

# “Wear It Loud”: How and Why Hearing Aid and Cochlear Implant Users Customize Their Devices

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We investigate the role of aesthetic customization in managing sociocultural issues of assistive technology (AT) use. First, we examined an online forum dedicated to customized hearing aids and cochlear implants to understand the breadth of activity occurring in this space. Next, we conducted a series of interviews to understand motivational factors and sociocultural outcomes related to expressive AT. We found that community members discussed customization tools and techniques, shared their customizations, and provided each other with encouragement and support. Community members customized their devices as a means of self-expression that demonstrated the wearer’s fashion sense, revealed favorite sports teams and characters, and marked holidays and personal milestones. We also found that aesthetic customization worked on multiple levels to create personal and meaningful relationships with one’s AT and with other AT users, and also to manage societal expectations regarding hearing loss. Our findings may inform the design of assistive technologies that better support personalization, customization, and self-expression.

CCS Concepts: • **Human-centered computing** → **Empirical studies in accessibility**; *Empirical studies in collaborative and social computing*;

Additional Key Words and Phrases: Do-It-yourself assistive technology, online communities, hearing aids, cochlear implants, deafness, social acceptability

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## 1 INTRODUCTION

Approximately 20% of the US population, representing 48 million individuals, report living with some degree of hearing loss [36]. Individuals with hearing impairments may use assistive

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technologies (AT), such as hearing aids (HAs) and cochlear implants (CIs), to compensate for loss of hearing. Despite the functional benefits that hearing aids and cochlear implants can provide to many individuals, use of these devices can present tradeoffs such as poor performance, device invasiveness, poor ergonomics, and high cost [32]. Additionally, some users and potential users may be dissuaded from using hearing aids and cochlear implants due to sociocultural concerns, such as worrying that using these devices will attract unwanted attention [14, 38]. Sociocultural concerns about the use of assistive devices may result in isolation or social stigma, intermittent use of one's AT, or even abandonment of the device [14, 29, 30, 44]. Device rejection may be especially high for hearing-related AT as it has been reported that abandonment rates for hearing aids may approach rates as high as 75% [42, 43].

Despite the potential benefits of using hearing aids and cochlear implants, some individuals may respond to these sociocultural concerns by avoiding their use. Hearing aid manufacturers have responded to these concerns by producing devices with smaller footprints, making them easier to conceal.<sup>1</sup> However, other users of hearing aids and cochlear implants have responded to potential sociocultural concerns by making their devices even more visible. We present a growing community of hearing aid and cochlear implant users that customize and stylize their devices to highlight the device, express their personal interests, manage societal expectations, or demonstrate pride in their disability.

Because off-the-shelf hearing aids and cochlear implants offer few options for self-expression, some companies have appeared to address this issue, creating accessories designed to mimic traditional ear-worn jewelry<sup>2</sup> or embellish the device with colors and patterns.<sup>3</sup> Such accessories include charms, clips, protective skins, colored tubes, and stickers, and range from purely ornamental to those that offer both functional and aesthetic benefits. Where commercial options are not sufficient, end-users have turned to do-it-yourself assistive technology (DIY AT) solutions [23]. Recently, we have seen the emergence of online forums and discussion groups related to sharing ideas, tips, and examples related to customized hearing aids and cochlear implants.

We present an analysis of one such DIY AT community, a Facebook group with over 4,800 group members, aimed at creating and sharing personal decorations of hearing aids and cochlear implants. Our analysis addresses both the customized devices shared in the group and the group's interactions through posts and comments, which include sharing customization tips, building community, and offering social support. In addition to the analysis of this online community, which sheds light on why and how users customize their devices, we expand this work through a series of follow-up interviews with members of this community to gain a deeper understanding of the motivational factors, personal experiences, and social outcomes related to the aesthetic customization of hearing aids and cochlear implants. Our findings may inform the design of AT devices that better support customization and online communities that facilitate and support sharing of customized AT devices. This article is an expansion of prior work [39]; in this version of the article we have included an analysis of comment threads in the online community and present findings from a new interview study that explores individuals' experiences in learning how to modify their hearing aids and cochlear implants.

## 2 RELATED WORK

As this article explores aesthetic modification practices of hearing aids and cochlear implants, we review prior work related to aesthetic enhancement of AT, the developing DIY AT movement, and the social aspects of hearing aid and cochlear implant use.

<sup>1</sup><http://www.npr.org/sections/health-shots/2013/04/08/176225511/listen-up-to-smarter-smaller-hearing-aids>.

<sup>2</sup><http://www.hearings.co.uk>.

<sup>3</sup><http://www.skinit.com/device-skins/medical-skins>.

## 2.1 Aesthetic and Expressive Assistive Technology

Early forms of assistive technology were developed to conceal their appearance by blending in with the wearer's body, mimicking a "missing" body part, or presenting a neutral design [40]. However, some recent AT devices have featured bolder aesthetic designs, intended to draw attention rather than avoid it, and intended in part to instill a sense of pride in their users. For example, a number of companies have developed more expressive and artistic prosthetic limbs [19, p. 195]. These devices, developed by companies such as Unyq,<sup>4</sup> Prosthetic Ink,<sup>5</sup> and The Alternative Limb Project,<sup>6</sup> feature elaborate visual designs such as patterned covers, tattoo-inspired body art, and designs that extend beyond biomimicry.

This approach of creating expressive AT has also been seen in other assistive devices, such as crutches, insulin pumps, wheelchairs, eyeglasses [40], and hearing aids [16]. Expressive devices for deaf and hard-of-hearing individuals include Hayleigh's Cherished Charms,<sup>7</sup> Hearrings,<sup>2</sup> and Tubetastic Pimps,<sup>8</sup> which include jewelry and other accessories that can be attached to hearing aids and cochlear implants. In our study, we document use of such hearing aid/cochlear implant accessories, along with do-it-yourself approaches that provide the wearers with similar expressive abilities.

Creating or wearing expressive assistive devices may represent a shift from a medical model of disability to a social model of disability. The medical model positions disability as a result of one's physical or mental differences, while the social model of disability takes into account the societal and environmental factors that may create barriers for individuals with differing abilities [19]. These models have shaped how disability is viewed and how prognosis is approached. For example, within the medical model, "treatment for individuals with disabilities is geared toward eradicating the cause of or *fixing* the impairment" [19, p. 195]. However, the social model looks at the sociocultural policies and infrastructure that may exclude individuals with disabilities from participating within society [19]. As individuals choose attire, accessories, and other worn objects to represent and reflect their identity [15], aesthetic AT devices may empower users to express themselves, their identity, and their disability in new ways [35], empowering users to move past societally imposed restrictions.

## 2.2 Do-It-Yourself Assistive Technology

The "maker movement" has promoted a shift toward DIY solutions to everyday problems, often leveraging technological developments, such as consumer-grade 3D printers, laser cutters, and other fabrication tools [17]. Some individuals with disabilities have begun to adopt DIY practices in order to develop AT solutions that meet their personal needs. As noted by Hurst and Tobias, do-it-yourself assistive technology can provide cost-efficient solutions to accessibility problems, give users a greater sense of ownership in their assistive devices, and increase the user's sense of personal agency in the design process [23]. This DIY AT movement has been supported by organizations such as e-NABLE,<sup>9</sup> an online network that supports individuals in designing, 3D printing, and distributing personalized prosthetic hands.

The DIY AT movement is growing worldwide, and DIY AT practitioners have explored many different types of assistive technologies. Buehler et al. [6] analyzed a subcommunity of

<sup>4</sup><http://unyq.com>.

<sup>5</sup><https://prostheticink.com>.

<sup>6</sup><http://www.thealternativelimbproject.com>.

<sup>7</sup><http://www.hayleighscherishedcharms.com>.

<sup>8</sup><http://www.tubetasticpimps.co.uk>.

<sup>9</sup><http://enablingthefuture.org>.

Thingiverse,<sup>10</sup> a large repository for 3D-printable models dedicated to developing assistive devices, and found that AT was created and shared by a variety of stakeholders, including friends and family of a person with a disability, engineers, students, and the person with the disability him- or herself. Hook et al. [22] interviewed DIY AT stakeholders and found several barriers to creating DIY AT, including perceptions that DIY AT would have poor aesthetics. Bennett et al. [2] and Hofmann et al. [21] found that the prospect of 3D-printed prosthetic hands encouraged their users to explore aesthetic and personally meaningful designs. We have also seen the use of DIY AT practices and methods to pursue the development of communication aids [20] and accessible learning materials [7, 46]. Our study presents an analysis of a community actively engaging in DIY aesthetic customization of hearing aids and cochlear implants and highlights specific motivations for producing DIY AT.

