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Framing diversity: designing hearing aids from a deaf culture perspective.

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Abstract | Deaf people are proud of their culture and the fact of not being able to hearing is rendered secondary to the positive experiences created by their social lives and 250-year-old history and culture. This reality is often misled by the adoption of medical criteria which regard Deafness as a medical condition measured against the "norm" of hearing people. This paper presents a research-through-design project which developed smart jewels to counteract the stigma of disability addressing functional and cultural needs of Deaf people. Workshops were organised involving Deaf people, makers/engineers, designers and Italian sign language interpreters who were engaged in a *Thinking-through-making* process where the experience of Deaf participants was exploited to drive embodied explorations of future hearing aids. The design case calls for a participatory design model in which designers and users can co-create solutions addressing not only the (dis)abilities of the body but and more importantly, the human experience.

KEYWORDS | DIVERSITY, DEAFNESS, HEARING AIDS, SMART JEWELS, PARTICIPATORY DESIGN

1. Introduction

According to the World Health Organization (WHO) (WHO, 2018), 466 million people worldwide, that is, over 5% of the world's population, have moderate to profound hearing loss (HL) in both ears (Tucci, 2010). Disabling hearing impairment in adults refers to hearing loss greater than 40dB. It is estimated that by 2050, over 900 million people will have disabling hearing loss.

The numbers are impressive, and reflect a very complex and nuanced reality where deafness and hearing impairment are often misunderstood.

First of all, it is necessary to distinguish between the terms physically deaf and culturally Deaf. A small 'd' is used when referring to people from a medical perspective, while a capital 'D' is used when referring to people culturally defined as Deaf (Woodward, 1972).

Deaf people (with a capital "D") have little or no hearing ability. They use the Sign Language of the country where they live as their primary language. Even if some of them may hear environmental sounds and understand some speech, they identify themselves as a linguistic minority.

Deaf people feel that they belong to the "Deaf Culture", an ethnic minority with a defined language composed of verbal (signs) and non-verbal elements (facial expressions and postures), communication and social protocols, forms of artistic expression, entertainment and recreational activities (e.g., sports, travel, and Deaf clubs). Being part of a cultural community means that they do not feel impaired or disabled.

Oral and late deafened deaf (with a lower case "d") also have little or no hearing, but, unlike Deaf people, they typically do not use Sign Language as their primary language. Oral and late deafened people do not identify with the "Deaf Culture".

Despite the benefits that people with HL can obtain from use of hearing aids and assistive technology, many of them refuse to use them (Vernon and Pratt, 1977). The main reasons for not owning/using hearing aids are the denial of the problem, discomfort, a sense of foreignness, and aesthetics ("it is a foreign object deep in the ear", "it pinches", "it hurts", "it is too big"), shame, social rejection and stigmatisation. This suggests that the hearing aids address HL in a way that is technically efficient but does not take the user's experience into due consideration.

Considering deafness from a sociocultural perspective, rather than as a medical problem or insufficiency to be compensated, implies addressing a complex tangle of needs of D/deaf people that go beyond hearing compensation. We argue that disability should not be regarded as a problem to solve or a lack to compensate but as a design opportunity (Pullin, 2009).

In this paper, we introduce the design case, describing the methodological approach that resulted in development of an interactive jewellery system composed of interactive modules

which continuously sense the acoustic qualities of the environment and notify the wearer of the occurrence of specific sounds through micro-movements, vibrations and light patterns (Marti & Recupero, 2019). The paper concludes with a set of recommendations that can support designers of future assistive devices in engaging vulnerable stakeholders, in particular Deaf people, as equal partners in the design process.

2. The Design Case

Quietude (www.quietude.it) is an EU project which develops assistive devices for people with hearing impairment and HL. It was funded within the H2020 WEAR Sustain (https://wearsustain.eu/) programme.

The project adopts a participatory design approach (Bjerknes et al., 1987, Smith et al., 2018) to learn about inspirational and actionable insights into the socio-cultural practices and expectations of D/deaf people.

