who wear aids so she can talk to them about them."* This caregiver went on to share: "*She likes to stand out from the crowd and having bright coloured and funky aids definetly [sic] helps her do that."* Here, customization was used as a way to express how Sally identifies as Deaf and to showcase her pride in being 'different' from others.

Another caregiver, Rachel, shared a story of how her daughter adopted customized HAs: "*Abby has always been very proud of her aids and likes choosing bright molds…when she was younger she used to show everyone when she got new moods or changed the look now she doesn't bother [sic] The fact people decorate their aid is to do it for their selves [sic] not for other people."* While customization was undoubtedly linked to showing pride in one's device, two practitioners emphasized the personal nature of customization. This, as with many of the other stories

[47] "*Disability identity* refers to possessing a positive sense of self and feelings of connection to, or solidarity with, the disability community. A coherent disability identity is believed to help individuals adapt to disability, including navigating related social stresses and daily hassles." (Dunn & Burcaw, 2017)

highlighted in this section, shows the role fluidity that aesthetic customization plays for the purpose of self-presentation.

Engaging in Advocacy. In addition to facilitating self-expression, aesthetic customization of AT was also viewed as an important mechanism to advocate for increased awareness and social acceptance of HAs and disability in general. For one user, wearing conspicuous hearing aid jewelry was a conscious decision aimed at starting a conversation and generating press about hearing aids, saying that she preferred her HAs decorated in order to *'make a statement'* and *'talk about it'* (see Figure 19a).

Using aesthetic customization to raise awareness through increased device visibility was likened to other accounts of disability promotion, such as media coverage of the Special Olympics. For one participant, aesthetic customization was deeply tied to eliminating *"the stigma of what it means to be deaf/hard of hearing…so that it is not something that is hidden but made to stand out and be individualized - lessening the of shame or embarrassment."* This participant went on to express that by increasing society's exposure to individual differences you lay the foundation for creating a more inclusive and accessible environment. For others, such as Jeannie, the music aficionado, expressive AT served to challenge societal expectations and norms.

Participants viewed aesthetic customization as a way to increase social acceptance of AT use. They noticed that aesthetic modification caused bystanders to treat them differently, often generating compliments from acquaintances and strangers alike: "*Where before it would be unwanted attention... it's now compliments of [sic] that makes sense."* This sentiment was mirrored by other participants who indicated how the stylized appearance seemed to cause bystanders

Figure 19. Hearing aid jewelry/art aimed at challenging perceptions, starting conversations, and making a statement. (a) Skull HA jewelry, (b) photoshopped tattooed HAs representing one's ideal aesthetic customization designed to intimidate bystanders.

to bypass prototypical interaction methods (e.g., over-pronounced lip mouthing).

As evidenced throughout this section, AT customization serves a unique role in managing stigma by raising awareness and promoting positive social interactions to change bystander perceptions.

Managing Communication Expectations. Participants noted that wearing hearing aids helped others know to communicate with them more carefully. The following narrative details how Constance makes explicit decisions about device use based on contextually-sensitive circumstances:

> *Constance runs an audiology practice and has worn hearing aids since she was 10 years old. She switches between wearing BTE and CIC hearing aids depending on the scenario. While her CICs functionally perform better, Constance recounted instances where her BTEs were indispensable for communicating her hearing loss to others: "when I was even in the maternity unit I had very, very obvious hearing aids…you've got surgeons wearing masks and you've told them once that you had hearing loss but actually if you wear very, very obvious hearing aids then it's quite obvious that they need to repeat themselves. So, there are some occasions where it can be quite useful to have obvious hearing aids."*

Constance indicated that she always wore her HA accessories when using her BTEs, making them even more noticeable. Other participants expressed a similar

predilection for the communicative advantages of decorated aids which, by generating greater attention, could enable more considerate bystander interactions.

> *"You can't just necessarily look at a deaf or hard of hearing person and say 'Oh, they're deaf'…and so I think that can be hard for them too…because they look like everyone else. If they're walking through a store and somebody's talking to them or trying to get their attention and you don't see any visible devices you're going to be annoyed. You're going to be like, 'Dude are they being rude or what's going on?', but if they are wearing a device that is noticeable, blinged out, or you can even see it… it might cause for more understanding or more patience." –P10, F*

Empowering Others to Use Assistive Technology. As gleaned from Study 2 and from participant interviews, it was common for caregivers to use aesthetic customization to empower children (and others) to use their device.

> *Marie is a self-employed cleaner who has been decorating her daughter's hearing aids for approximately 4 years. Her daughter is currently 7 years old, has severe bilateral hearing loss, and received her hearing aids slightly before her 3rd birthday. Marie indicated that she started decorating her daughter's aids roughly 6 months after her daughter received them, noting how her daughter beamed with pride at each new design. For Marie, decorating her daughter's hearing aids was a conscious act tied to her desire to instill a sense of confidence in her daughter: "I want her to be super confident with being deaf and having aids and never want her to see them as a burden, I think to get into [sic] her while she's young that they can be made cool and bring lots of positive attention will definetly [sic] help her as she gets older." Marie went on further to describe how bystanders often lack a general understanding of how to communicate with deaf individuals, hopeful by the possibility that stylized aids could create a positive feedback loop of user confidence and societal acceptance.*

Marie views decoration as a powerful and effective agent of change granting her daughter the fortitude to navigate life's obstacles as they relate to disability. Here, aesthetic customization is viewed as a mechanism to encourage device use. Marie's story parallel's other accounts related to setting a positive example of AT use for children with hearing loss.

> *Ashley, a newly minted British Sign Language (BSL) instructor, recounted her story of personal bullying which caused her to reject her hearing aids in her teenage years: "I started [wearing my hearing aids] again about 2 years ago when I realised I had to wear them as I was struggling more and also because that's when I started working with deaf children and for them to see me with my*

hearing aids empowered them so I became a role model". Ashley's comfort with reincorporating her hearing aids into her life appeared to be highly contingent on the ability to aesthetically enhance them. Her colorful aids were met with enthusiasm by her students who often eagerly awaited her next design.

Here, decoration was used to set a positive example for others and served to counter the stigma triggered by one's personal experiences of social exclusion imposed through AT use.

While most stories revolved around empowering young HA and CI users, Constance, an audiologist by profession, spoke of her experience interacting with older adults and reported their reaction to her adorned HAs: *"A lot of…[those]…in their 80s would look at my hearing aids and say, 'Wow, I like your earrings.' I'd say, 'No, actually they're hearing aids.' And they say, 'Oh wow! I wouldn't mind wearing them if they looked like that.'"* Constance recognized the role that aesthetics played in changing the way individuals perceived these devices. For years, HA use signified an individual who was *"over the hill",* suggesting that older individuals were unwilling to accept these devices because what they represented was at odds with how these individuals perceived themselves. By revamping the appearance of HAs and CIs to reflect a more stylized aesthetic, older adults felt less threatened by what these devices traditionally symbolized and, thus, expressed a greater willingness to incorporate this AT into part of their presentation of self.

Generating Excitement and Community Bonding. Aesthetic device customization appeared to set a positive tone for how individuals engaged with and responded to the prospect of using their AT and also fostered community interest in this practice. The following account details one teacher's experience decorating devices for her student DHH class:

Paula is a teacher for 5th grade DHH students at a mainstream grade school campus. She has served as a DHH teacher for the past 14 years and has been decorating HAs and CIs for her students for the past 6 years. She currently

> *oversees 4 DHH students in her class (varies yearly) and indicated that she decorates AT devices for both male and female students. Given that Paula has worked in the school system with DHH kids for multiple years, she was able to comment on the increasing popularity of decorated HAs and CIs – noting that what started as a once a year event has escalated into a monthly activity abounding with student excitement and anticipation. Word of Paula's customization activity spread throughout the school and multiple campuses, and students in the 4th grade expressed their eagerness to enter 5th grade so that they, too, could decorate their aids: "They get excited, they're like, we're going to 5th grade next year we'll get to decorate our…processors then." Paula also indicated that her practice is heavily supported by her students' parents: "and their parents love it. You know, their parents will even send in Duct tape."*

Paula's experience showcases a change in attitude toward AT use. While prior anecdotal and empirical evidence has suggested that AT use has been met with limited enthusiasm and user reluctance, customization appears to have influenced these students' relationship with their AT in a positive light. Paula even commented that children, in general, appeared more willing to wear their AT than in the past, noting how she did not remember any instances within the past two years of struggling with students to convince them to wear their devices. Enthusiasm to wear one's AT extended across different types of customizations, as one of Paula's students expressed an eagerness to upgrade their device to the color white so that it could resemble an Apple iPhone. User excitement is reflected in other participants' accounts, as children in general were keen to swap out designs as much as possible: "*she would want them doing [sic] everyday if she could…She [sic] calmed down a lot recently but it [changing decorations] used to be about every 2/3 weeks."* A desire to change designs appeared to also be closely linked to societal reactions: "*She liked showing them off to her friends and family so I think once the attention wore off from one design it was time for her to want them changed so she could talk about them again. She is very proud of having hearing aids."* For this child, aesthetic customization resulted in her excitement to show off a unique and important aspect about herself.