### 2.3 Social Factors of Hearing Aid and Cochlear Implant Use

In the United States alone, only 20% of hearing-impaired individuals who would benefit from hearing aids or cochlear implants use them.<sup>11</sup> Existing research has shown that the social stigma associated with hearing aid use is a critical component of decreased hearing aid uptake [13, 25, 47]. Wallhagen [47] interviewed older adults and found three dimensions of stigma related to assistive technology use: alterations in self-perception, ageism, and vanity. This stigma can significantly impact adoption and use of hearing aids, including seeking treatment, selecting hearing aids, accepting hearing aid use, and ongoing use. This sense of stigma appeared to be related to the conspicuous appearance of most hearing aids and the connotations of being seen to wear a hearing aid, such as being seen as old, less able, and deficient. As a result of this stigma, individuals often rationalized nonuse or selective use of their hearing aids and de-emphasized the severity of their hearing loss. As stigma can be considered a social construct dictated by the behaviors and judgments of others [37], individuals may seek to avoid stigma by avoiding use of otherwise helpful assistive devices.

A survey of hearing-aid-related stigma research showed that stigma was considered the primary reason for hearing aid nonuse in one-third of the 21 published studies [13]. In many of these studies, device size, conspicuousness, and cosmetic appearance were the primary causes of stigma [5, 10, 26, 27, 31, 33]. Despite the significance of device appearance on adoption or abandonment of hearing aids, little research has explored the impact of aesthetics (aside from size) on hearing aid use [16]. In contrast to the research on hearing aids, most research on stigma surrounding the use of cochlear implants has focused on the ethics of implanting these implants and the impact of cochlear implants on Deaf culture [18, 24, 45]. Our research explores how to improve the aesthetic appearance of hearing aids and cochlear implants and the effects of modifying device appearance, based on end-users who have taken it upon themselves to alter and improve the appearance of their devices.

## 3 RESEARCH OVERVIEW

To explore how individuals with disabilities, as well their friends and family members, aesthetically customize their assistive technology, we conducted research in two phases. First, we studied an online community dedicated to sharing aesthetic customizations of hearing aids and cochlear implants. Next, we conducted interviews with individuals who engaged in aesthetic customization of hearing aids and cochlear implants to understand their motivations and goals. Prior work on assistive devices such as prosthetics has demonstrated that AT use is closely intertwined with identity

<sup>10</sup><http://www.thingiverse.com>.

<sup>11</sup><https://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=95>.

production, experimentation, and presentation of self [2]. In a similar vein, this work explores the breadth of activity as it relates to aesthetic customization of hearing aids and cochlear implants, and what purpose this activity serves for those who choose to engage in this modification practice.

## 4 SHARING ASSISTIVE TECHNOLOGY CUSTOMIZATIONS IN AN ONLINE COMMUNITY

In this study, we examined an online community engaged in do-it-yourself customization of hearing aids and cochlear implants. Online communities for deaf and hard-of-hearing individuals are an emerging area of study [3, 8] as they can provide a means for individuals to build a support network and social connections when they may otherwise lack a physical counterpart. This study sheds light on who engages in aesthetic customization of hearing aids and cochlear implants, the types of customizations produced, and how community members customize their devices. This research also sheds light on the role of community in supporting aesthetic modifications of AT. A description of this study was previously published [39]; here we add further analysis of users' comments and questions attached to posts.

### 4.1 Online Community

We analyzed a growing Facebook group dedicated to DIY and aesthetic modification of hearing aids and cochlear implants. A review of online activity related to aesthetic AT modification for hearing loss revealed this community to one of the largest online communities of individuals engaging in this practice, with 10 moderators and 4,830 community members. Before beginning our analysis of this community, we reached out to the community moderators to seek permission to do so. We received approval from both the group administrators and our university's institutional review board to conduct this research. For privacy purposes, our report focuses on larger-scale trends observed in this community. Direct consent was obtained for use of specific quotes and images used in this study.

### 4.2 Procedure

Data was collected in the form of posts made over a 4-month period from September 1, 2015, to December 31, 2015. This period was chosen in order to capture customization activity over time and to observe holiday and seasonal trends. In total, 365 posts were collected and analyzed.

We captured an HTML file containing all posts and images during the study time period and conducted our analysis based on this document. Posts and comments were assigned unique IDs. To preserve anonymity, participant names were replaced in the captured data with numeric user IDs. We analyzed these data using an open coding approach. Our analysis includes posts made on the community, including images, and comments to those posts.

*4.2.1 Analysis of Initial Posts and Images.* Data were analyzed using an open-coding approach [12]. For the first stage of analysis, two coauthors independently reviewed 50 data points to uncover underlying themes and patterns within the data. These themes were then used to generate a coding manual. A third coauthor was consulted to reconcile inconsistencies. To check for consistency, two coauthors used the finalized coding manual to independently code an additional 40 data points and compared their codes for these data. Table 1 provides an overview of themes, with definitions and interrater reliability measures [11]. The coding manual was used by two coauthors to independently code the remainder of the data. Data were coded twice, once based on the posted text descriptions and once based on the posted image (as not all posts were accompanied by the appropriate alternative text descriptions). Posts containing more than one theme were coded according to each theme.

Table 1. Posts Shared in the Online Community, Categorized by the Researchers

Code	Definition	Interrater Reliability	Prob. Rdm Agreement	$\kappa$
Community Participation	Community building, appreciative comments, comments on group etiquette	98.36%	71.44%	.94
Questions	Questions about potential customizations (e.g., materials, suitability of specific devices for customizing)	98.63%	61.63%	.96
Resource Sharing	Posts sharing DIY materials, supplies, or deals that one has decided to share with the group	98.08%	86.06%	.86
Social Factors	References about perceptions, pride, shame, and attitudes about using one's AT	98.63%	70.55%	.95
Shared Excitement	General excitement and anticipation to participate in DIY customization	98.08%	72.33%	.93
Design Aesthetics	Customizations that reflect themes: holidays, sports teams, clothing/nail coordination, seasons, life events, etc.	95.07%	51.59%	.90
Sharing a Customization	General sharing of a customization or related post	90.41%	52.45%	.80
Tech Issues and DIY Tradeoffs	General lessons learned, impromptu modifications, appropriations, or technical issues or challenges with devices or customizations	96.71%	67.00%	.90
Stories and Experiences	Sharing one's AT or customization experience	96.16%	62.53%	.90
Post for Self	Member is posting on behalf of him- or herself	98.08%	61.89%	.95
Post for Another	Member is customizing on behalf of another	96.71%	55.85%	.92

Categories are not mutually exclusive. Coding categories are validated with interrater re-liability, the probability of random agreement, and Cohen's kappa.

After the first stage of analysis, thematic categories were further analyzed to understand the types of activity that made up each theme, for example, the types of questions posted to the group as well as a breakdown of customization themes, methods, materials, challenges, and tradeoffs.

### 4.3 Findings

We observed a number of trends with respect to the types of customization activities and interactions that occurred in this online community. The following sections describe the composition of the community, the types of posts within the community, techniques and themes for customizing devices, and challenges encountered when customizing devices. We also introduce an analysis of community interactions in post comments (Section 4.4).

**4.3.1 Community Structure and Conventions.** Our dataset, which contained 365 posts, included posts from 191 group members. We collected information about the posters' gender if it was included as part of their public Facebook profile: 150 group members publicly disclosed their gender on their Facebook profile. We found that more women participated in the community than men: 143 community members were female and seven were male; the remaining 41 members did not include gender on their Facebook profile.

We also wished to examine the age of community members. However, the age of community members was generally not available via their Facebook profile. Our observations of posts and images did suggest that customization activities included people of varying ages, from children to older adults.

An important component of online communities is active and prolonged participation from community members. Our dataset included both occasional and frequent posters: of the 191



individual contributors in the dataset, 133 individuals created only one post (not including comments), 27 posted twice, and 31 posted three or more times ( $M = 1.9$ ,  $SD = 2.6$ ).

As discussed below, many of the posts involved community members sharing their customized hearing aids or cochlear implants. This practice was commonly referred to via slang: community members described “blinging” their device or “pimping” the device (perhaps a reference to *Pimp My Ride*, a television show about customized cars).

**4.3.2 Posting for Self versus Posting for Others.** In our initial exploration of this data, we noticed that many posts seemed to reference people other than the person who created the posts. These posts often discussed a child or other family member. We analyzed all of the posts that contained a customized device to determine who the device was for: posts included designs made for the poster him- or herself (94 posts, 25.8%,  $\kappa = 0.95$ ) and designs that appeared to be made for somebody else, such as a parent customizing a device for his or her child (177, 48.5%,  $\kappa = 0.92$ ). The following quote shows an example of how community members shared designs they made for family members:

My 1st proper attempt at pimping my granddaughters [sic] cochlear implant'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.

As in the above quote, many of these posts seem to involve designs that the community members made for children. Although we were not always able to identify the recipient of a customized device, a keyword search revealed that 45 posts (12.3%) contained the word “daughter” and 22 posts (6%) contained the word “son.” The higher proportion of female-to-male children is consistent with the overall gender representation of this community.

In other cases, community members shared designs made by children because the children themselves were not part of the online community. The following post illustrates a community member sharing the design work from another person, possibly a family member:

The girly amazes me everyday [sic]. 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. [She is] Completely blind.