Participatory approaches to design (Sanders et al., 2008) engage stakeholders in co-creating artefacts destined for them, ensuring that their viewpoint and interpretations are considered in research throughout the design process. These methods are pursued throughout the entire research project with the goal of not just empirically understanding the problem at stake, but also envisioning, shaping, and transcending it in ways users find satisfactory (Spinuzzi, 2005).

2.1 Workshop series

The project included two workshops which were adapted to respond to different forms of expression (Sanders et al., 2008). Activity based on visual expressions, material exploration and hands-on techniques intertwined with verbal discussions mediated by Italian sign language interpreters.

Workshop 1

The initial inspirational workshop took place over six days in the Fab Lab of the University of Siena (Italy), with the involvement of four women who had been Deaf since birth, two sign language interpreters, an ethicist and a mixed group of designers, technology experts and makers (Marti, Iacono & Tittarelli, 2018). The group of Deaf participants was composed of an architect (40 years old), a psychotherapist (41 years old), a special education teacher (30 years old), and a university student (21 years old). A free and informed consent form was signed by all participants.

The aim of the workshop was to inspire each other, encourage empathic understanding of Deafness and HL, and start developing concepts of hearing aids to address some concerns of the current devices.

On Day 1, participants were prompted to reflect on feelings of Deafness which were mapped on body maps using simple post-it notes (Figure 1).

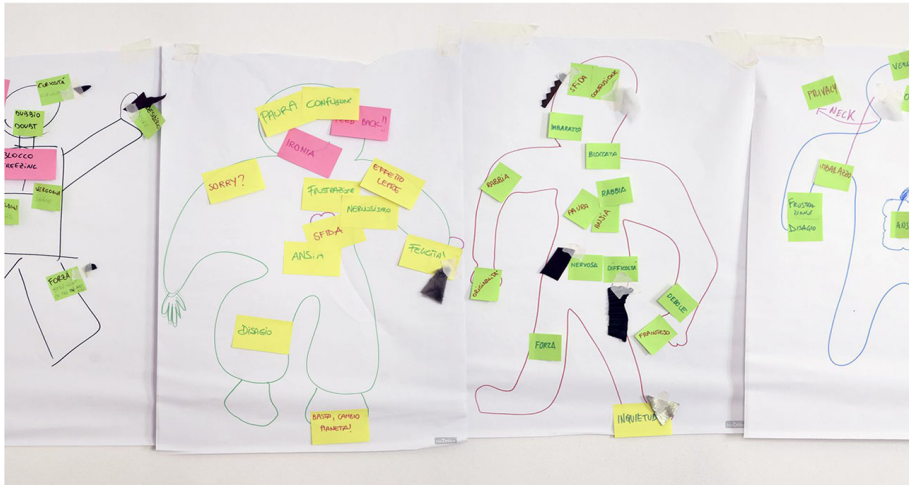

Figure 1. Body maps.

For example, embarrassment and shame were located around the ears and referred to hearing devices. Originality was located on the hands to underline the unique features of sign language.

Day 2 focused on selecting forms and materials (Figure 2) and experimenting with simple vibrations motors (Figure 3). Deaf and hard of hearing people are familiar with the use of vibration. Though not all participants perceived the vibration in the same way, the neck, the bones around the ears and the wrist seemed to be the parts of the body most sensitive to vibration.

Figure 2. Exploration of materials.

Figure 3. Experimenting with vibration motors.

Day 3 focused on developing concepts; Days 4–5-6 were devoted to materialising ideas and developing low-fidelity prototypes (Figure 4):

- A bobby pin with parts that move according to the ambient sound detected by directional microphones embedded in a brooch. This object signals deafness to others and notifies the wearer of crucial sound events.
- An armband that translates different sonic qualities in the environment, including range, volume and direction, into vibrations.
- A 3D shape-change necklace that expressively enacts live or recorded sounds, translating the sounds into micro-movements.