Aesthetic customization also led to increased community interest and support. The parents' donation of DIY materials demonstrates that they are not only receptive to this practice, but that they also want to contribute and support this teacher who volunteers personal time and money to create expressive DIY customizations for their children. This positive community response is consistent with Marie's experience as a member of a deaf children's charity. Marie received so much interest in her daughter's customized aids that she was asked by members of the charity to hold a decorating session for the other mothers.

Community bonding was a key component of aesthetic customization. As previously mentioned, caregivers and 'caregivees' collaborated closely to produce their DIY creations. Another user, Nadeen, discussed her experience about starting her blog to share stories and customizations, indicating that she probably wouldn't have carried on with the practice if she hadn't been able to connect with others like her. For Nadeen, having a supportive community was a large motivator to continue her creative explorations. In fact, belonging to a physical or digital HA/CI community was consistent across the majority of participants. Six of the ten practitioners belonged to the aesthetic customization FB group evaluated in Study 2, two belonged to or were administrators of other HA/CI FB groups, and one participant maintained a personal blog that allowed her to connect with others.

As a whole, the presence of these community-based networks and the shift towards increased enthusiasm surrounding AT use demonstrates how aesthetic AT customization reinforces positive social interactions with respect to disability.

6.4 Discussion

As revealed by these practitioners' stories, it is evident that aesthetic customization plays a critical role in enabling increased personal and social comfort

associated with using one's AT. However, the manner in which aesthetic customization achieves this differs based on the objectives and personal experiences of each user. For some, aesthetic customization allowed users to express their personality by showcasing their hobbies and interests. For others, control and agency in the customization process granted participants a greater sense of ownership of their devices. And yet, for others, 'loud' devices communicated to the outside world that these individuals fully embraced their AT. This section will reflect on additional socio-cultural insights of aesthetically-modified devices, including: customization as a social activity, outcomes of AT customization, and the role of aesthetic customization in promoting normalized views of AT.

6.4.1 Customization as a Social Activity

While aesthetic customization undoubtedly worked as a mechanism to showcase one's individuality, it was clear that the act of customization was anything but an individual process. Often, individuals engaged in this activity to help people that they cared about. For caregivers, customization was a very close-knit and collaborative activity (one may even classify it as a bonding experience) between caregiver and 'caregivee'. For those who pursued self-implemented designs, sharing or obtaining ideas through the Internet (and online networks) was a commonality and also worked to reinforce the desire to continue activity in this space. This aligns with the amplification effect of positive feedback (Hallett, 2003), which, in online communities, has been shown to foster participation (Said et al., 2014). Similarly, the increase in social affirmations generated through public display of customized AT is likely to bolster positive associations with AT use.

Of interest (and great surprise) was the limited awareness of aesthetic customization to both nascent and long-term HA and CI users. This reality suggests

either a lack of unification amongst the deaf community as a whole, a lack of industry knowledge about aesthetic customization, or limited incentive for industry to promote stylized AT solutions. Instead, participants learned about aesthetic customization through bottom-up approaches such as personal networks or serendipitous web browsing.

6.4.2 Making the Invisible 'Visible'

While each user faced their own set of challenges, one unifying aspect was the fact that aesthetic AT was able to positively impact their AT use experience regardless of how one came about their hearing loss. For some, customized designs appeared to instill an increased level of pride, and participants leveraged customization to express themselves. For many of these users, aesthetic customization elicited the desire to share this form of personal expression with the outside world. This is of particular interest due to the fact that hearing loss is inherently an invisible disability, and participants' willingness to highlight their disability suggests the efficacy of aesthetic customization in de-stigmatizing AT use. Other participants seemed comfortable with their device regardless of the appearance (though admittedly enjoyed or preferred stylized aids). The question that remains is whether decorated HAs/CIs instill confidence in end users or whether inherently confident personalities appear to be attracted to bold assistive devices. Perhaps both factors are at play. While acceptance partially appeared to manifest in a prideful outward display of expression, two end users emphasized the realization that decoration was ultimately an intrinsically rewarding activity.

Another interesting point is the visible gender distinction exhibited in this form of DIY practice. While Maker communities are traditionally male-dominated[48],

[48] http://cdn.makezine.com/make/sales/Maker-Market-Study.pdf

participants who engage in this form of customization chiefly trend female. And, more specifically, those who adopt (purchase in addition to implement) stylized AT are typically elementary-aged girls and boys, young adult females, and older adults. Is this primarily because this form of DIY is much more cosmetic in nature? Or, is some other factor at play? Perhaps female practitioners feel more comfortable with the materials used for expressive AT and thus are more receptive in engaging in this form of DIY practice. Additionally, we see how aesthetic AT upends the institutionalized appearance associated with most medical devices (and their inherent associations), potentially making elderly individuals more willing to adopt assistive technologies.

6.4.3 Promoting Normalized Views of AT

It is evident that aesthetic customization had a profound ability to change one's relationship with, and perceptions of, AT. The fact that participants reported the change in societal response (e.g., compliments versus being *'talked to'* differently) demonstrates the efficacy with which customization positively mediates interaction between the two parties. As reported in Bennett et al. (2016), *"What at first stifled conversation now accelerates it"* (p. 1750). What was uncovered in Bennett et al. (2016) for prostheses holds true for AT for hearing loss. However, unlike prosthetic limbs, HAs and CIs physically facilitate communication between two parties. The fact that bystanders not only complimented users but also seemed to abandon their old ways of *"talking very clearly"* demonstrates that customization works to bypass many of the ingrained misconceptions formulated about how to engage with HA/CI users. Customization creates a positive feedback loop – it signals to others that users are comfortable with their AT and their disability,

which ultimately makes onlookers comfortable as well. Bystanders are no longer *over thinking* how to act and instead engage unhesitatingly.

While all individuals began customizing *after* adopting HAs or CIs, the data did suggest that customization could potentially be used as a mechanism to encourage adoption. As Constance, the audiologist, conveyed, many of her patients and bystanders appeared to 'rethink' getting hearing aids after seeing HA jewelry. Thus, stylization appeared to impart a humanizing quality on AT. The fact that individuals respond more positively to AT when customized suggests that customization creates a symbolic representation of the device that more naturally aligns with how users perceived themselves. While we do not conclusively know the degree to which customization influences adoption, looking at the impact of aesthetic customization on "psychological readiness" (Scherer, 2005, p. 98) for AT adoption merits further study.

Bispo and Branco (2009) state that the primary difference between assistive technologies and consumer technologies is the ability to choose – to choose different colors, to choose different models, to choose what suits the user's personality. Thus, the act of customization works toward normalizing AT by treating it like consumer technology. Though not previously discussed, participants also mentioned the ubiquity of consumer-grade 'hearables' on the market and how they are making bystanders more desensitized to ear worn apparatuses - suggesting a synergetic relationship between technology innovation and perception of ear worn AT devices.

CHAPTER 7

THIRD-PARTY ACCESSORY DEVELOPERS: TRENDS, TRADE-OFFS, AND GETTING STARTED

This chapter will catalog insights discussed by developers of stylized AT accessories. While this chapter does not directly answer one of the proposed research questions, it gives an overview of third-party developer initiatives, challenges, and trends as they relate to HA and CI accessories and thus is considered pertinent supplemental information that merits inclusion in this manuscript. As all developers first started out as end users of aesthetically customized AT, they can provide insights toward the particular implementation challenges should others choose to pursue developer roles.

7.1 Participants

Four developers from three different third-party accessory companies (one company was co-owned) were interviewed for this study. Participants (3 female, 1 male) ranged in age from 17 to 62. One developer was retired and three developers operated their business on top of a full-time workload (either a primary job or school). Two developers were diagnosed with early onset hearing loss and wore bilateral HAs for the majority of their lives, and two developers had late onset hearing loss, with one having received two HAs within the past year, and another receiving a bone-anchored hearing aid (BAHA) for the right ear five years prior. The participants who co-owned their business were interviewed concurrently.

7.2 Third-Party Accessory Companies

This section will provide a brief overview of the companies and the types of accessories they produce. Companies will remain anonymous for privacy purposes.

7.2.1 Company 1

Company 1 (associated with developer 1) was founded circa 2008. This company offers a number of hand-crafted accessories that resemble traditional ear-worn jewelry and are designed to affix to the tubes of one's listening device. Company 1 offers a wide selection of products including, but not limited to, seasonal, holiday, religious, and special order designs. This company also has products dedicated to CI and receiver-in-the-ear (RITE) aid users as these products require different attachment mechanisms. These products were inspired by the developer's desire to wear jewelry similar to that of her mother and were created as a response to the fact that no accessory options existed on the market. This company's products are geared toward users of all ages and genders.