**4.3.3 Types of Posts.** We analyzed the set of 365 posts to better understand how community members interact with each other. Our dataset included several types of posts: sharing customized devices, asking questions to the community, sharing advice and tips related to customizing devices, sharing life experiences, and building community. Some posts fell into more than one category, such as posts that included a photo of a customized device with links to the materials used to perform the customization. The following sections describe each of these post types in descending order of frequency.

**4.3.3.1 Sharing Customizations.** The most common post category consisted of posts that involved showing off a customized hearing aid or cochlear implant. Of the 365 posts in our dataset, 330 posts involved sharing a customized device (90.4%,  $\kappa = 0.80$ ). Examples of these posts are shown in Figures 2, 3, 4, 5, and 6. Sections 4.3.4 and 4.3.5 provide a detailed overview of the types of aesthetic customizations created.

One interesting and unexpected practice within this community was to provide alternative text descriptions for images. The community’s guidelines noted that some members might have vision impairments and encouraged posters to describe their images. Many posts therefore contained a

Table 2. Questions Asked by Community Members

Question Type	Description and Examples	# Posts
Questions about obtaining supplies	Where to obtain supplies; sales on supplies	36
Questions about functional issues	How to avoid damaging hearing aids and cochlear implants during customization; managing wear and tear; removing glue and other residue; how to customize specific devices	19
Questions about how to use supplies or techniques	How to apply materials such as washi tape and nail stickers	14
Requesting feedback	Asking for feedback on a customization; choosing between different designs or materials	14
Requesting examples	Requesting examples that use specific supplies; gender-specific design examples; requesting examples from specific members	11
Questions about general deafness-related issues	Questions about how adopting cochlear implants will affect life; how to adapt to increased hearing loss; how to negotiate with clinicians or equipment suppliers	6
Requesting help	Requests for someone else to create a specific design for them	2

photo with an accompanying text description, such as “Starkey 3 series i110 covered with Jamberry nail foils that are multicolored diamonds with a metallic shine. Also has a small heart jewel on the corners. Hearing aids have clear molds. Sitting on a wood surface.” When community members posted an image without a description, they were often encouraged by moderators or community members to add a description.

**4.3.3.2 Asking Questions.** The second most common post category consisted of questions about customizing one’s devices, representing 102 posts (27.9%,  $\kappa = 0.96$ ). Types of questions included questions about specific supplies, questions about how to customize certain devices, and general requests for feedback. Table 2 provides an overview of the types of questions asked.

Because community members often considered customizing their devices to be a form of self-expression, their questions often included a description of the poster and his or her style preferences. For example, one community member asked for suggestions about how to decorate her hearing aids to reflect her “tomboyish” style:

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].

**4.3.3.3 Sharing Advice, Tips, and Resources.** Community members often shared advice learned from customizing their own devices. Out of the 365 posts, 25 involved members sharing advice, tips, or resources (6.8%,  $\kappa = 0.86$ ). These posts included advice on how to customize certain devices, where to find certain materials, and other strategies. Of these 25 posts, 14 included pointers to interesting materials, six included pointers to discounted items, three provided tips about specific





Fig. 1. Community members often shared examples of materials they found that could be used to customize AT devices. This image shows a low-cost decorative material, specifically a Halloween-themed nail foil, that could be applied to a hearing aid or cochlear implant.

customization techniques, one involved a custom tutorial prepared by a community member, and one shared a link to a relevant news story. Figure 1 shows a photo, taken by a community member, which showed a specific material that the member had found to be useful in customizing AT devices.

**4.3.3.4 Sharing Life Experiences.** Community members shared stories of their own experiences in customizing their devices and using customized devices. These posts represented 25 of the 365 posts (6.8%,  $\kappa = 0.90$ ). These posts often described the work that community members had done to customize their devices and the positive impacts of wearing their customized devices. For example, this quote from a teacher describes how students, who themselves used hearing aids and cochlear implants, reacted to her customized devices:

I wore Jamberry Jams [a commercial decoration] 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.

New community members sometimes expressed their enthusiasm about the group, and in doing so shared their prior negative experiences or negative experiences of a family member:

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.

**4.3.3.5 Building Community.** The online community, which contained nearly 5,000 members, was supported by an active team of 10 volunteer moderators. Moderators encouraged participation by posting about community rules and norms (such as providing alternative descriptions for images), posting community polls, directing members to community rules and documentation, and introducing themed decoration contests. Of the 365 posts in the dataset, 11 of these posts addressed administrative issues (3%,  $\kappa = 0.97$ ). Moderators tracked new community members by pointing them toward the list of community rules and asking these members to “like” the post to indicate that they had read the rules.

One noteworthy activity led by moderators was to post contests around specific themes. For example, in October, a moderator posted a contest that solicited Halloween-themed designs. These



Fig. 2. Community members used a variety of materials and techniques to customize their devices: (a) Commercially procured hearing aid with a purple ear base and a shimmering emerald ear mold; (b) hearing aids with My Little Pony tube riders (third-party accessories); (c) DIY blue and silver glitter-decorated hearing aids with coordinated nails.

contests seemed to encourage community members to decorate their devices and share their customizations with the group.

**4.3.4 Customization Materials and Techniques.** Examining posts that featured customized designs allowed us to analyze how community members created their customized devices. Community members primarily used three types of materials: aesthetically pleasing commercial devices, commercial accessories, and do-it-yourself craft materials. Figure 2 illustrates several methods used to customize devices.

**4.3.4.1 Aesthetically Pleasing Commercial Devices.** Some community members chose to purchase attractive off-the-shelf devices rather than modify their devices; these individuals still shared images of their devices. Aesthetically pleasing devices included colorful or patterned device cases, colorful ear hooks, and customized molds with embedded glitter or gems (Figure 2).

**4.3.4.2 Third-Party Accessories Designed for Hearing Aids and Cochlear Implants.** A second, low-effort technique for improving the appearance of one's device was to purchase accessories from online vendors and companies. These accessories may be found on sites such as Etsy.com, Facebook product pages, or personal company websites and include charms, clips, protective skins, colorful tubes, and stickers. Some accessories, such as charms, were purely aesthetic, while others, such as protective skins or clips, also provided functional benefits.

**4.3.4.3 Craft Materials.** Despite the availability of off-the-shelf devices and accessories, the majority of devices shared with the online community involved do-it-yourself customization of standard hearing aids and cochlear implants. Most of these customizations involved repurposing craft materials and adapting them to be used with hearing aids or cochlear implants. Table 3 lists the most common materials used, as identified in alternative text descriptions of the images. Other craft materials that were mentioned include nail polish, beads, pearls, googly eyes, elastic, felt, pipe cleaners, chains, fabric, hair clips, hair bands, foam, glue, thread, water decals, tape, baubles, a buckle, a nail file, a Sharpie marker, buttons, string, "tapefetti," nail varnish, and scissors.

**4.3.5 Customization Themes.** We analyzed posted images to identify general themes of community members' device customizations. Participants expressed themselves by producing a range

Table 3. Craft Materials Used for DIY Modifications of Hearing Aids and Cochlear Implants

Material	Description	No. of Times Mentioned
Nail art	Nail foils, stickers, and wraps, especially those with mild adhesives	61
Stickers	Generic stickers, not intended for hearing aids or cochlear implants	31
Gems	Gems and rhinestones with adhesive backings	30
Duct tape	Easily removable tape that is often available in bright colors	28
Tube riders	Commercial accessories and charms that hang from the hearing aid tube	27
Washi tape	Colorful tape often used in scrapbooking	23
Glitter	Glitter, glitter tape, and glitter foil added to the hearing aid or cochlear implant.	21
Charms	Charms representing characters, symbols, or shapes	19



Fig. 3. Community members decorated their devices using various materials and themes: (a) two bronze hearing aids with stickers of fox heads; (b) one hearing aid with a pink flower sticker; (c) two beige hearing aids with holographic stickers; (d) a cochlear implant with adhesive gems; (e) a beige cochlear implant with dangling repurposed ankle bracelet.

of designs and aesthetic enhancements. Design themes included decorative enhancements such as colors, patterns, and textures; designs reflecting seasons, holidays, and life events; favorite characters and team affiliations; and coordination with other clothing items. Themes are presented based in order of decreasing frequency.

*4.3.5.1 Adding Colors, Patterns, and Textures.* Many customizations involved the addition of colors, shapes, patterns, and textures (Figure 3). Decorations included embellishments such as happy faces, flowers, or geometric patterns; bright colors; and adhesive gems. Some community



Fig. 4. Holiday-themed customizations: two cochlear implants, decorated red and green, with Santa heads on the coils (left); two hearing aids with red foil, Christmas tree cutouts, and red and silver adhesive gems (right).

members combined these embellishments to create intricate designs with multiple layers of tape, foils, stickers, and gems.