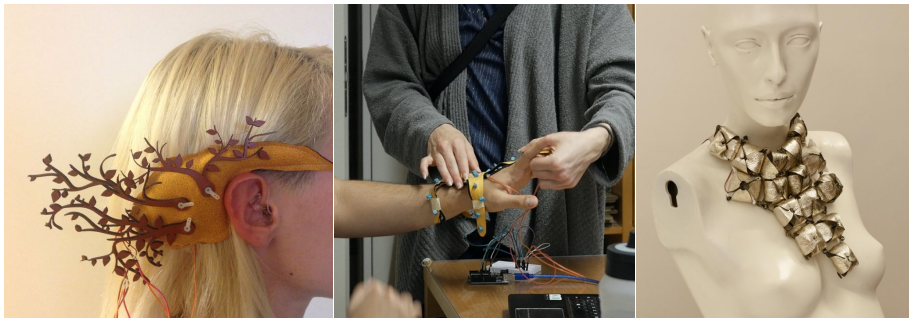

Figure 4. Bobby pin, armband and 3D shape-change necklace.

In this activity of thinking-through-making (Ingold, 2013) the prototypes served as a vehicle for generating research questions and collecting complex needs/requirements in a research through design process. Discussion topics included:

1. Awareness about personal sounds (e.g., doorbell, name, etc..) and public notifications, such as alarms, announcements in public spaces, and more.
2. Safety to prevents sounds requiring a quick response from going unnoticed.
3. Personalisation according to individual preferences and sensitivity.
4. Cross-modal experience of sound through sight, touch, on-body vibrations.
5. Aesthetics: hearing aids should be beautiful, smart and comfortable to wear.

Workshop 2

The second workshop was hosted by Mason Perkins Deafness Funds Onlus, a non-profit organisation which provides services and training for the deaf community in Siena (Italy). The organisation supported the project, facilitating contact with the local deaf community and providing interpreters. In this second workshop, we tried to balance the number of Deaf and hearing participants and also to propose a place that was familiar to the Deaf experts, to give them more confidence in their ability to contribute. The workshop lasted 1 day, in

consideration of the difficulties that the Deaf participants had encountered participating in the previous workshop for several days.

Five participants who had been deaf since birth and used the Italian Sign Language participated in the session: 4 women from 20 to 50 years of age and one 17-year-old boy. A free and informed consent form was signed by all of them. The group of hearing experts was composed of a psychologist, a designer and two technology experts. Two design researchers facilitated the workshop, supported by a sign language interpreter.

The aim of the workshop was to reflect on the needs and desires that emerged during the first workshop, engage the participants in a thinking-through-making activity and evaluate the prototypes developed during the first workshop.

Thinking-through-Making

After a card sorting activity aimed at identifying desires and prioritising the needs emerged during the first workshop, participants were involved in a making activity based on a desire selected from the previous phase. Various materials including textiles, paper, cardboard, tape, pens, glue and hooks were put on the table. All participants were encouraged to fabricate their own personal accessory, give it a name and present it to the others. The idea was to transform what had been discussed verbally in the previous phase into design probes, moving from abstract to concrete, to invite all participants to be kinaesthetically engaged and to reflect together (Luck, 2018).

One Deaf participant made an accessory named “Alive”, a shape-changing jewel that moves like a living object in response to sounds (Figure 5 left).

Figure 5. The probe "Alive" (left) and "Stella" (right)

Another Deaf participant developed "Stella", a bright necklace that looks like a shining star to underline how important it is for hearing aids to be able to express a personal sense of style (Figure 5 right).

The young boy developed an armband, explaining that he would like to wear an accessory that can notify him of sounds that would otherwise go unnoticed (Figure 6 left). A Deaf girl developed a belt to be placed around the shoulders or chest. The belt acts as an undergarment that allows the wearer to feel sounds through vibrations (Figure 6 right).

Other probes were developed by the hearing participants to underline equality in the participatory process.

Figure 6. Armband and belt probes

Evaluation of prototypes

The third part of the workshop was devoted to presenting the prototypes developed during and after the first workshop, trying them out and collecting feedback. The evaluation regarded both the jewellery and an early prototype of the App. The bobby pin, armband and necklace were put on the table along with other prototypes developed at the Fab Lab after the first workshop, including an interactive ring which translates sounds into lights in continuous listening mode (Figure 7).