7.2.2 Company 2

Company 2 (associated with developer 2) was founded in 2008. Of interest to note is that Company 1 and Company 2 emerged around the same time due to the limited availability of existing HA accessory options. Company 2 produces HA jewelry that affixes to the mold of the hearing aid based on a specialized coupling system originally developed for body-worn hearing aids. Developer 2 is an audiologist and used her experience in this profession to create her designs. She indicated that since manufacturers and ear mold specialists would be familiar with the coupling for body-worn hearing aids, then it would be easier for industry

professionals to manufacture and accommodate this feature. This developer pairs with a particular ear mold manufacturer to produce the specialized mold and provides ordering instructions on the product website so that any audiologist can place a mold order for clients wishing to acquire the associated accessory. This company's products are geared towards individuals of all ages and genders, however, due to the fact that these accessories require a mold for attachment, only individuals who use behind-the-ear (BTE) hearing aids can use this product.

7.2.3 Company 3

Company 3, co-run by developers 3 and 4, was founded circa 2011 and creates stylized retainer clips. Their product was originally developed as a functional solution to protect processors by tethering HAs, CIs, or bone-anchored hearing aids (BAHAs) to one's hair or ear. Traditional safety lines are designed to attach to one's coat or shirt, which means that they can be easily displaced by removing a jacket and forgetting to unclasp the line. Company 3 creates retainer clips in numerous styles, predominantly featuring precious metals and stones to mirror ear-worn jewelry. This product it marketed primarily toward adults of any gender. While Company 1 and Company 2 focused strictly on aesthetic accessory options, Company 3 manufactures a product with both functional and aesthetic qualities.

7.3 Getting Started: Motivation, Start-Up Experiences, and Challenges

As is typical of many start-up endeavors, creating a business is an unpredictable venture met with unique experiences and challenges. Here, developers recount the motivations, experiences, and challenges they've encountered as they transitioned from end users to accessory developers.

7.3.1 Motivation

Motivational factors for starting these accessory companies stemmed from both personal and external considerations. Two developers indicated that the idea for their business arose when they were unable to find an existing product for a very personal want or need. The remaining company was created as the result of a presentation the owner delivered on, *"Making Hearing Aids Sexy."* For this developer, *"the initial plan was to get people talking about hearing aids and also in the press…".* When preparing this presentation, this developer indicated:

> *"I looked on the Internet for lots of different things to do with hearing aids but… there wasn't really anything quite for adults really, so, that's why I created them." –D2, F*

While initial product development seemed to be largely spurred by personal motivators (e.g., an individual need), deciding to pursue business-related ventures appeared to be facilitated by external factors (e.g., encouragement from friends and family). Developer 1's mother encouraged her daughter to seek a patent on the product idea, while developers 2, 3, and 4 were encouraged by others in their community to turn their ideas into full-fledged companies:

> *"…when I was doing the presentation I sort of made a mock version of it, and simultaneously they had a person from…Cosmopolitan Magazine…she came up to me at the end and said 'Really, I think you should market this I think it's a really good idea.' And, so that's how it really started". -D2, F*

> *"He wore the one [retainer clip] that he designed to one of his audiology appointments and his ENT said 'Damn, that is a great idea! You should sell those.' Sooooo..." -D3, F/D4, M*

This external validation appeared to not only motivate developers to pursue their business endeavors but also appeared to play a pivotal role for maintaining their practice. Each developer relayed client commentary about how their products had a positive impact on their clients' lives. The fact that the majority of developers balance their accessory business (with marginal profit) on top of another full-time

work schedule suggests an intrinsically rewarding component derived from helping others. As one developer relayed, helping to *"eliminate the stigma of what it means to be deaf/hard of hearing"* was a huge component of pursuing her accessory business. This sentiment was shared across all developers.

7.3.2 Start-Up Experiences

The interviews reveal the accessory development process to be riddled with extensive planning and experimentation. This section will talk about the start-up experiences of these companies and how these experiences shaped the final product.

Company 1. Developer 1 discussed the evolution of her trial-and-error prototyping experiences, starting with drawings and appropriated supplies (e.g., earrings) before moving to materials such as clay and silicone. It was an intentional choice to focus on accessories that could be affixed (via clips or hoops) to tubes as adhesive-based decorations could obstruct device functionality. All accessories were handmade (though this developer had no jewelry-making experience prior to the business). She conveyed that many new design ideas come from customer requests or from appropriating something unrelated to HAs. Company 1 relied heavily on the Internet, free press, and word-of-mouth for product promotion, maintaining three product sites: a personal product page, a Facebook product page, and an Etsy store.

Company 2. Developer 2's professional experience as an audiologist allowed her to approach HA jewelry design from a unique perspective. As previously indicated, this developer leveraged a pre-existing ear mold coupling to create her accessories. She recounted her detailed decision process, noting that her desire to focus on mold-mounted jewelry was due to the fact that the accessory should be visible, flush with the ear, and not weigh down or obstruct any part of the HA or

mold. Her accessories were also designed to work alongside magnetic loop systems. The development of the mold attachment also enabled a way to accessorize one's HAs without interfering with the processor. This was noted as an important feature as many individuals in the UK receive their HAs through NHS and personally modifying the processor may be seen as interfering with government property:

> *"The idea behind the…ear mold was that you could use it, you know, you could get a free hearing aid but then choose to customize without affecting it." –D2, F*

Due to the specialized coupling mechanism, developer 2 decided to pursue a product that could be mass manufactured using a mold and cast process - allowing her to scale production based on customer demand. Once a user has the specialized mold, customers can purchase multiple accessories and interchange them as needed. This feature, she expressed, was based on a memory of an old pair of glasses that belonged to her mother which permitted for swappable colored frames.

The costs and benefits of mass production were apparent. While the casting for one design took multiple months to perfect, a finalized mold could then produce the same design in multiple colors. However, creating a design with new physical dimensions meant starting from scratch, thus, limiting the number of designs this developer chose to pursue. Finally, developer 2 manages the business through her product website. Similar to other developers, this participant relies heavily on the Internet, self-promotion, conference attendance, and press to promote her products.

Company 3. While this company's fashionable retainer clips originally started out as a functional solution for developer 4, it quickly evolved into an aesthetic accessory under the influence of his co-founder.

> *"with her background [in jewelry-making]…it just seemed to kind of evolve into that [jewelry] and it turns out that it…really does look more like jewelry." -D4, M*

The resulting products were handmade metal-based chain linkages or beaded tethers that can either attach to one's hair with a hairclip or can attach to one's ear using an ear cuff. The developers designed their safety lines with clasps on both ends for interchangeability. Developer 3's background was beneficial as she already had all the tools necessary to create safety line jewelry, and she would visit garage sales or second-hand shops to find vintage jewelry that could be repurposed into safety lines. For these developers, product quality was of the utmost importance, using sterling silver or gold to create products that would last a long time, were allergy-free, and were still affordable. For developer 3, product implementation was the result of three factors: time, ease of sourcing parts, and the know-how/tools required to make their designs. The most simplistic design could be produced in 3-4 minutes, making it highly manageable to run the business on top of a full-time job.

Like developers 1 and 2, prototyping involved significant experimentation. They initially consulted a jewelry designer and also currently retain a jeweler to make highly specialized designs. While these developers restrict their designs to precious metals, crystals, and beads, they also dabble in creating 3D printed designs sourced from a third party. These developers rely predominantly on the Internet, word-of-mouth, and self-promotion (personal conference travel) to promote their products. They maintain a product website and a FB page to sell their accessories.

7.3.3 Challenges Maintaining the Business

Developers reported many of the challenges to pursue their businesses, such as seeking patents (3 companies), dealing with patent infringement (1 company), and the prohibitive costs and effort of mass production (2 companies). This was compounded by the fact that each business was met with overwhelming popularity and success, making the demands (for 2 companies) even more difficult to maintain.