**4.3.5.2 Celebrating Seasons and Holidays.** The second most popular design theme involved designs that referenced holidays and seasons (Figure 4). We observed 59 holiday-themed customizations: 41 designs that referenced Christmas, 17 that referenced Halloween, and one that referenced Remembrance Day. These designs incorporated colors and symbols related to that holiday, such as spiders for Halloween and red and green colors, Santa Claus, and candy canes for Christmas. Community members also referenced changes in season: there were three references to winter, two references to autumn, and one reference to summer.

These holiday-specific designs were motivated in part by contests posted by community moderators. During our data collection period, moderators conducted design contests for both Halloween and Christmas. Members contributed to the contest by posting their designs and marking their posts with the relevant hashtag. For instance, during the Christmas design contest, we observed 26 instances of the hashtag *#christmaspimps*.

**4.3.5.3 Showing Favorite Characters.** Community members sometimes decorated their devices with stickers or charms representing a favorite character from a cartoon, TV show, or movie. Our dataset included 36 designs that featured characters from popular culture (Figure 5). Characters added to these designs included Elsa and Olaf (Frozen), Lego characters, Minions, My Little Pony, Buzz Lightyear and Lotso Bear (Toy Story), Cookie Monster and Elmo (Sesame Street), Darth Vader (Star Wars), Stewie (Family Guy), Disney's Cars, Peppa Pig, Minnie Mouse, Hello Kitty, Ninja Turtles, and Sonic the Hedgehog.

**4.3.5.4 Coordinating with Clothing and Other Devices.** At times, community members stylized their hearing aids and cochlear implants to match their clothing, jewelry, or other worn items. We observed five devices that were designed to match the wearer's fingernails (Figure 2(c)), two devices designed to match clothing, and one device designed to match a Halloween costume (one instance). Community members also designed their hearing aids to match other AT devices: seven posts included customized AT devices other than hearing aids, such as a ComPilot audio streaming device; three of these were shown to match the user's hearing aid or cochlear implant. Other decorated devices included crutches, a hand splint, earbuds, and a battery keychain caddy.

**4.3.5.5 Celebrating Life Milestones.** Community members also decorated their devices in celebration of life events or milestones. Our dataset contained eight posts that showed designs that





Fig. 5. Some customized hearing aids and cochlear implants referenced popular characters: (a) two hearing aids with My Little Pony tube riders; (b) two cochlear implants with Elmo and Cookie Monster faces on the coils; (c) two hearing aids with Minion stickers; (d) two hearing aids with Lego character tube riders; (e) two cochlear implants with Olaf stickers and an Olaf-themed retainer clip.



Fig. 6. Additional techniques used to customize hearing aids and cochlear implants: (a) hearing aid decorated with a butterfly and rosary for attending church; (b) a device decorated with stickers and gems referencing the Green Bay Packers sports team; (c) a practice decoration made on a stuffed animal.

recognized life events, including three designs referencing the first day of work or school, two designs referencing a wedding, one design made for when attending church (Figure 6(a)), one design made for participating in a parade, and one design referencing Children in Need, a BBC UK charity for children with disabilities. In some cases, these designs referenced other objects related to that life event, such as one community member who shared an image of a birthday cake that was decorated with an image of the child's cochlear implant.

**4.3.5.6 Showing Team Affiliations.** Three posted designs referenced sports teams: one design that referenced the Green Bay Packers (Figure 6(b)), another that referenced the Seattle Seahawks, and a third that referenced a South African rugby team.

**4.3.6 Customization Strategies and Challenges.** Community members shared their experiences in customizing their devices and often shared tips or requested help in overcoming specific challenges. Common experiences in modifying hearing aids and cochlear implants included

trial-and-error attempts to solve problems, learning and practicing how to customize a new device, learning about appropriate materials, and adapting to limited time and materials.

**4.3.6.1 Trial-and-Error Experimentation.** Because community members were often inventing new ways to modify their devices, and because making a mistake in modifying a device could damage a very expensive device, members tested and refined their techniques through a process of trial and error. New community members often posted about how they were starting with simple designs and moving on to more complex projects after some practice; 16 posts described the poster's experience as a new designer.

Because there were not always clear ways to practice techniques without damaging their expensive devices, community members sometimes came up with clever solutions. In this example, a community member describes how she practiced decorating a cochlear implant on her daughter's stuffed animal (shown in Figure 6(c)), which itself had a cochlear implant:

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 cochlear implant 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.

**4.3.6.2 Adapting to Specific Devices.** Customizing a hearing aid or cochlear implant using off-the-shelf materials often required careful planning. These devices, which are often quite small, also contained features such as microphones, ports, control switches, FM radio connections, and battery doors that could potentially be damaged by an improper modification. Customizing these devices could present a tradeoff between appearance and risk in modifying the device; clever designs often involved strategically cut tape or foil and carefully placed stickers. Modifying a hearing aid or cochlear implant could also affect the device's warranty or the owner's insurance plan. In light of these concerns, many posts included discussion of the poster's specific device model, as posters sought off-the-shelf components or techniques that could be adapted to their specific device. In this post, a hearing aid wearer asks for help finding add-ons for a specific style of hearing aid:

Hi everyone. I'm 22 and have these BTE [behind-the-ear] 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.

**4.3.6.3 Tradeoffs in Material Qualities.** Community members also considered tradeoffs between appearance and functionality when choosing craft materials. A material's adhesive strength, flexibility, durability, and ease of cutting, applying, and removing were often considered as tradeoffs between the material's color, texture, or other aspects of the material's appearance. Community members often shared their experiences in trying new materials and pointed other community members to interesting and safe materials to try out.

**4.3.6.4 Time Constraints and Access to Materials.** As described above, the process of adapting one's device was often challenging and time-consuming; modifying a device often required practice beforehand and several attempts to get the modification right. However, community members were not always able to create their ideal design due to time constraints, lack of access to tools and materials, and lack of skill. Community members often noted that their designs were made in a rush or made with less ideal materials that were on hand. In some cases, community members



later posted that they had redone a design that they were not happy with, when they had more time or found new materials.

#### 4.4 Community Responses to Questions

A key activity in this online community is asking questions and requesting feedback from others who have experience with customizing similar devices. To better understand whether community members' questions were answered and who answered these questions, we conducted qualitative analysis of all posts in our dataset that contained a question and their associated comments. Our goals were to measure how commonly questions were answered and how active various members of the community were in answering questions and providing feedback. We analyzed all posts in our dataset that contained questions, a total of 102 out of 365 posts. In total, we analyzed 696 comments.

It is important to note that the online community discussed here maintained a separate discussion group for social interactions. Our analysis here focuses only on the area of the community related to sharing and discussing customized devices.

**4.4.1 Procedure.** We developed two new coding schemes for post comments. The first coding scheme was intended to characterize the type of interaction in the response: answers to questions, clarification questions, and general discussion. The second coding scheme was intended to capture the theme of the post: materials and sources, customization methods, praise for the work of others, sharing stories, general chatter, and moderator posting. Each comment was coded for both interaction type and theme. Because comments can vary widely in their content, and a single comment may include multiple discussion points, these codes were not mutually exclusive: each comment could have more than one type or theme. The coding scheme was iteratively developed by three members of the research team; one researcher coded the entire set of comments.

**4.4.2 Findings.** Analyzing the comments to community members' questions enables us to better understand the types of interactions that occurred between community members and moderators. Our analysis focuses on three core questions: "Did the community respond to questions?", "Who responded to questions?", and "What did community members discuss?"

*Did the community respond to questions?* Our dataset consisted of 102 posts that contained some form of question directed toward the community. Of these 102 posts, 95 questions received at least one response. The number of comments on posts varied widely: some posts received only a few comments, while other posts generated long, multithreaded discussions. The number of comments responding to a question ranged from one to 58 comments. Overall, the vast majority of questions were answered by at least one community member.

We coded each comment based on its general type (answers, clarification questions, and discussion). Of the 696 comments, 292 comments provided an answer to the original poster's question, 81 comments raised a clarification question, and 367 comments featured general discussion. Overall, the community was committed to answering questions; community members were also engaged in active conversation with each other.

*Who responded to questions?* As discussed previously, the administrators of this community played a key role in maintaining an active community by encouraging, sharing informative resources, and reminding community members about rules and guidelines. Not surprisingly, moderators were also active in responding to posters' questions. Overall, 122 of the 696 comments (about 18%) were made by moderators, which is impressive when considering that there were only 10

moderators and more than 4,000 community members. However, it is clear that community members were also active in community discussions, providing the remaining 574 (82%) post comments.

*What did community members discuss?* We coded comments made by the general types of response. As noted above, some comments included multiple pieces of information. From the total set of comments, 123 comments provided some praise to the original poster, most often when the original poster requested some feedback. Other comments provided guidance regarding customization itself: 160 comments discussed materials used for customization, and 119 comments discussed customization methods. Community members also used post comments to discuss themselves: 96 comments included personal stories or experiences. A total of 51 comments included administrative comments from moderators, most often pointing community members toward rules and guidelines, reminding posters not to provide direct links to vendors, or reminding posters to add alternative text. A total of 316 comments included general conversational chatter, including general comments such as “thank you” and “lol.” Overall, the discussion among community members was quite active, and included both helpful comments, such as pointers to resources and feedback on designs, and friendly conversation.