Figure 7. The interactive ring prototype lighting up with sound

Participants were free to try out the jewels and comment on them. One of them who had participated in the first workshop was amazed to see that most of the comments raised previously had been integrated into the prototypes. These included the aesthetics of the jewels, the possibility of exploring the sonic qualities of environmental sounds and therefore addressing Deaf people's curiosity about sound, and the possibility of choosing the accessory that best suits their preferences.

The ring was criticised because it interferes with the use of sign language, in which the hands must be used only to sign. The light could confuse the interlocutor.

The hair clip was discarded because the vibration produced by the embedded motor could interfere with a hearing aid located behind the ear.

The necklace and the armband were considered the most interesting accessories. Deaf participants stressed the importance of being aware of the environment (quiet or noisy) and of recognising specific sounds of interest.

The last part of the workshop was devoted to evaluation of an early prototype of the App. Before the workshop, the App had been demonstrated to one of the participants who usually plays a leading role in the group. She drove the evaluation session by explaining the functionality and performing a live demonstration of the service. Her mediation was essential. She was able to create an atmosphere of trust and empathy which greatly

facilitated engagement of the other participants. No major defects were identified in the App. The participants appreciated the ease of use, the possibility of customising the intensity and type of feedback on the accessory, and the idea of creating a personal library of sounds to be recognised by the jewels, alerting the wearer.

In summary, the two workshops marked important milestones in the design process in terms of exploration of the complex needs of Deaf people, elicitation of requirements and preliminary evaluation of early prototypes.

3. The jewellery system

After the second workshop, a suite of jewels was designed as a modular system to allow different types of formal configuration and personalisation of use. The modules embed sensors and actuators allowing self-actuation and kinetic modifications in the presence of particular sounds.

The suite of jewels includes three necklaces which notify the wearer of incoming sounds with different behaviours: dynamic light (Figure 8), vibration (Figure 9) and a change in shape (micro-movement of the modules) (Figure 10). A video of the system's behaviour can be viewed at: http://www.quietude.it/wp-content/uploads/2018/03/Quietude_DemoHD.mp4?_=1.