"…it was to the point that I was getting inundated with questions and queries…and actually I was A) trying to run [my accessory company], B) trying to run my [audiology] practice, and it was just a bit… WOW." –D2, F

The small-scale nature of these businesses revealed that one of the largest challenges was obtaining proper advertisement to reach those who would benefit most from these accessories. Given that traditional advertising routes are cost prohibitive, all companies relied heavily on the Internet, word-of-mouth (friends and audiology offices), or free press to raise product awareness. In fact, the Internet proved to be essential in circumnavigating costly barriers to entry:

"If you wanted to buy a list…from audiologists, it costs $5000 dollars and we didn't have $5000 dollars to spend. So basically it was just word-of-mouth and Facebook…and stuff like that." –D4, M/D3, F

Two developers noted attending conventions to promote their products but commented on how the time commitments were extremely unsustainable:

"It's [the Internet] very much just a huge…I wouldn't be able to do it really, I mean, if I was flying and speaking to every single dispenser in the country... whereas you can just do it direct...you can have global reach." –D2, F

However, reliance on the Internet proved to be a challenge for developer 4:

"The other issue we had…was the whole Internet setup…[My co-owner] was familiar enough with that…to be able to kind of work through setting a store up….if we would have had to pay for someone to do that I don't know that we'd have gotten as far as we did because we certainly…aren't making enough money, to pay $1500 dollars for someone to design a website." –D4, M

Additionally, developers were met with different types of challenges depending on the type of product (mass produced versus handmade). For example, Company 2's mass produced designs required more time and energy up front, while handmade products demanded a higher baseline of energy input long-term. Those who pursued handmade designs had to learn the development process along the way. Here, prohibitive factors such as expensive or inaccessible equipment (3D

printers) made it difficult to pursue fully self-sufficient business practices, creating the added challenge of sourcing affordable quality parts and materials.

For Company 3, another major challenge was form factor inconsistency. These developers noted that each processor has a different aperture placement and hole size for retainer clips, creating an added layer of difficulty when producing designs. As a workaround, these developers collected sample devices from manufacturers at audiology conferences so that they could design for these devices accordingly.

7.4 Trends

Participants were asked to comment on overall industry-related trends with respect to expressive AT. Participants shared their experiences and insights about their customer base, HA and CI manufacturers, and the changing nature of AT.

7.4.1 Customer Demographics

All developers reported having primarily female customers. Developer 1 indicated that her items were most popular amongst women, elementary-age boys and girls, and RITE aid users. Developer 2 noted that many of her customers were surprisingly older than expected, estimating them to be in their 80s. Company 3 relayed their customer breakdown tracked via Google analytics:

> *"…at least 10-15% are parents ordering for their children. It's mostly women and maybe another 10% men…the age range is interesting too, it fluctuates at times but normally it's in the 40-60 year old range."–D3, F*

Developer 4 was most surprised by the volume of international orders to the UK as well as other countries such as Australia, Italy, and countries in South America. This developer also noted the number of repeat customers, indicating that

individuals will order one just to test drive the product and then, once satisfied, come back to order more. This company indicated that their order volume was rather manageable, getting roughly 20-30 orders a month (with multiple products per order). Product popularity appeared to shift based on external forces (e.g., holidays), prompting these developers to source parts on an as-needed basis. Developers for Company 3 also discussed order patterns across customers:

> *"Your standard guy has, at least the guys that order from us, they have one [accessory] and that's the one they wear and that's it. It's simple, it works, and all I need is one. The women, oh no, the women have like two or three." –D3, F*

Developers were asked to make recommendations about products that would appeal to male customers. Two developers indicated that males seemed to care more about function. One developer reported getting a decent number of requests from males asking for football emblems or other brand name emblems such as BMW or Mercedes.

7.4.2 Manufacturers Trends

Participants were asked to comment on why they thought manufacturers had not caught on to the increased demand for product customization. All developers indicated that they felt that it was unlikely for manufacturers to pursue large-scale production of expressive AT due to the lack of profitability involved:

> *"As a small business, I am able to personalize each of the orders. Some people have 1 hearing aid, 1 cochlear implant, 1 RITE and no aid on the other side. For my business, it would be taxing on the larger company to make the modifications on my product for each order." –D1, F*

Three developers did note the Oticon hearing aid company as the most progressive from a user experience approach. However, one developer reported Oticon's prior attempt with the Delta hearing aid, a hearing aid with

interchangeable color covers, which was met with limited success, suggesting an underlying reason for manufacturers' unwillingness to pursue aesthetic options.

One developer who had worked with manufacturers for many years expressed their stance of sticking to the *"tried and tested",* as companies primarily focused on research and development with little *"thinking outside the box*". Another developer noted an inability to partner with manufacturers due to their lack of incentive to sell jewelry. While one developer did comment that her company previously distributed products through a major manufacturer, the items had to be so severely discounted that it was unsustainable. There was, however, recognition of CI companies starting to catch on through their use of vibrant color and cover options (see Appendix B). Thus, though industry appears to make spotted attempts at expressive AT, the change is slow, leaving room for small businesses to enter this space.

7.4.3 Changing Nature of the Industry

Developers were also able to comment on the changing nature of the industry as well as their own experiences with AT devices over the years. Original devices included body-worn HAs *"that were pretty awful."* HA development was more bespoke in nature, but as manufacturers moved away from this model into mass production, audiologists, ENT doctors, and general practitioners stepped in and provided this initial examination and hearing aid fitting for the user. This allowed HA manufacturers to focus solely on producing the technology. Though HAs have improved dramatically over the years, one developer commented that today manufacturers have an industry monopoly, operating under the assumption that their devices are superior and that individuals will still turn to them. This has resulted in manufacturers wanting *"to sell the most product for the least research*

and development". The result has been feature overload, as manufacturers appear to continuously change models without truly understanding user needs. One developer referred to it as *"change for the sake of change",* noting clunky interaction techniques such as being restricted to changing the volume through an application solely compatible with iPhones:

> *"…it's silly…you have to have another piece of technology to control that piece of technology…I think that's exactly what happened when they were doing the design for the new one everybody was app crazy. Like, 'Oh my god, we'll make it an app!'… That's one of our little pet peeves." –D3, F/D4, M*

Developers also commented on the industry's oversight that technology is changing. One developer noted a *"nervousness"* amongst audiologists as many new mainstream 'hearable' devices are self-programmable, significantly more affordable than HAs, and have the added advantage of not looking like hearing aids. Such technology could likely disrupt the hearing aid industry by granting users the possibility to exercise greater agency in the AT transition process.

7.5 Discussion

The findings highlight developer-specific experiences as they navigate an industry that, up to this point, has been heavily dominated by proprietary AT. With aesthetic customization on the rise, understanding the industry climate and design space of aesthetic AT can prove useful for further development in this space.

As we reflect on the tumultuous relationship between third-party developers and manufacturers, we can glean that manufacturers' attempts to produce expressive AT ebb and flow. It is clear that the level of personalization required to meet every end user need and preference is unsustainable. This opens up a natural doorway for DIY and third-party accessory development to take hold. To facilitate this, we can see the profound impact of the Internet in lowering the threshold to

allow independent parties to enter this space and make a contribution. The accessibility of the Internet has enabled developers from multiple backgrounds to bring their design solutions to the DHH community. One must note the existing barriers to entry, and despite the far-reaching power of the Internet, the presence of a digital divide is a very realistic obstacle that may prevent other HA/CI users from benefitting from aesthetic customization (as the majority of HA users are elderly individuals). This is especially important because the findings reveal that one of the largest purchaser groups of third-party accessories are older adults. Why older individuals are attracted to third-party accessories is of particular interest, as the results from Study 2 revealed that aesthetic DIY activity trends young. Perhaps older individuals resonate more with professionally-crafted jewelry (as DIY might not reflect their personality). Or, perhaps purchased accessories are easier for older adults to manipulate as they don't require the fine motor skills necessary to implement DIY customization. Future work can help uncover the range of aesthetic customizations that meet the needs of a variety of hearing aid and cochlear implant users.

CHAPTER 8

DESIGN CONSIDERATIONS FOR AESTHETIC CUSTOMIZATION OF WEARABLE ASSISTIVE COMPUTING DEVICES

This chapter will discuss insights and findings as they relate to the final research question:

> **What design considerations and strategies can be applied to worn assistive computing technology to support personal and social comfort?**

The design considerations presented in this chapter have been amassed from the findings generated by Studies 2 and 3 with respect to the challenges, trade-offs, and trends of aesthetic customization. Given that current design implementations and limitations were derived from a number of sources that operate at different scales, recommendations range across a number of entities (single end users, developers, larger online communities, and different customer bases). To support the multiple dimensions of aesthetic AT customization, user-generated best practices will be reported and accompanied by proposed recommendations. This will be followed by a larger discussion of limitations as they relate to the research question and appropriate future work, which will be encouraged by way of design probes, small-scale group workshops, and user evaluation.

8.1 Best Practices and Design Recommendations

Users reported their personal experiences about what did and did not work with respect to aesthetic customization. The following sections will discuss best practices and recommendations to support expressive AT modification.

8.1.1 Supporting How to Get Started in AT Aesthetic Customization

As previously mentioned, the Internet has proven to be invaluable for individuals engaging in varying degrees of HA/CI customization. For those looking to get started in this space, turning to the Internet can help individuals find the types of AT customization and resources that meet their needs. For those seeking DIY customizations, individuals can look to existing social media sites or personal blogs that document user experiences and offer greater support networks for getting started. YouTube tutorials for HA[49,50] and CI[51,52] decoration also exist and serve as indispensable go-to resources for individuals with limited experience in this space. Outside of DIY customization, there are a number of companies that sell HA and CI accessories that can provide interested parties with numerous customization options while simultaneously supporting small businesses.