#### 4.5 Contributions and Limitations of This Study

In this section, we have described an analysis of posts and comments in an active online community devoted to aesthetic customization of hearing aids and cochlear implants. This research has provided insight about how individuals are customizing their hearing aids and cochlear implants, including how community members adapt devices for themselves and others, techniques and materials used to modify devices, design strategies and themes for customizing devices, and challenges encountered when modifying devices. Our analysis of posts and comments also illustrates how community members and moderators support each other and the broader community.

The primary limitation of this study was that we only looked at existing posts within the community and did not directly engage with community members. While this approach allowed us to understand current practices in the community, our analysis was restricted to explicit comments made in the community and did not provide us with access to deeper insights about how community members began the practice of modifying their devices or how modifying their devices has affected their everyday lives. These limitations are addressed in the second part of this research.

### 5 INTERVIEWS WITH CUSTOMIZED DEVICE USERS ABOUT THEIR EXPERIENCES

Our study of the online community provided insight to how individuals are customizing their hearing aids and cochlear implants, and how the broader community supported this activity. However, our analysis was limited to comments made publicly on the discussion group. Our follow-up study, presented here, explores the significance of AT customization in the context of their everyday activities. We conducted a series of interviews with individuals who use and develop customized hearing aids and cochlear implants, focusing on their motivation in customizing their AT devices, their path to becoming device customizers, and the effects of wearing customized hearing aids and cochlear implants on the experiences of the wearers.

#### 5.1 Participants

We recruited 10 participants (nine female, one male) who engaged in the practice of customizing hearing aids and cochlear implants. Participants ranged in age from 17 to 62 ( $M = 39.9$ ,  $SD = 14.77$ ). Five participants were recruited from the online community, four were recruited through personal outreach, and one was recruited at an assistive technology conference. Of these 10 participants, seven primarily customized their devices for their own use, and three primarily customized devices

Table 4. Interview Participants (Pseudonyms Are Used for Each Participant)

Name	Age	Sex	Loc.	Occupation	Role(s)	Hearing Loss	Assistive Technology	Customizations
Jeannie	52	F	USA	Librarian	End-User	Severe hearing loss in right ear, moderate hearing loss in left ear	Cochlear implant	Commercial
Nadeen	50	F	UK	Teacher	End-User	Bilateral hearing loss	Hearing aids	Do-it-yourself
Ashley	23	F	UK	Teacher of deaf and hard of hearing	End-User	Bilateral hearing loss	Hearing aids	Commercial, do-it-yourself
Constance	40	F	UK	Audiologist	End-User, Developer	Bilateral hearing loss	Hearing aids	Makes and wears accessories
Terri	54	F	USA	Technology writer	End-User, Developer	Bilateral hearing loss	Hearing aids	Makes and wears accessories
Roger	62	M	USA	Retired	End-User, Developer	Severe hearing loss in right ear	Bone-anchored hearing aid	Makes and wears accessories
April	17	F	USA	Student	End-User, Developer	Bilateral hearing loss	Hearing aids	Makes and wears accessories
Marie	26	F	UK	Self-employed home cleaner	Caregiver for child	Child has bilateral hearing loss	Hearing aids	Commercial, do-it-yourself
Rachel	40	F	UK	Unemployed	Caregiver for child	Child has bilateral high tone deafness	Hearing aids	Commercial, do-it-yourself
Paula	35	F	USA	Teacher of deaf and hard of hearing	Caregiver for students	No personal hearing loss; students are deaf and hard of hearing	Varies	Do-it-yourself

for another person. For the sake of simplicity, we will refer to these participants as *end-users* and *caregivers*, respectively. The three caregivers were two parents and one teacher, were female, and ranged in age from 26 to 40.

In our previous study of online community posts, we noticed that some wearers of customized hearing aids and cochlear implants had gone on to sell their customizations online. As we were interested in understanding the perspective of those who had progressed from do-it-yourself activity to creating products for others, we sought out individuals who had done so. Four of our participants (three female, aged 17 to 62) had experience in selling customized accessories for hearing aids or cochlear implants. We refer to these individuals as *developers*; however, all four of these individuals used some customized device, often one that they had created themselves. Table 4 summarizes our interview participants.

## 5.2 Method

All participants participated in a semistructured interview session with the first author. As participants were located in different countries, and as participants may have their own preferences for accessible communication, each participant chose his or her own method for participating in the interview. Four participants communicated via video chat, four communicated via text chat, and four communicated by phone (each method was approved by our university's institutional review board). Each interview lasted between 1 and 2 hours.

Each interview was recorded using a method appropriate to the communication medium: video and audio conversations were audio-recorded and transcribed, and text conversations were logged. During each interview, the first author recorded detailed field notes. Unfortunately, one audio recording was lost due to a technical malfunction; this interview was documented through field notes only. Participants received no monetary compensation for participating in the interview.

Table 5. Motivations for Customizing Hearing Aids and Cochlear Implants

Motivation	Explanation
Demonstrating Agency	Customizing assistive technology demonstrates control over one's disability and assistive technologies.
Self-Expression	Customizing assistive technology provides means to share one's interests or personal style.
Pride and Confidence	Customizing assistive technology promotes feelings of pride and self-confidence.
Disability Advocacy	Customizing assistive technology raises awareness of deaf and hard-of-hearing people.
Communication Signaling	Customizing assistive technology can make this technology more visible, signaling to others that the wearer is deaf or hard of hearing so that they can communicate in an appropriate way.
Caring for Others	Customizing assistive technology can directly support friends and family.
Encouraging Adoption	Customizing assistive technology can encourage others to use that technology.
Community	Customizing assistive technology can support one's participation in a community of like-minded device customizers.

**5.2.1 Data Analysis.** We performed a qualitative thematic analysis of all interview transcripts and field notes. Our analysis focused on several broad themes: how participants began customizing their devices, how they practiced the work of creating customized devices and accessories, and their motivations for creating and wearing customized devices.

As we were particularly interested in understanding the motivations and effects of customizing devices, we conducted a thematic analysis of all interview content related to motivation. We used affinity diagramming to identify themes in this data. The first author performed this analysis, iteratively creating codes over a period of 2 weeks. Key findings were written on sticky notes and were arranged and sorted to identify relationships between data. The selected themes focused on practices of aesthetic customization of hearing aids and cochlear implants; all data that were not related to these themes were excluded from this analysis. This process resulted in a final set of eight themes: demonstrating agency, channeling self-expression, fostering confidence and pride, engaging in advocacy, managing communication expectations, empowering others, generating excitement, and building community (see Table 5 for formalized themes and definitions).

### 5.3 Findings

Our findings focus on three broad categories: how participants began customizing their devices, how they practiced the work of creating customized devices and accessories, and their motivations for creating and wearing customized devices.

**5.3.1 Discovering Assistive Technology Customization.** We asked participants about how they discovered and became interested in customizing their assistive technology devices. Participants discussed several starting points for learning about device customization: three participants learned via word of mouth, three began searching for device customization options due to the lack of available commercial options, and three discovered customization activities by accident. The majority of participants learned about hearing aid and cochlear implant customization via Internet search or through online communities, which is common across many types of

do-it-yourself practices [34]. Once participants had found communities and resources related to device customization, they often returned to these resources to learn more about customization practices, find interesting materials, and participate in a community of device customizers.

*5.3.2 Device Customization Practices.* Building on our previous study of the online community, we asked our participants about how they customized their hearing aids and cochlear implants, including the materials they used, their techniques for customization, their strategies for managing customization tradeoffs and challenges, and the role of collaborative work in customizing devices.

*5.3.2.1 Finding and Using Materials.* Our interview participants used many of the same materials as participants in the online community, especially craft materials such as tape, nail art materials, cloth, beads, jewelry, and wire. Participants mentioned that they were drawn to materials that were inexpensive and that were known to be safe to apply to hearing aids. For example, two participants mentioned that they enjoyed using colorful duct tape as it was inexpensive, easy to find, and long-lasting and could easily be attached and removed without leaving residue or damaging the device. Participants mentioned that they preferred to use materials that had been tested by other do-it-yourself device customizers. Participants who created do-it-yourself customizations tended to purchase materials at local arts and crafts shops and on online stores or auction sites such as eBay.

*5.3.2.2 Customization Techniques.* Our participants described their process of choosing and applying customizations. In general, participants preferred to plan out their designs in advance, rather than directly experimenting with their devices. Several participants noted that they would often think about potential designs for days or weeks beforehand and would sometimes wait to find the appropriate materials before modifying their device. As in our previous study, participants noted that they sometimes considered “themed” customizations, such as customizing their device to match clothing or accessories, or customizing their device to represent a holiday or other event. Inspiration could come from surprising sources: for example, one participant designed a Christmas-themed hearing aid cover by repurposing a sewing pattern intended for a Christmas tree ornament.