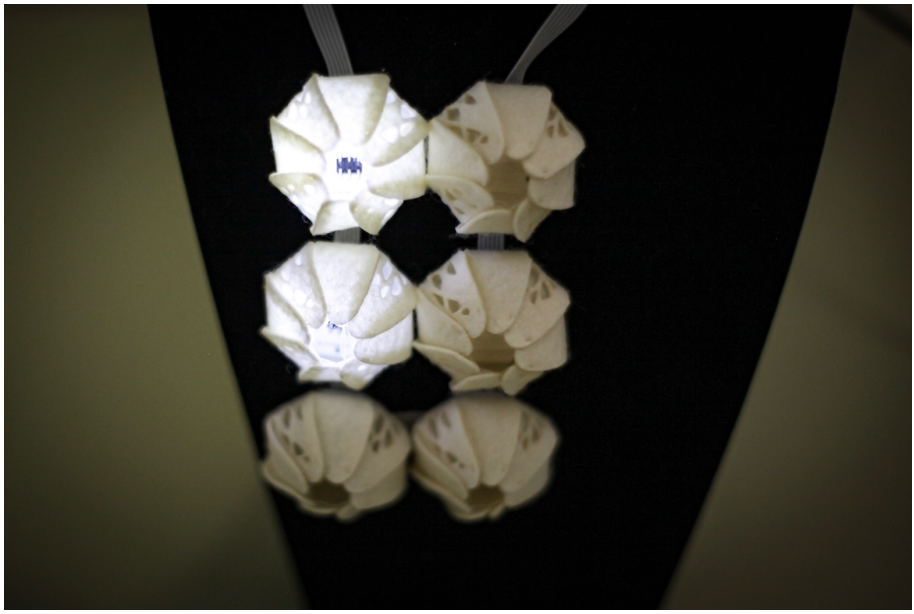

Figure 8. Necklace with dynamic light

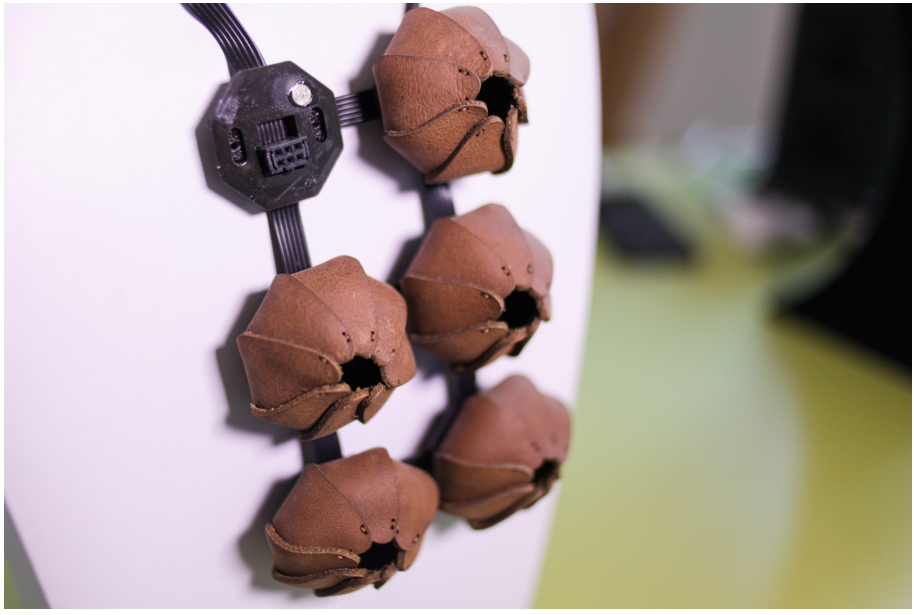

Figure 9. Necklace with vibration

Figure 10. Shape changing necklace

The formal design of the modules was inspired by a powerful metaphor that emerged during the first workshop. One of the participants used the expression “feeling under water” to describe deafness as hushing of the perception of sound.

Drawing on this metaphor, the suite of jewels was inspired by the undersea world. The modules resemble sea urchin shells, and the colour palette reflects images of sand, deep oceans and coral. The jewels were conceived as modular structures which can be assembled to create the wearer’s own personal jewels. Modularity addresses the need that emerged during the workshop for placing and playing out the jewellery on the parts of the body which are most sensitive to vibrations and micro-movements.

The jewels are handcrafted: modules are sewn by hand, connectors are fabricated by recycling flat connectors from obsolete computers, and, most importantly, no glues or adhesives were used. In this innovative design, modules are connected through 3D-printed interlocked supports. The system’s behaviour can be defined and fine-tuned through a smart phone app that works with the accessories.

Modules are made using laser-cut eco-leather, felt or fabric petals which are folded and sewn to create a shell-like shape (Figure 11).