As observed in Study 2, there were instances where adult individuals were under the false impression that customized manufacturer products were only available for child end users. However, there are many decorative mold and device color options that are also available for adult users and can be sought through follow-up with one's hearing care professional.

[49] https://www.youtube.com/watch?v=cLiVf_CKeVo
[50] https://www.youtube.com/watch?v=7kxiTMZCfOE
[51] https://www.youtube.com/watch?v=74FxtWwQvh4
[52] https://www.youtube.com/watch?v=kH6N5eYGlsw

8.1.2 Supporting Customization while Maintaining Device Functionality

As revealed by the data, there are a number of tried and true materials and techniques that work well for DIY customization while simultaneously upholding device functionality. Duct tape, Washi tape (without glitter), stickers, and nail foils (that can be removed without acetone) were amongst the most popular materials that supported safe and flexible DIY designs. As observed in Studies 2 and 3, it is a good idea to practice designs and test materials on a sample or replica device before committing the design to one's personal AT. One user specifically wished for a mock device so that she could construct papier-mâché designs without harming her HA. While she did not have a replica device on-hand, the option to obtain sample devices (either through manufacturers or through a repository of donated/recycled HAs) could benefit end users who engage in DIY customization.

Avoiding covering microphones, switches, and battery doors is paramount. Some individuals even choose to remove the device battery, ear mold, and tube altogether before decorating. As one end user recounted a negative experience with a purchased accessory interfering with sound quality, it is then considered best practice to conduct device sound checks after applying decorations.

8.1.3 Supporting Flexibility in Changing Device Designs

DIY customization or pre-made accessories are the most straightforward ways to support flexible design as they permit for ease of interchangeability based on shifting end user needs, contexts, or desires. End users came up with unique ways to implement DIY designs to support modularity. As observed in Studies 2 and 3, some end users wrapped their HA tubes with thread, allowing them to change the appearance of the tube without the need to order multiple tube colors. Another end user ordered a large number of clear tubes that she would then color with a sharpie

based on her daughter's preferences. These strategies promote customization flexibility. Given that it was very common for end users to want to change their devices based on the situation (e.g., school dress codes, seasonal designs, wardrobe coordination), exploring how this could be supported through other means (e.g., digital systems) merits further exploration. Future devices may have integrated color-changing displays that can be modified through an application (i.e., taking a picture of the shirt color that you are trying to match) or through pre-programmed toggle features located directly in the device. Furthermore, HA and CI manufacturers could expand their customization options, offering a number of 'plug and play' solutions similar to the concept of a Mr. Potato Head[53] or Crocs shoes and accessories[54] which offer a generic 'body' and user-selected add-ons.

Speed and scalability were other common themes amongst practitioners, especially for developers and caregivers who were tasked with creating customizations frequently. With time, some end users developed strategies to increase decoration speed. One caregiver demonstrated her streamlined customization system that allowed her to produce decorated HAs and CIs in under 3 minutes. This process entailed applying a square piece of decorated Duct tape to the processor, flipping the device over, tracing around the device with a pen, removing the tape, cutting along the marked outline, and finally reapplying the tape to the device. For this caregiver, speed and scalability were of the utmost importance as she decorated devices for her entire DHH class. This caregiver proposed a software program with pre-loaded brand-specific HA and CI templates that would allow her to select the appropriate template and 'print' the cutout to some type of vinyl cutter loaded with Duct tape. This would allow the caregiver to quickly create multiple designs that could then be easily applied to her students' devices.

[53] http://www.hasbro.com/en-us/brands/playskool/mrpotatohead
[54] https://www.amazon.com/Jibbitz-Crocs-Charms-Birthday-Balloons/dp/B0076MG842

8.1.4 Supporting Members in Online Communities

As discussed in Chapter 5, members of the online community frequently posted questions about the best practices, materials, tools, and device-specific designs. For these individuals, creating an online repository of tutorials, design ideas, and design techniques can be helpful. For example, members often had questions about designing for a specific make and model of hearing aid, or requested inspiration for theme-based customizations such as cartoons or holidays. Implementing a feature that can catalog designs based on device brand or theme (perhaps through the use of hashtags) can serve as a reference for individuals to quickly obtain multiple resources based on their requests.

8.1.5 Supporting Third-Party Businesses

For developers, one of the most challenging aspects entailed finding proper advertisement channels to spread the word about their products. While the Internet, word-of-mouth, and audiology offices served as indispensable resources for product promotion, it is clear that HA and CI end users remain highly unaware of existing customization activity in this space. As a workaround, it is in these developers' best interests to use as many online product page sites as possible to reduce access barriers. For example, one developer maintains a personal product page, a Facebook product page, and an Etsy product page. Additionally, it may behoove the industry as a whole if third-party developers had manufacturer support in advertising customization activity. In fact, one caregiver did report that Cochlear[55], one of the leading manufacturers of cochlear implants, posted a message that acknowledged customization activity and promoted safe modification practices:

[55] http://www.cochlear.com/wps/wcm/connect/us/home

"I think it was last week I saw a, I don't know if it was a tweet or Facebook, but it was from Cochlear, and it said, it was giving tips on personalizing, and the one thing that they did say was, 'Just remember not to cover microphones', you know to keep the integrity of the buttons and everything. So it's like they were advocating it saying this is a cool thing." -P10, F

Another issue that plagued third-party developers was the inconsistency of physical form factors across devices. End users and developers alike noted the standardized size and broad shape of CIs facilitated decoration, while HAs and BAHAs posed more challenges due to inconsistencies in device size and placement of retainer clip apertures, respectively. Creating standardized devices (or, at least, extending the use of manufacturer sample devices) was noted as a highly desirable feature by two of the three accessory companies.

As a whole, it appears that third-party developers may benefit most from entering into a symbiotic relationship with manufacturers. Such an association can be mutually beneficial – spreading awareness about customization and also possibly encouraging potential end users to be more open to adopting AT for hearing loss.

8.1.6 Supporting Diverse Users

The studies revealed insights with respect to different user groups that will benefit from future research. The following section will briefly discuss ways to support children, males, and older adults in aesthetic customization practices.

Children. Customization proved to be highly popular amongst children. Some interesting takeaways included that children are often highly involved in the customization process, even if a caregiver is the one implementing the design. Thus, supporting the participation of children by allowing them to collaborate and take part in the design process is essential. As one caregiver reported, her DHH students commonly prefer patterned designs over solid colors. This is a particular insight that manufacturers and third-party developers may find of interest to explore. The

creation of child-friendly materials could also be beneficial as a way to allow children to express themselves without using tools that could potentially harm them or the device (e.g., injury that may result from using scissors or X-ACTO knives).

Males. As reported by all developers, males participated in aesthetic customization less. This is perhaps due to the customization type (e.g., reflects ear-worn jewelry) or the fact that men might just prefer functional characteristics to aesthetic ones. However, there were exceptions. Elementary-aged boys appeared to be rather receptive to aesthetic customizations, especially those involving cartoon characters. Developers also noted special requests by male clients, such as designs with football and BMW emblems. It's possible that pursuing customizations to support male users may require accessories that move away from a classic jewelry aesthetic and embrace symbolism that males may feel more comfortable wearing.

Older Adults. Developers reported older individuals as one of the more heavily represented customer bases of third-party accessories. Older adults may gravitate toward these designs due to the ease of the customization (as DIY implementation likely requires a high degree of dexterity). Understanding other ways to support these users (e.g., ensuring that accessories have easy attachment mechanisms, ensuring that accessory advertisements reach these users, understanding the types of customizations these users prefer) may help support end users in their willingness and personal comfort to use these devices.

8.2 Opportunities and Next Steps

While the current research has provided an understanding of the existing design processes and implementation challenges of expressive HAs and CIs, a more rigorous approach is needed to critically understand the potential design space for

future HA and CI development. There are a few alternate routes and important next steps that can build on this research foundation. One of the first avenues would involve developing one or multiple design probes to explore different facets of expressive AT, for example, a software tool to support customization, an application interface designed to facilitate on-the-go expression, or toggle-driven analog and digital device features that can help mediate interactions with the outside world. Such probes could be used to further understand different aspects of AT design, such as a baseline of expressive design options (perhaps linked to user type or personality), form factor and symbolism signification[56], interaction modalities, feature overload, and how to support changing needs and user agency.

Design probes would benefit from workshops with different population representations, including: individuals with early onset hearing loss, individuals with late onset hearing loss, children, teenagers, males, older adults, and DIY practitioners, to name a few. These workshops could be further subdivided to understand how to support underrepresented groups or 'hesitant' AT adopters as well as how to further support highly represented groups. Feedback from the workshops can inform the next phase of prototype design to create higher fidelity devices and tools that can be evaluated via usability and user experience testing. This future work can help shed additional insights on the AT customization features that can further support social acceptability and self-expression.