As in our previous study, participants noted that they sometimes practiced designs. For example, one participant who created customizations for her child noted that she would practice customizations using a replica hearing aid in order to see the effects of adhesives and other materials.

Several participants described how they became more effective customizers with practice. Often this meant learning to perform routine customization activities more efficiently. For example, one participant noted that she had mastered a quick customization process that allowed her to decorate a device in 3 minutes. In other cases, participants noted that they learned through making mistakes. For example, one participant described accidentally covering a hearing aid’s air vents with tape, causing the device to overheat (and teaching her not to do that in the future). Participants learned to use tools to support their customization practices, such as using pliers to work with jewelry components.

Finally, some participants considered sharing their customization, including pictures and instructions, as part of the process of creating a device customization. One participant described the process of coming up with a customization concept, testing the customization on her devices, writing instructions for implementing the customization, and posting those instructions on her personal blog.

*5.3.2.3 Customization Challenges and Tradeoffs.* Participants often described the challenges they encountered when creating and implementing customization designs. Similar to posters in

the online community, our participants noted that they considered material costs, time, and difficulty of execution when planning their customizations. These considerations often affected what participants chose to do with their devices: for example, do-it-yourself customizations were often inexpensive but required more time and effort than an off-the-shelf solution. One participant, Jeannie, praised the ease of using SkinIt device skins that she had purchased, saying, “I don’t have to do anything extra, I apply them and they are good to go.”

In one case, our participant considered not only what customization method to use but also which device to wear. This participant owned both behind-the-ear (BTE) and completely-in-canal (CIC) hearing aids, and while she noted that her CICs functionally performed better, she would often choose to wear her BTEs as they were easier to decorate.

**5.3.2.4 Collaborative Customization.** While most of our end-user participants performed customization for themselves and by themselves, three of our participants primarily created customizations for other people. In all three cases, the primary recipients of these customizations were children. In general, children were discouraged from customizing their own devices out of concern that they might damage an expensive piece of technology.

When describing their customization practices, all three caregiver participants noted that the children who would use the customized devices were involved in the design of the customization, including choosing materials and patterns. These participants noted that the children themselves considered it very important to be involved. For example, Marie noted that her child expected to be involved in any device customization, stating, “I don’t think she would allow me to do them without her input, she’s too independent.” Thus, even though the adult was responsible for performing the customization, the child’s involvement was shown as evidence of her independence. The adult caregivers sometimes described how they encouraged the children in their lives to participate in device customization, such as by maintaining a supply of customization materials.

**5.3.3 Motivations for Customizing Assistive Technology.** A major focus of our interviews was to explore *why* our participants customized their assistive technology devices. What were their goals in performing customization? How did participants perceive the impact of customizing their devices? Based on our discussions with our interview participants, we identified eight broad themes that motivated our participants in customizing their devices. Table 5 provides a summary of these motivations, which we discuss in further detail in the following sections.

**5.3.3.1 Demonstrating Agency.** Some people with disabilities may feel that they lack control over aspects of their lives or may feel that others believe they lack control [42]. Our participants described how the act of customizing one’s assistive technology can promote feelings of agency and independence and can support a sense of empowerment [1].

As an example, we present the story of Rachel. Rachel is a mother of a deaf 13-year-old daughter. As a citizen of the United Kingdom, Rachel’s daughter is entitled to receive free hearing aids through the National Health Service (NHS). However, when Rachel’s daughter found an exciting pair of hearing aids with a giraffe pattern, she was disappointed to learn that the NHS would not subsidize the purchase of “designer” hearing aids. In response to her daughter’s disappointment, Rachel learned how to customize hearing aids using do-it-yourself methods and craft materials and created a pair of DIY customized hearing aids that matched her daughter’s style preferences.

In this example, Rachel’s daughter experienced a lack of control in her choice of assistive technologies. Rachel was able to overcome this barrier by creating her own custom design. These customized hearing aids have the further advantage that they may be redecorated as Rachel’s daughter grows older and as her interests change. This feeling of empowerment was echoed by other participants. For example, Paula noted:



I think [decoration] empowers [the children]...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.

In other cases, even when customizations were available, they sometimes did not reflect the wearer's preferences or introduced unacceptable tradeoffs. For example, one participant encountered challenges in adapting off-the-shelf accessories to her daughter's hearing aids, as adding the accessory reduced the sound quality. She found that creating her own customization gave her the flexibility to work around this tradeoff, as the do-it-yourself customization ensured that "all [the] bits that need to be uncovered are left uncovered."

**5.3.3.2 Self-Expression.** Many of our participants described how customizing their devices enabled them (or their care recipients) to express something about themselves that would not be possible using an off-the-shelf device. Marie, a mother to a daughter with hearing loss, noted that her daughter "likes to stand out from the crowd" and that "having bright coloured and funky aids definitely [sic] helps her do that."

As another example, consider Jeannie, a cochlear implant user with a lifelong passion for music. Jeannie was diagnosed with bilateral hearing loss in third grade and wore hearing aids until the age of 35. During her interview, Jeannie described the isolation she felt growing up as the only child with hearing loss in her town, and how it led to self-conscious behavior such as covering her hearing aids with her hair. When she went to college, Jeannie chose to attend a university for deaf and hard-of-hearing students, which helped improve her confidence and pride in being hard of hearing. When Jeannie finally lost her remaining hearing, she considered giving up on her assistive technology, but eventually decided to undergo surgery to receive cochlear implants. Jeannie described how receiving cochlear implants helped affirm her identity as a deaf individual in a hearing world. Jeannie now decorates her cochlear implants with SkinIt featuring musical notes, which she wears to share her love of music.

For other participants, the very act of customizing their devices conveyed the concept of being a creative person. Paula, a teacher of the deaf and hard of hearing, described the act of providing a "personal mark" on a new piece of personal technology:

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.

The general theme of expressing an artistic, creative, or technical personality was mentioned by five of our 10 participants. In another example, Constance, who both makes and wears customized accessories for hearing aids, noted her lifelong interest in connecting her creative work and creative identity to hearing aids and issues of deafness:

I was quite a witty 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.

Other participants incorporated this combination of creative work and deaf identity into other forms of creative work. Nadeen, a university design instructor, was diagnosed with bilateral hearing loss at the age of 43 and struggled to accept her need for hearing aids. Later, discovering the community of do-it-yourself hearing aid hackers helped her to embrace her identity as a person



Fig. 7. Nadine, a design instructor, creates creative and comedic imagery to explore and document her experiences as she incorporates hearing aids into her everyday life. The left image addresses the awkward size and overtness of many hearing aids; the right image uses handmade, fabric hearing aid covers as an example of how to “cute-ify” hearing aids.

who wears hearing aids. In addition to customizing the design of her hearing aids, Nadeen created a number of digital art pieces that explored imagery related to hearing aids. Nadeen’s work, shown in Figure 7, incorporated comedic elements that helped her to document her experiences with hearing loss. Nadeen noted that her creative work in this area both let her explore her experiences and served as a creative outlet. Nadeen now considers customizing her hearing aids to be part of her identity and feels “naked” with undecorated hearing aids.

However, in a few cases, the unconventional appearance of some customized hearing aids or cochlear implants could confuse bystanders, who might not know that the wearer has hearing aids at all. Constance, who sometimes decorated her hearing aids to look like jewelry, described how some of her patients did not recognize them as hearing aids:

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.”

**5.3.3.3 Confidence and Pride.** Participants also described their assistive technology customization as a way to express self-confidence as well as pride in their role as a deaf or hard-of-hearing person. Our participants expressed this notion in several ways. Some participants contrasted their use of customized hearing aids and cochlear implants with the notion of hiding them.

Ashley, who as a teenager had rejected her hearing aids due to chronic bullying, recently read-opted hearing aids. She noted that she considered wearing customized hearing aids as an expression of pride:

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.

For some participants, wearing highly visible hearing aids or cochlear implants was a way to share their deafness unapologetically, reflecting an attitude of being “loud and proud.”

One's motivation for wearing customized hearing aids or cochlear implants might also change over time, in some cases focusing less on what others perceive and more on what the wearer wishes to express from him- or herself. Rachel described how her daughter used to show off her colorful hearing aids more often but now rarely does so, suggesting that her daughter is now choosing the design of her hearing aids for her own enjoyment:

[My daughter] 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.

**5.3.3.4 Disability Advocacy.** Along with personal pride and confidence, some of our participants discussed how wearing conspicuous hearing aids or cochlear implants could help convey positive attitudes about deafness itself. Thus, deliberately choosing the appearance of one's assistive technology connects with the long history of disability advocacy [9].

This focus on advocacy was expressed in several different ways. For some, wearing conspicuous devices was tied to projecting an identity as a deaf or Deaf<sup>12</sup> person. Marie noted that her daughter often introduced herself by describing her Deafness and used her hearing aids as a way of prompting discussion with other deaf people:

She is very proud of having hearing aids.... She introduces herself by saying "hi [sic] I'm 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.