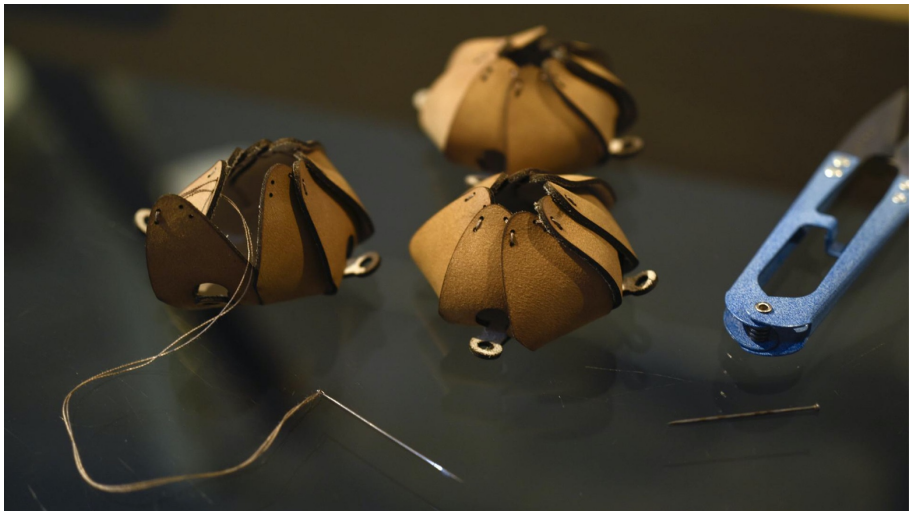

Figure 11. Sewed eco-leather modules

The electronic components are placed in an octagonal PCB that keeps the modules fixed and stable in a horizontal position (Figure 12). Some modules contain electronic boards and sensors (e.g. the Bluetooth communication board and microphone), some contain actuators (e.g. LEDs, servo-motors, vibration motors), and others are empty, and are simply used to add to the aesthetic value of the system. This modular system permits creation of a variety of fashionable jewels, including necklaces, armbands, brooches, etc.

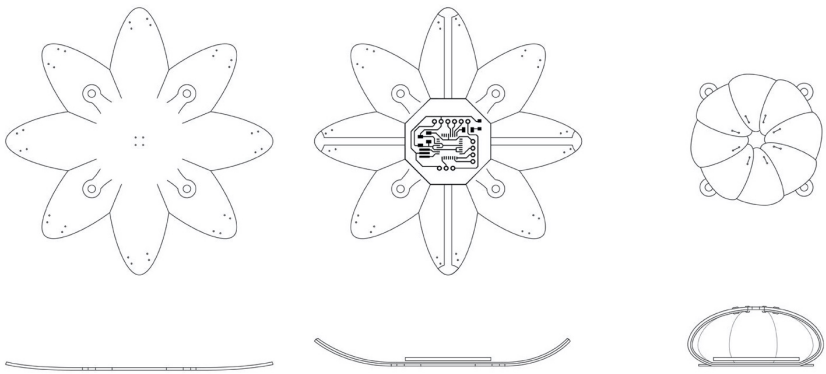

Figure 12. Laser cut module, electronic components and final seam

The jewels can sense sounds in two different ways: through real-time continuous monitoring, to notify the wearer of the frequencies and amplitudes of sounds in the surrounding area; or upon occurrence of certain specific sounds, defined by the wearer using the mobile app.

The necklaces with light and vibration behave differently. Instead of using simple on, off, and blinking behaviours, we have adopted a richer vocabulary. Drawing on Harrison's study (2012) of what kinds of information are typically communicated by point lights, we designed light and vibration patterns that follow the spectrogram of the incoming sounds (Figure 13).

The 3D shape-changing necklace performs micro-movements in response to external sounds. The actuators embedded in the three necklaces are directly mapped to the intensity and amplitude of incoming sounds bending them towards the lower centre of the module.

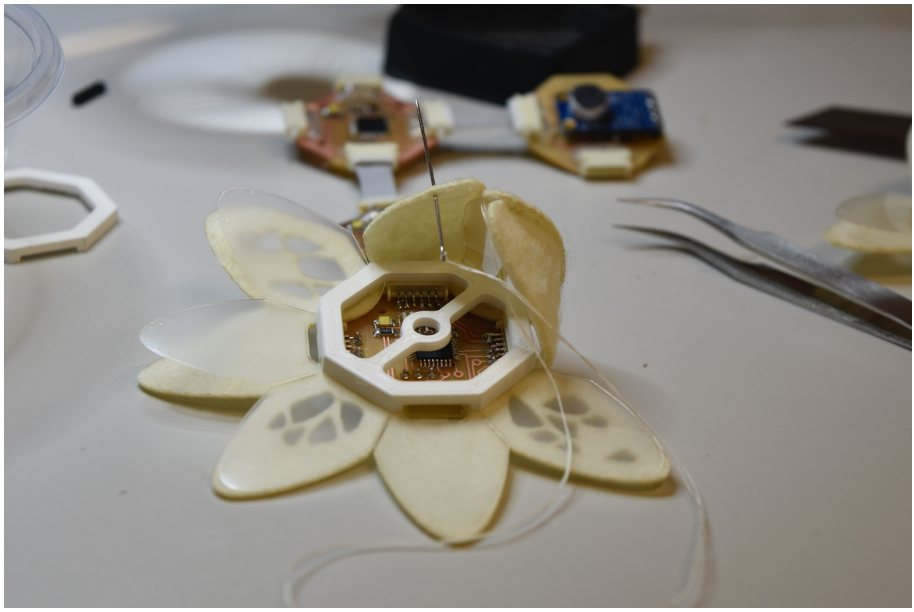

Figure 13. Embedded electronics

The combination of the micro-movements of the petals of different modules results in a coordinate and expressive movement of the overall structure (Figure 14).