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[56] "Umberto Eco…distinguishes between a process of communication and one of signification in any given object, being the first characterised by the existence of an intention to transmit a specific message and the second a cultural process uncontrolled by the designer. In the case of objects that are specifically designed for people with disabilities a process of signification occurs that associates the use of the object with a set of socially depreciated characteristics such as fragility or inaptitude that spoils the social identity of the disabled person…This process of signification is not planned nor controlled by the brands that produce these objects. Nevertheless, they lead to the situation in which its usage becomes a stigmatizing symbol with negative repercussions on both the emotional and the public image of the user." (Bispo & Branco, 2009, p. 1)

CHAPTER 9

DISCUSSION AND OBSERVATIONS

The studies in this manuscript raise interesting questions for the design of future wearable assistive computing systems. Study 1 demonstrated that disclosing the assistive context about device use reflects positively on bystanders' perceptions. However, it is unrealistic to assume that all AT users will explicitly share or 'over share' information about one's disability status to generate increased societal acceptance. Thus, the next logical manner in which to effectively convey information about the device or the user is through physical design features integrated into the assistive technology. The follow-up work executed in Studies 2 and 3 demonstrated how aesthetic qualities may change attitudes toward device use despite the fact that these devices (HAs and CIs) have retained their classic form factor. This section will expand on a larger discussion about the role of design in managing socio-cultural factors, the self-sufficient nature of this AT community, designing for changing needs, supporting aesthetic customization, the impact of accessibility on technological evolution, and limitations of the study.

9.1 Mediating Socio-Cultural Factors through Design

This work was spurred by the negative impact that socio-cultural factors can have on AT adoption, use, and acceptance. Through in-depth analyses, this work has detailed how DIY and customization practice methods can dramatically impact perceptions and personal and social comfort with respect to AT use. This demonstrates the undeniable power of design (and context) in changing views about

assistive technology, which will undoubtedly prove useful as we develop and deploy new wearable assistive computing devices. Within the hearing aid and cochlear implant communities, design has been used successfully as a de-stigmatizing agent, empowering users to wear their AT with pride while simultaneously reclaiming their identity. We see similar effects across other DIY AT communities as well, such as e-NABLE (Bennett et al., 2016), demonstrating how creative design solutions and AT communities can promote positive outcomes with respect to managing the personal and social comfort of AT use. The implications of design interventions are amplified when we note the substantial change in bystander behavior toward device use (detailed in Study 3), as some bystanders completely overlooked the presence of the AT altogether. The result is a community of individuals that recognizes and effectively uses aesthetic customization as a tool to navigate personal and social comfort as it relates to disability and assistive technology use. Such findings reveal the significance of design in mediating impressions of device use and should be looked at as a resource for positively impacting other disability communities and future AT development.

9.2 A Self-Sufficient Community

By nature, assistive technology works toward increasing user independence for activities of daily living. However, through the rise of DIY and third-party aesthetic customization, we see a greater emphasis on end user decision-making for both functional and expressive aspects of their AT devices. Industry's slow uptake of expressive customization options has resulted in users gradually exercising greater independence in this process, pursuing their own aesthetic enhancement solutions and even creating thriving customization-specific communities. Such self-organization is facilitated by the Internet and social media sites that offer features

which enable these communities to operate in a safe, respectful, and controlled environment. The role of the FB group administrators and their willingness to volunteer their time represents the grassroots effort that we might see of future AT communities. This community not only shows steady and successful growth but reflects a coordinated effort to maintain the group to support continued pursuits of expressive freedom. This most notably is a detachment from prescribed industry standards which have often dictated technological enhancements, upgrades, and new features (e.g., different color options). While some manufacturers are responding by offering increased customization options, it is clear that such benefits are only granted to those fortunate enough to use those specific brands, leaving the remaining HA/CI users without options. Furthermore, the fact that some participants stated a preference for personally decorating their devices, even if manufacturers offered abundant solutions, suggests that many individuals who engage in DIY practice find some intrinsically rewarding elements to creating personal customizations.

One of the more interesting points to arise is the large amount of collaboration and community feedback that this activity generated. This was particularly interesting amongst the caregiver-'caregivee' relationship and merits future study. Here, the customization process was highly collaborative and intimate, and it will be interesting to understand how customization evolves within this relationship. At what point do children start decorating for themselves? What does the transfer of knowledge between caregiver and 'caregivee' look like? Caregivers may inherently teach 'caregivees' these self-sufficient DIY practices.

The trend of self-sufficiency extends to other areas of hearing aid and cochlear implant use as well. One practitioner used aesthetic customization to 'hack' the sound quality of her hearing aids. Another participant, in particular, the audiologist, spoke of the *'nervousness'* in the audiology industry due to the influx of

self-programmable hearables flooding the market. This participant reflected the consensus (amongst audiologists) that those with hearing loss will have an increased willingness to adopt or try hearable devices due to the significantly lower cost and one-stop-shop benefits of these devices (allowing users to bypass appointments with hearing care professionals altogether). This, coupled with the fact that hearables are designed to look like mainstream products, may likely reinforce their appeal as viable alternatives for those with hearing loss. These facts alone suggest a trend that could quite possibly disrupt the hearing aid industry and is a promising option for the overwhelming number of individuals who could benefit from hearing aids but still choose to forgo device use.

Additionally, self-sufficiency poses interesting questions for future wearable assistive computing devices in general. What would the impact of open source platforms be for hearing aids, cochlear implants, or other assistive devices? The DIY nature of open source may solicit greater end user buy-in. Given that the most successful open source initiatives arise from community participation (Heron, Hanson, & Ricketts, 2013), open source projects may be a natural extension for those DIY AT networks characterized by a community-based structure.

9.3 Designing for Changing Needs

At their core, effective assistive technologies will be able to meet the changing needs of users on all levels. This includes not only functional needs but personal and emotional considerations as well. As uncovered in Study 3, many users prefer the flexibility granted through DIY customizations, noting the ability to change designs based on different moods, occasions, and requirements (e.g., school dress code). Designing with this flexibility in mind will not only allow individuals to successfully use their AT to reflect their personality, but will also support users in

dynamic contexts. As unveiled in Study 1, not all technologies will be met with the same level of acceptance depending on the situation. Enabling devices (whether assistive or mainstream) to adapt to different scenarios at the user's discretion can grant greater support to navigate many of the structures imposed by society.

For assistive technologies, we are beginning to see an increased focus on aesthetic design offered through third-party companies. Such designs either promote multiple aesthetic options or focus on one product with universal aesthetic qualities (e.g., the Eone Bradley Timepiece – see Figure 3). Flexible design that can be activated 'at will' can also be strategically used with respect to new or changing disability policies. Assistive technology can leverage physical design, software capabilities, and interaction techniques for improved accessibility and inclusivity. It's no longer adequate to merely support physical device upgrades. Users want features that accommodate them in all aspects of their lives and will find ways to implement strategies that bypass manufacturer- and insurance-based restrictions. In a climate often dictated by industry, we see a natural stepping stone for DIY initiatives to take hold and foster increased user independence. Such grassroots efforts are only likely to grow as we increase the reach of community networks and pertinent information accessible through the Internet.

9.4 Supporting Aesthetic Customization Practices

By and large, one of the more surprising revelations was learning that aesthetic customization was essentially an 'unknown practice' amongst participants when first starting out. This limited awareness of a seemingly innocuous and highly creative practice suggests that individuals are not introduced to aesthetic options when first fitted with their hearing devices (making it perhaps a perfect place to start implementing change!). This raises the question, whose responsibility is it to

enlighten prospective end users about customization options in their transition to AT? And, since this role is clearly lacking within the classical hearing care professional pipeline, should it now become someone's responsibility? Audiologists or Ear, Nose, and Throat (ENT) doctors are often an end user's first and main point of contact in the fitting process. They already introduce end users to stylized ear mold options, thus, their role in the front lines could have a tremendous impact on promoting aesthetic options capable of contributing to a user's positive AT experience. As it is, many third-party accessory developers still heavily rely on word-of-mouth and do indeed use willing audiologists to spread the word about their products. Thus, the continued limited awareness suggests that these efforts might not scale well (especially outside of the DHH community where a number of potential users remain) suggesting that the Internet could again be an indispensable resource to promote this practice.

Furthermore, manufacturers likely have a vested interest to positively promote and support customization practices since they themselves seem less incentivized to pursue these initiatives. Given that aesthetic customization was suggested to potentially have a positive impact in changing one's willingness to adopt hearing devices (Study 3), manufacturers could potentially see a dramatic increase in customer activity as a result of aesthetic customization awareness. End users would likely benefit from this symbiotic relationship as well. Study 2 revealed many end user concerns regarding modification inadvertently interfering with device functionality. Industry support of customization practices could prompt manufacturers to release pamphlets or how-to guides for best practices on 'blinging' one's hearing aid or cochlear implant. Industry acknowledgement, acceptance, and cooperation may also quash fears about possible insurance violations. Again, manufacturer support can serve to help promote the practice, increasing its visibility and reaching a broader audience.