For others, wearing customized and conspicuous hearing aids or cochlear implants provided a way to address stigma. One participant noted that decorating a hearing aid or cochlear implant can work to eliminate "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 shame or embarrassment." This participant also stated that increasing society's exposure to individual differences may help to lay the groundwork for creating a more inclusive environment.

Some participants had noticed that reactions to their hearing aids or cochlear implants had changed since they began to customize their devices. One participant described the changing reactions of both acquaintances and strangers: "Where before it would be unwanted attention...it's now compliments [if] that makes sense."

Finally, some participants described how their exploration of hearing aid aesthetics could be used to challenge societal expectations about deafness and disability. Jeannie, who loves music, decorates her cochlear implants with stickers featuring musical notes. She notes that "some people might find it ironic that you have music notes on a hearing device, but it expresses me, it really does." Another participant shared photographs and art featuring hearing aids decorated with skulls, tattoo art, and other imagery that may be at odds with the stereotype of a deaf person (Figure 8). Constance, an audiologist, discussed how her patients were sometimes reluctant to wear hearing aids because it suggested that they were old and "over the hill." However, she hoped that the creation of more attractive hearing aids could help to dispel these negative connotations and encourage hearing aid use.

**5.3.3.5 Communication Signaling.** One practical benefit of wearing more visible hearing aids was to communicate to bystanders that the wearer is deaf or hard of hearing, which sometimes

<sup>12</sup>"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" [45, p. 135].



Fig. 8. These hearing aid designs present a tough or intimidating personality that may challenge conventional expectations of a deaf person: (a) hearing aid accessory featuring a bejeweled skull; (b) digital art piece that features tattoo art placed on hearing aids.

resulted in easier conversations. This effect is similar to that seen by Shinohara and Wobbrock [44], who found that some people with low vision intentionally carry a white cane to signal their (otherwise hidden) visual impairment to others.

As an example, Constance, an audiologist who worked in a hospital, found that wearing more conspicuous hearing aids sometimes made it easier to communicate with her coworkers. While she felt that her CIC hearing aids provided better audio quality, she sometimes wore more conspicuous BTE hearing aids, and even added accessories to these hearing aids, to remind her coworkers to speak clearly:

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.

Interestingly, some participants noted that wearing visible hearing aids caused others to moderate their compensatory behaviors, such as overpronounced lip mouthing. While participants were not usually negatively affected when others exaggerated less, it seems possible that the effect of broadcasting one's hearing impairment could clash with the expectation of being treated as normal. It is possible that the availability of customized devices provides a normalizing force of its own: Bispo and Branco [4] stated that the primary difference between assistive technologies and consumer technologies is the ability to choose different colors or models to match the user's personality [4]. Thus, the availability of customized assistive technologies may normalize these technologies by making them more like consumer technologies.

**5.3.3.6 Caring for Others.** Three of our 10 participants primarily customized devices for others, typically children. In discussing these practices with those participants, they often discussed the motivations expressed above, including instilling a sense of pride and supporting the child's self-expression. However, for these participants, customizing hearing aids and cochlear implants served as a form of care for a friend, family member, or student.

This practice of customizing devices as a form of care was described by Marie, the mother of a 7-year-old daughter who has worn hearing aids for most of her life. When asked about decorating her daughter's hearing aids, she talked about the pride that her daughter felt when receiving new

hearing aids, and about the possibility that people who see her daughter's hearing aids may learn to be more accepting and understanding of deaf and hard-of-hearing people. Marie also discussed her hope that wearing attractive hearing aids might help her daughter feel more positively about wearing hearing aids:

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 definitely [sic] help her as she gets older.

*5.3.3.7 Encouraging Adoption.* Another way in which our participants supported others in their use of hearing aids and cochlear implants was to generate a sense of excitement around the use of hearing aids and cochlear implants, possibly encouraging them to adopt these devices. Creating a feeling of excitement can help to encourage adoption and use of technology [28]. Our participants described how the children in their lives were excited to customize their hearing aids and cochlear implants, thereby increasing the attractiveness of using them.

For example, Paula is a teacher of fifth-grade deaf and hard-of-hearing students. For several years, she has worked with her students (both male and female) to decorate their hearing aids and cochlear implants. Paula noted that her students can become quite engaged in the decoration of their devices, and that students in her class rarely refuse to wear their devices. Paula stated that even parents were excited about the activity, sometimes sending materials to school along with their children.

In addition to encouraging her own students, Paula described how word of her class's activities spread throughout the school:

[The fourth graders] 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."

In some instances, people might decorate their own devices not just for their own purposes but also to inspire others. Ashley, a British Sign Language (BSL) instructor, had avoided wearing hearing aids for many years but has recently begun to wear them again. Ashley described how her use of her own colorful and customized hearing aids might have had a positive effect on the children she teaches:

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.

*5.3.3.8 Community.* Engaging in the practice of customizing hearing aids and cochlear implants supported the development of both local communities and online communities. For example, Paula noted that her students' parents often became engaged in the process of customizing devices, donating materials to the classroom. Marie described how her daughter's customized hearing aids were noticed by a deaf children's charity that her family had worked with. The charity organization was impressed by the attractive hearing aids and encouraged Marie to hold a workshop to teach other parents to decorate their children's hearing aids and cochlear implants.

Several of our participants also participated in online communities related to customizing one's own assistive technologies. Six of our participants had participated in the Facebook community we explored in the first study, and two others belonged to other hearing-aid-related online



communities. One participant, Nadeen, had created a blog in which she shared her customized hearing aid designs, along with instructions on how to create similar designs. Furthermore, four of our participants had graduated from customizing devices for themselves to creating and selling accessories to others. Our participants were motivated by their peers in these communities and praised the inspiration and support they received from participating in these communities.

#### 5.4 Contributions and Limitations of This Study

This interview study provides further insight into the practice of customizing hearing aids and cochlear implants. Our interviews revealed several motivations for customizing devices, including supporting one's own sense of pride and self-expression; supporting friends, family members, and students; and participating in an online community of practitioners. This study also showed how wearing customized devices could affect perceptions of the individual, and of deafness, by members of the public.

As with the former study, one limitation of this work is the relatively small number of participants. Also, as in the first study, the vast majority of our participants were female. In Section 8, we discuss how we might extend this work in the future to develop a more robust view of assistive technology customization.

## 6 DISCUSSION

Our two studies present a variety of examples of how creative individuals have adapted their assistive technologies to meet their personal needs and provide insight about why and how people customize their devices. While these studies have focused on a specific type of assistive technology and have largely explored a single community, our findings raise a number of questions about the practices surrounding do-it-yourself customization of assistive technologies.

### 6.1 Aesthetic Customization as Do-It-Yourself Assistive Technology Practice

While the notion of do-it-yourself assistive technology has recently been studied in various contexts (e.g., [6, 23]), the activities we have studied here differ from recent DIY AT research in several ways. The most notable differences between the present research and related work is that the majority of the work has involved changing the aesthetics of the device, rather than the functionality, and has focused on relatively minor modifications to existing devices, rather than significantly adapting or creating new devices.

Despite these differences, we argue that these activities are indeed DIY AT practice, in that they are driven by personal needs of the assistive technology users who are learning to use new tools and collaborate with others in order to reach their desired technology goals. Our study participants encountered many of the challenges that have been found in other studies of DIY AT practice, such as difficulty in learning new tools and techniques, asking for help from others with complementary skills, and learning to overcome barriers presented by the original, unmodified technology platform.

Furthermore, if we consider the broader community of customizing hearing aids and cochlear implants as an example of DIY AT, it is noteworthy in a number of ways. The online community we studied is quite large, with over 4,000 members, and involves a relatively large number of active participants. Furthermore, many community members seem to be customizing the assistive technology for their own personal use, while some other communities, such as Thingiverse [6], feature a much lower percentage of makers with disabilities. There are several reasons this community may be so successful. First, it is clear that many hearing aid and cochlear implant users are dissatisfied with the existing options that are available to them, which may lead to a large and motivated community. Second, we note that these customization activities are likely much easier to perform



than other DIY AT activities, such as 3D modeling and printing, and may be especially welcoming to novices. Third, we note that this type of customization is easily shared online through photos. Finally, we note that the online community we studied is supported by an active group of moderators. While some of these features may only apply to a subset of DIY AT activities, it is possible that understanding why this community is successful may lead to insights that help support other DIY AT communities in the future.

## 6.2 The Many Motivations for Customizing Assistive Technology

While our study of the online community showed that individuals have different approaches to customizing their assistive technologies, our interview study revealed a variety of motivations for customizing one's device and for wearing conspicuous devices. Motivations included personal motivations, such as supporting one's self-confidence and expressing one's personality; interpersonal motivations, such as supporting a family member and acting as a role model; and outward-facing motivations, such as supporting a broader community and projecting positive images of disability.