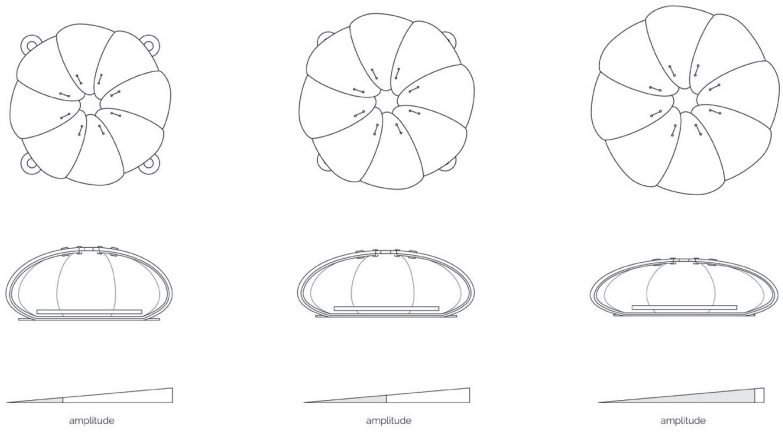

Figure 14. Micro-movements of the shape-changing modules

3.2 Smartphone application

The jewellery system is connected to a smartphone application (Figure 15) permitting personalisation of sound recognition in input and kinetic transformation and shape change in output. The jewels and the smartphone communicate via Bluetooth.

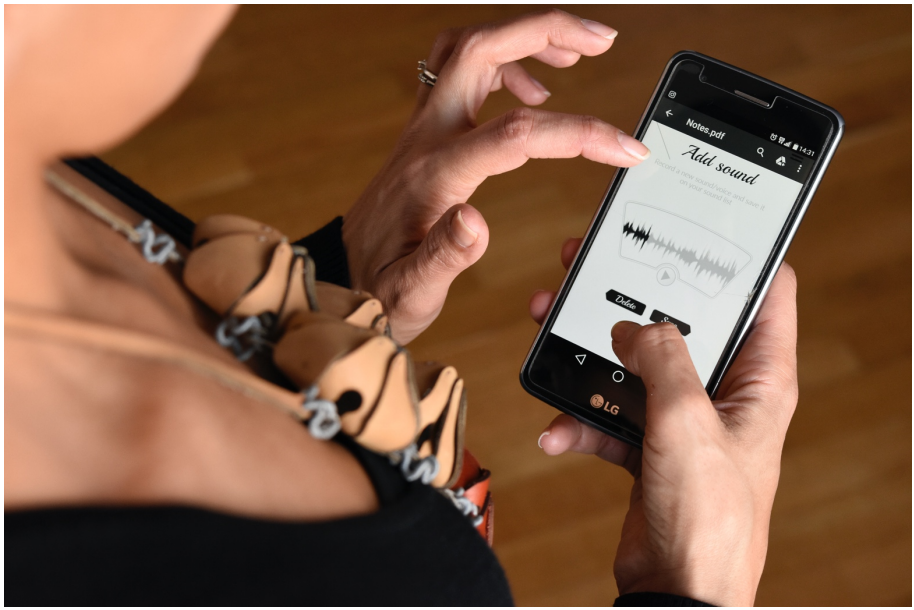

Figure 15. Smartphone app

The app permits customisation of both input and output, with construction of a personal library of sounds that can be monitored and replayed on demand through the accessories (Figure 16). The key feature of the application is management of the kinetic, light or vibration output on the basis of a comprehensive sound recognition process.