In addition to promoting aesthetic customization, it is important to pave the way for DIY practice and third-party accessory developers since they are the practitioners making strides in this area. Without their hard work (as these activities are often balanced on top of other full-time schedules), there would be very little activity in this space. Producers of craft supplies could create affordable material solutions designed specifically for hearing aids, cochlear implants, and other assistive devices. Or, craft suppliers could start to recognize the tremendous DIY AT activity involving their products and could incorporate helpful instructional information about proper use with AT devices.

9.5 Accessibility is the New 'Design'

Accessible design has slowly found its way into more and more products and services. Companies are placing greater emphasis on inclusivity, usability, and user friendliness. The sudden push for accessibility 'thinking' in corporations demonstrates a recognition for the need to support users with diverse backgrounds and abilities, especially as we create novel digital products with less established interaction modalities.

Historically, designing for diverse populations has resulted in inventions that provide large-scale utility. The development of the telephone and text messaging are two notable examples of inventions that arose from designing for deaf individuals yet quickly gained widespread popularity across a non-deaf user base (Law, 2006). As we continue to develop new digital technologies, approaching user interface design from an accessibility perspective is likely to have advantageous outcomes for individuals with a range of abilities. Designing digital technologies has been known to introduce a number of usability challenges, also commonly referred to as situational impairments (Sears, Lin, Jacko, & Xiao, 2003), which can lead to

decreased performance and unintended negative consequences. Designing for disability can solve many of the interaction challenges that arise from everyday use. For example, voice recognition systems facilitate cell phone use for individuals with low-vision but are also useful for non-blind users by reducing the need for two-handed operation and dedicated visual attention.

As we move into the design space for mainstream wearable and 'hearable' systems, we can look to accessibility design to inform the development of new interaction paradigms that will ultimately arise. For example, this research has reinforced the fact that physical device cues can help communicate important information to bystanders. As hearables gain popularity, understanding what the affordances of device form factor communicates to bystanders may critically impact interaction dynamics. For example, the noticeable placement of a hearing aid behind the ear signals to others that the ear is free from obstruction and that the user is ready for engagement. However, mainstream earphones, headphones, or other commercially available hearable devices often remain in the ears even when not in use, communicating to bystanders that they should not (or cannot) be engaged with. This, however, might not have been the end user's intention and creates a mismatch between user and bystander interaction expectations. As the technological evolution and popularity of hearables will likely create increased acceptance for HAs and CIs, learning from the general usability issues and challenges of hearing aid and cochlear implant users will undoubtedly serve a mutually beneficial relationship between the two classes of assistive and non-assistive devices.

9.6 Limitations

Socially-situated research is inextricably tied to the cultural-climate and time period of study - the outcome of which is subject to change based on advances in technology, shifting societal norms, and enacted institutional and governmental policies. As a result, these findings are limited to the awareness and cultural attitudes of the devices, disabilities, and interactive media platforms evaluated in this manuscript.

The findings from Study 1 were limited to participants' *expressed* perceptions of device use. Further insights could be gained by capturing more implicit biases toward device acceptability (e.g., eye gaze). For Study 2, the origin and community-base of this FB group was fairly centralized, though they accepted and welcomed global membership. Thus, the general trends about group activity may be highly representative of only one or a few geographic regions. Additionally, analysis was restricted to members within this FB community. However, from Study 3, we can glean that a substantial amount of aesthetic customization activity occurs outside of this FB group and that this activity may even take on different forms. Finally, Study 3 was limited to a small set of interviews and did not have equal representation across gender, age, and practitioner-role. Thus, the findings are limited to the group of interviewees and their willingness to engage in the research. Though generalizability is constrained, these findings can serve as a foundation and comparative lens for other like-minded research initiatives aimed at understanding the interplay of wearable assistive computing devices, socio-cultural considerations, and design interventions.

CHAPTER 10

FUTURE WORK

Expressive assistive technology is on the rise, with examples surfacing across a range of devices, including fashionable walking canes, wheelchairs, and prostheses. To our knowledge, this is one of the first in-depth analyses of the socio-cultural considerations of AT use across a range of wearable assistive computing devices (more specifically, Google Glass, hearing aids, and cochlear implants). We view this as the beginning of a larger body of work aimed at understanding how design interventions can impact assistive technology, disability, accessibility, and social comfort. Here, we discuss many possible avenues for future work.

10.1 Supporting Personal Expression

A natural extension of this work would be to understand what specific expressive properties support different user groups of hearing aids, cochlear implants, and other forms of assistive devices. For example, aesthetic customization of prosthetic limbs is gaining increased popularity, however, prosthetic legs, for example, may face a different set of design trade-offs as customizations may displace the weight of the device and interfere with gait performance. As with any form of assistive technology, one size does not fit all. Exploring the most important aspects of expression for different genders, age groups (older versus younger populations), disability statuses (congenital versus late onset), and diverse populations (and how best to access these resources) can work toward supporting device use, adoption, and social acceptability. Running design workshops with these

different cohorts can help generate a discussion around the 'next phase' of aesthetic enhancements for AT users.

Furthermore, for those who prefer DIY modification as opposed to commercial customization, understanding what new resources, tools, and materials can best support them in this practice can encourage continued work in this space. The development of software tools or applications with customizable HA/CI templates that support color matching or ad hoc design creation may grant users more opportunities to create meaningful and expressive designs. Evaluating these ideas as well as other more classic marketing strategies, such as brand name associations or form factor signification, may prove useful as we enter an age of increased technological innovation and the Internet of Things.

10.2 Exploring Perceptions

This research revealed how context (Study 1) and appearance (Studies 2 & 3) can change people's views of wearable assistive computing devices. From these studies, new and interesting questions arose with respect to AT use that merit further investigation. In Study 1, third-party expressed perceptions were gauged of a HMD used by an individual with a vision impairment. Future work evaluating other disability presentations, devices, device design characteristics, and actors could shed light on attitudinal distinctions between these different factors. Additionally, for this study only expressed perceptions were captured. Conducting complementary follow-up work to assess other more implicit factors (e.g., gaze detection) can supplement the explicit findings from Study 1.

Of additional interest would be to understand bystander perceptions of hearing aids and cochlear implants. One possibility would be to replicate the study design of Study 1 and substitute the HMD with stylized hearing aids or cochlear

implants. To build on this, it would be thought-provoking to understand if a 'continuum of acceptability' exists based on the degree of decoration. Do patterned hearing aids generate more positive attitudes than solid colors? What about recognizable cartoon character charms? Do these attitudes change based on the appearance of the user (and the associated societal expectations)? Understanding the role of design in mediating this societal response can shed insight on designing for acceptability.

CHAPTER 11

CONCLUSION

This work has produced new insights regarding the role of context, design, and DIY practice in managing the personal and social comfort aspects of wearable assistive computing technologies. In particular, the three studies documented in this manuscript brought to light how expressed societal perceptions challenge wearable computer use, the importance of online communities in fostering creative and aesthetic AT solutions, and how these aesthetic solutions establish personal expression, user agency, and a detachment from prescribed societal expectations and industry standards.

Study 1 revealed that attitudes toward wearable computer use are influenced by the user's disability status. This relationship potentially complicates issues related to mainstream accessibility technologies and policy-making as we navigate the trade-offs of accommodation and public information disclosure. Finding ways to mediate these trade-offs of AT use (e.g., through design interventions) may help to negotiate the competing challenges of maintaining end user privacy, independence, and social acceptability.

Study 2 captured how users of existing wearable computer AT (hearing aids, cochlear implants, and other hearing devices) implement design and DIY strategies to create unique and aesthetic AT solutions for the purposes of self-expression, community building, and to encourage AT use. It was found that the Internet and online sites are indispensable resources for empowering practitioners to pursue these design interventions, and that individuals went to great lengths to exercise

their creative freedom. The successful uptake of this DIY practice for HAs and CIs can perhaps be viewed as a progressive shift against the constraints and social norms that often pervade assistive technology use.

Study 3 revealed that aesthetic customization empowers personal comfort with AT use while simultaneously serving as a mechanism to challenge preconceived notions about assistive technology and disability. Here, the act of aesthetic customization (in addition to the end product) was seen as a critical component with respect to participants' choices about self-presentation. For these participants, aesthetic customization served to promote a positive disability identity both within their disability community and within a greater societal context.