We should not expect that all motivations will apply to all individuals: not every hearing aid user feels the need to serve as a public representative of Deaf culture or project a unique sense of style. Furthermore, the factors that motivate an individual may change over time. For example, Ashley described how she previously did not wish to wear hearing aids but found that when she began teaching, she saw the importance of acting as a role model for her students.

Understanding the space of motivating factors, and how individuals are drawn to different motivations over time, may be a powerful tool for understanding device adoption. In this study, we have examined individuals who have already taken on the role of a maker and/or wearer of customized assistive technologies. While some of our interview participants discussed their previous negative feelings about using hearing aids or cochlear implants, participants were generally positive about the roles of these customized devices in their lives. Engaging with individuals who are currently customizing their devices raises questions about those who are not customizing their devices. For some, it may be that they have not discovered this activity or the communities that support it. For others, it is possible that they have not yet been exposed to the motivational factors that might affect their behavior, and that making these factors clearer could promote more engagement and creative experimentation with one's assistive technologies.

## 6.3 Who Does (and Does Not) Customize Their Assistive Technology?

While our two studies include people with a variety of ages and abilities, our sample lacks several other types of diversity. Our study had relatively little participation from younger children and older adults, but the most underrepresented group would seem to be men.

Why are men underrepresented in these communities? While traditional maker communities tend to be male dominated,<sup>13</sup> prior research has shown that online communities related to clothing and fashion may be female dominated [41]. It may be possible that some men care less about the appearance of their hearing aids and cochlear implants or are more interested in concealing their devices. Alternatively, men may be less drawn to activities involving craft materials or to the types of visual effects that can be created using these materials. The latter explanation has some support in our data as many of the designs intended for men or boys that were shared online tended to feature characters or sports teams, rather than colors, patterns, or jewelry-inspired designs. However, because we have few men in our sample, and only one male participant from our interview study, more information is needed to fully understand this discrepancy.

<sup>13</sup><http://cdn.makezine.com/make/sales/Maker-Market-Study.pdf>.

If the strong evidence for a gender imbalance in the use of customized hearing aids and cochlear implants reflects an underlying trend, what are the implications of this trend? On one hand, we may not necessarily expect or desire a perfect gender split for this activity. On the other hand, given that the practice of customizing one's assistive technology seemed to provide significant benefits to the wearer, it may be worth exploring how existing online communities could recruit more boys and men, or whether other kinds of do-it-yourself customization activities could provide similar benefits while being more attractive to boys and men.

## 7 DESIGNING SOCIALLY APPROPRIATE ASSISTIVE TECHNOLOGY

Our two studies provide examples of how individuals have altered the appearance or functionality of their assistive technology in order to support their personal needs and provide insight into how contextual factors and individual preferences may affect decisions about adopting and using assistive technologies. As such, these studies suggest future directions for designing assistive technology that better supports users' personal needs. Here we identify several suggestions that may lead to more socially acceptable assistive technologies.

### 7.1 Support Visibility and Controllable Disclosure

Historically, many assistive technologies have been designed to remain inconspicuous and even to avoid notice [40]. Throughout these two studies, assistive technology users (and their friends, teachers, and family members) have demonstrated their desire to have more visible and conspicuous assistive technologies. We have shown that making assistive technology visible serves a variety of purposes, including supporting the wearer in personal self-expression, showing pride for one's deafness, inspiring other deaf people to use their own assistive technologies, and supporting easier and more natural conversations with coworkers and strangers. For all of these reasons, it is important that we design assistive technologies that can be visible, aesthetically pleasing, and personalizable.

At the same time, this may not mean that all assistive technology should be visible or that these technologies should always be visible. Prior work has shown that assistive technology users are often self-conscious about how bystanders might perceive them and may sometimes prefer to remain inconspicuous [29, 44]. Furthermore, visible and stylish assistive technology may not be appropriate for all occasions: while hearing aids decorated with skulls might be popular in an informal social setting, they may not be appropriate for job interviews or visits to the hospital. This tension between the desire for expressivity and the occasional need to remain inconspicuous suggests that future assistive technologies should enable the wearer to control disclosure by changing their visual appearance and conspicuousness.

### 7.2 Support Situational Changes

A common theme across our two studies was that assistive technology users not only wished to own attractive devices but also found value in the process of creating customizations. The act of creating one's own customized assistive technology supported a sense of control and provided a means of self-expression and identity management. Some individuals chose to frequently change the design of their devices to match their outfits, mark special occasions, or simply refresh their look. Thus, it is important that assistive technology devices support some level of user customization, allowing the user to change the device's appearance or augment it with skins and accessories.

### 7.3 Support End-User Customization

While some of our study participants simply purchased aesthetically pleasing devices or augmented their devices with premade accessories, most participants performed some self-directed

customization and decoration of their devices. However, this do-it-yourself practice sometimes required substantial effort, including learning new techniques, acquiring materials, and practicing the customization. If the customization practice went awry, the designers risked damaging an expensive (and sometimes irreplaceable) device. Concerns about damaging the device during customization also excluded some individuals, such as children, from modifying their own devices.

Given that many people are customizing their assistive technology devices despite these risks, device manufacturers should take steps to support end-user modification and reduce the possibility of damaging a device during modification. Manufacturers could provide their own instructions for modifying devices and could provide tutorials and templates for creating customizations. Assistive technology devices could also be designed to be more robust to tinkering, for example, by shutting down safely if the user accidentally covers a vent, or by providing feedback if an important device component is blocked by an end-user's customization.

#### 7.4 Support Documentation and Collaboration

Our two studies showed that customizing one's assistive devices can be a fundamentally social activity. Community members often shared their customizations with others and exchanged tips about how to more effectively customize devices. Device manufacturers could provide guidelines for writing tutorials and could follow the lead of fashion companies such as Warby Parker by creating their own online forums for sharing customizations [41]. Device manufacturers could also gain inspiration from do-it-yourself sites such as Thingiverse<sup>10</sup> and Instructables<sup>14</sup> by highlighting interesting designs and their creators.

### 8 LIMITATIONS AND FUTURE WORK

This article combines an analysis of online discussions with longer interviews with community members. Through these two studies, we have gained both a broad understanding of interactions within a community of makers and a deeper exploration of personal motivations. We believe our study provides useful insights about the practices of customizing one's own assistive technology devices and presents several opportunities for future work.

One future direction for this research is to more deeply explore customization of assistive technology by including a broader population of assistive technology makers. We might consider how to reach other individuals who might customize hearing aids and cochlear implants specifically, such as men (who were vastly outnumbered by women in this work), younger children and older adults, or individuals who are interested in customizing their devices but have not, either because they are afraid to try or because they have previously tried and failed. Including these groups might help us understand how different types of people engage with assistive technology customization. We might also compare customization of hearing aids and cochlear implants with customization of other assistive technologies, such as prosthetic limbs or wheelchairs, or across types of customization, such as aesthetic versus functional customization. Comparing customization practices across different types of assistive technology would help us understand how the features of a specific technology may support or hinder customization.

A second direction for future research is to explore how an individual's customization practices change over time. In the studies presented here, we saw several examples of how participants' customization practices changed over time, such as when some users frequently redesigned their devices but did so less over time, and when some users transitioned from customizing their own devices to creating and selling customized devices. Exploring changes in customization activity over time might help us understand opportunities and barriers to customizing one's devices.

<sup>14</sup><http://instructables.com>.

Given that many study participants changed the designs of their devices based on the situation, such as to match outfits or mark occasions, it might be useful to explore how the devices themselves could be made more adaptable, such as by incorporating color-changing displays or through more modular designs similar to Mr. Potato Head<sup>15</sup> or Crocs shoes<sup>16</sup>, which offer a generic “body” that can be augmented with user-selected add-ons.

Finally, as we have seen that customizing one’s hearing aids and cochlear implants is a form of do-it-yourself assistive technology practice [23], it may be valuable to explore how new maker tools could better support these activities. Such tools could include templates, software tools for creating device skins, or tools to support collaborative design and development of customized devices. These tools could provide increased support for self-expression via one’s assistive technologies while maintaining the feelings of agency and independence that may be fostered through do-it-yourself practice.

## 9 CONCLUSION

Assistive technologies, especially those worn on the body, may have a significant impact on how wearers perceive themselves and how they are perceived by others. As the availability of attractive and aesthetic devices falls short of wearers’ desire to express themselves, assistive technology users have increasingly turned to do-it-yourself solutions. In this article, we have explored how hearing aid and cochlear implant users have customized their devices to better support self-expression. Through an analysis of online community discussions, and through interviews with makers of these customized devices, we have shown that individuals have many different motivations for modifying their devices and often rely on local and online communities to support their customization work. Our findings suggest ways in which device makers could make their devices more easily customizable and could support assistive technology users in matching their devices to their preferred forms of self-expression.

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<sup>15</sup><http://www.hasbro.com/en-us/brands/playskool/mrpotatohead>.

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