Over the years, wearable assistive technologies have evolved considerably, taking incremental steps toward addressing socio-cultural aspects of AT use. However, there is still a fair amount of work to be done before AT can fully support users in all aspects of their lives. As this research has demonstrated, aesthetic customization is a powerful tool in supporting individuals with disabilities on many levels, including: promoting personal comfort, fostering community, and facilitating greater agency in stigma-managing practices as they relate to worn AT. Furthermore, design interventions can play a critical role in regulating many of the competing interests of AT use, for example, privacy disclosure, functional performance, and bystander perceptions. Thus, further consideration of the impact of context and design on the quality of one's AT experience will be indispensable as we develop future wearable computing devices to support accessibility, personal expression, and social acceptability.

CHAPTER 12

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APPENDIX A: EXISTING HEARING AID COLOR OPTIONS

HA Company	URL	Neutral Colors - Flesh tone and Hair Tone	Non Neutral Colors
Audibel	http://www.audibel.com/hearing-aids/receiver-in-canal-hearing-aids/standard	Sterling, slate, espresso, black, bronze, champagne, bright white with sterling, black with sterling, pink (flesh tone), light brown, medium brown, dark brown, black, chestnut	
Audina	http://www.audina.net/en/content/index?category=product-styles	Colors not named - discerned from image: grey, beige, brown, white	
Beltone	http://www.beltone-hearing.com/Products/Hearing-aids	Beige, brown, grey, light grey, black, charcoal, white, sterling grey	
Bernafon	http://www.bernafon.com/Consumers.aspx	Sand-beige-mac, metallic-silver, antique-bronze, metallic-anthracite-mac, sand-beige-msil, metallic-anthracite-msil, cocoa-brown, jet-black, cobalt-blue, gray, dark-brown, gray-brown, beige, metallic-anthracite, metallic-beige	Cobalt-blue, baby-pink, baby-blue
Eurion	http://www.eurion.ch/En/Default.htm	Beige, tan, grey, brown, transparent	Blue, red, yellow, multicolored
Hansaton	http://www.hansaton.de/us/	White pearl, sterling silver, carbon black, sandy beige, cloudy grey, space titan, sparkling bronze, light grey, warm taupe, dark graphite, jet black, dark brown, natural beige	
Micro-Tech Hearing Instruments	http://www.microtechhearing.com/hearing-aids	Sterling, slate, espresso, black, bronze, champagne, bright white with sterling, black with sterling, pink (flesh tone), light brown, medium brown, dark brown, black, chestnut	
Micrable Ear	http://www.miracleear.com	Colors not named - discerned from image: silver, beige	
Oticon	www.oticon.com/	Black, beige, terracotta, brown, silver, grey, steel grey, silvery grey. Children: beige, terracotta, brown, silver, black, pure white	Adults: royal blue, blue sensei. Children: red, emerald green, pink, aquamarine, purple
Persona Medical	http://www.personamedical.com/evok-features.html	Colors not named - discerned from image: beige, gray, black, white, brown	Red, blue, green
Phonak	http://www.phonak.com/	Adults: alpine white, velvet black, graphite grey, silver grey, champagne, chestnut, sandalwood, sand beige, beige, tan, cocoa brown, brown, black, white, white transparent. Children:	Adults: ruby, petrol, pink, red transparent, blue transparent. Children: precious pink, blue ocean, majestic

		silver grey, velvet black, sandalwood, chestnut, beige, champagne, amber beige, alpine white, sand beige. Ear Hook Colors: beige, sand beige, amber beige, sandalwood, chestnut, champagne, silver grey, velvet black, alpine white	purple, lava red, petrol, electric green, caribbean pirate (teal). Ear Hook Colors: lava red, blue ocea [sic], majestic purple, petrol, electric green, caribbean pirate (teal), precious pink
Resound	http://www.resound.com/en-US/hearing-aids/enzo2	sterling grey, silver, pearl white, anthracite, black, beige, light blonde, medium blonde, dark brown, gloss black	Forest camo, desert camo, ocean camo
Rexton	http://www.rexton.com/us/en/	Colors not named - discerned from image: silver, beige, brown, black, white, grey, bronze	
Rion	http://www.rion.co.jp/english/product/audiological/hearing_instruments/custom_made_type/	Silver, gold, black, brown, beige, gray, light brown	Pink, blue
Sebotek	http://www.sebotek.com/	Colors not named - discerned from image: light beige, brown, black, transparent black	Colors not named - discerned from image: light blue, light pink, transparent red, transparent blue
Siemens	https://usa.bestsoundtechnology.com/siemens-hearing-products/ric/	Beige, granite, grey, silver, pearl white, golden blonde, sandy brown, dark granite, spirit (gray + black), black, dark champagne, brown, elegance (white), dark brown, color.ite mocha.title (mocha), tan	Deep red, candy pink, galactic blue
Starkey	http://www.starkey.com/hearing-aids	Sterling, slate, espresso, black, bronze, champagne, bright white with sterling, black with sterling, pink (flesh tone), light brown, medium brown, dark brown, black, chestnut	
Unitron	http://unitron.com/unitron/us/en/consumer/hearing-aids/styles.html#show_colors-2	Amber suede, sandstorm, platinum, pewter shine, pewter, expresso boost, espresso, cinnamon, charcoal, beige, amber, tan, brown, cocoa, black	Teal blast
Widex	http://www.widexusa.com/	Beige, dark brown, medium brown, winter silver, warm beige, tan silk, titan grey, midnight black, cappuccino brown, copper brown, summer gold, pearl white, silver white	Mediterranean turquoise, shocking pink, sporty red, lime green, metallic blue

APPENDIX B: EXISTING COCHLEAR IMPLANT COLOR OPTIONS

CI Company	URL	Neutral Colors - Flesh tone and Hair Tone	Non Neutral Colors
Advanced Bionics	https://www.advancedbionics.com/	Alpine white, onyx, beige, gray, dark brown, sand castle, petrol	Caribbean pirate, ruby, princess pink
Cochlear	http://www.cochlear.com/wps/wcm/connect/intl/home	Covers: white, black, blonde, brown, copper, silver, maize, silver grey, chocolate brown, copper brown, slate grey, golden blonde, slate black, sandy blonde	Covers: teal, orange, purple, blue, pink, red, red patterned, white/black patterned, blue patterned, skull and cross bones pattern, zebra, leopard, purple patterned, blue/silver patterned, camouflage, pink/orange patterned, red/orange patterned, soccer ball patterned, pink camouflage
MED-EL	http://www.medel.com/us/	Covers, unit, coil, or cable: black, beige, anthracite, white, nordic grey, ebony, sienna brown, creme, cool grey	Covers, unit, coil, or cable: baby blue, pacific blue, baby pink, green, orange, bordeaux red

APPENDIX C: STUDY 3 INTERVIEW QUESTIONS

Semi-Structured Interview Questions

1. Please describe how you use your technology/assistive devices to perform daily tasks:
2. What are your thoughts about the technology you use?
3. What are your thoughts about the technology you previously used?
4. Has there ever been a time where your felt uncomfortable using your technology in general?
5. Which devices do you prefer to use and why?
6. Have you ever decorated/modified one of your devices?
   a. If yes, why did you decorate/modify your device?
   b. If yes, how did you decorate/modify your device?
7. How did decorating your device make you feel personally?
8. How did using your decorated device make you feel in social settings?
9. Have you ever bought a piece of technology because it was aesthetically appealing to you?
   a. If yes, why did you buy the device with this aesthetic quality as opposed to another device with a different aesthetic quality?
   b. How does this device make you feel personally?
   c. How does using this device in social settings make you feel?
10. Have you ever received a compliment for your decorated or aesthetically appealing device?
    a. If yes, tell me about this time/experience:
    b. If yes, how did these compliments make you feel?
11. Have you ever rejected or abandoned a device because it was ugly or not to your liking aesthetically?
12. Have you ever tried to hide your technology from others?
    a. If so, how did you try and hide it?
13. Are there any other steps that you've taken in the past to try and cover up your device? (e.g., hiding it under clothing, putting your hair down, wearing/using it only in your office/home?)
14. Why, if ever, did you feel the need to hide your device?
15. Does your decorated/aesthetic/modified device make you feel differently than your hidden device?
    a. If yes, how so?
16. Have you seen the recent articles/websites about the beautification of assistive devices such as the Alternative Limb Project/Prosthetic Ink/Hayleigh's Cherished Charms?
    a. What are your thoughts about this?
    b. Can you comment on what these initiatives are trying to do?
    c. Why is this important?
17. Do you prefer to wear/use mainstream devices as opposed to dedicated assistive devices (e.g., a standard cell phone versus an assistive PDA)?
    a. If so, why?
18. How does using mainstream technology make you feel in comparison to using a dedicated assistive or medical device?

Developers/Distributors of Assistive Technology

19. Why did you go into this field?
20. What are your thoughts/feelings on aesthetic variations of assistive technology?
21. Do you find that there is more of a demand now for assistive technology, as opposed to in the past?