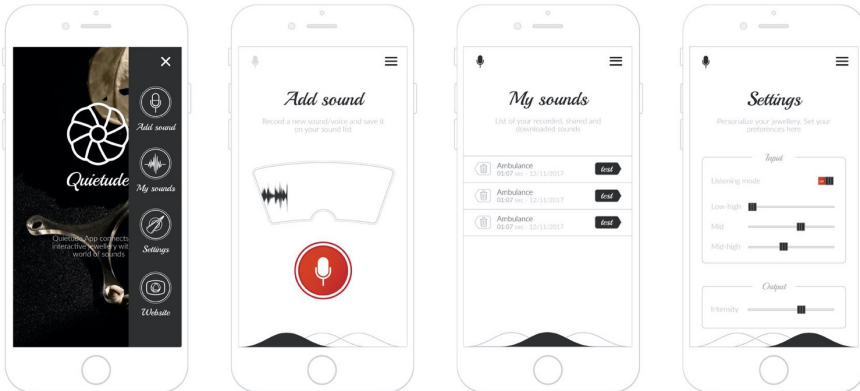

Figure 16. Smartphone app screenshots

The user can create a library of sounds by recording personally meaningful sounds through the microphone embedded in the jewels. These sounds are then labelled and stored in the app, permitting real-time sound monitoring and on-demand playback.

4. Conclusions

This paper moves from an analysis of Boys's (2014) research calling for a shift in the attitude toward disability from a medical model to a sociocultural model.

Transforming hearing aids into fashion accessories is an attempt to stimulate reflection on diversity and provoke a cultural shift, reconsidering the continuous entanglement between disability and ability beyond the tendency to standardise or normalise human skills.

The design case described in the paper highlights the importance for the designer to understand the sociocultural context of use as well as the meanings people give to the designed artefact. In the project, this led to adaptation of participatory design methods that engaged with the community and allowed persons with diverse auditory skills to contribute and co-design solutions.

The proposed approach poses several challenges, due to cultural differences and understanding of experiences of the participants, and due to suitability of methods and techniques that may not be appropriate or need adjustment as highlighted also by Slegers et al. (2014); Hendriks et al. (2015); Tucker (2015); Marti & Bannon (2009).

The challenges that emerged during the project are summarised in the following.

Prior knowledge of the deaf culture

Researchers and designers often have limited knowledge of deaf culture which is sometimes confused with hearing impairment. They often rely on the reported experiences of their stakeholders that are individual and sometimes fragmented or conflicting due to the specific level and typology of deafness. To minimise this problem, some researchers suggest to assign to the impaired participants the role of experts, hiring them as paid team members (Hendriks et al., 2015). In our project, we learned the importance of forming a solid prior knowledge of deaf culture before involving deaf people in participatory design. Deaf culture includes practices related to a suitable arrangement of the working space that hosts the co-design activities. In the DeafSpace project (https://www.gallaudet.edu/campus-design-and-planning/deafspace) Hansel Bauman developed a catalog of architectural elements to design built environments for deaf people (Hope, 2017). These include: ensuring proper sensory reach (visual and tactile) in 360 degrees to extending Deaf people's awareness and making spatial orientation easier; arranging space and proximity to allow signers maintain enough distance to accommodate each other's signing space when conversing; maintaining clear visual communication while walking and conversing; avoiding shadow patterns and

backlighting that disrupt visual communication; preventing acoustic reverberation that can be only distracting and also painful to deaf people use hearing aids or cochlear implants. All these architectural elements have to be accommodated in any comfortable co-design space for deaf people.

Choosing appropriate spaces for participation

Spaces of participation should not only comply with the guidelines reported above. They should be also familiar to the deaf participants. The second workshop worked much better than the first one since it was hosted at the Mason Perkins Deafness Fund Onlus, a familiar place for the participants where the deaf community is used to meet and socialise.

Using the appropriate language

“Hearing impaired” is an equivocal term which mixed up people with different levels of hearing loss, communication modes and cultural identities under one definition. Some deaf people don’t like to be defined as “hearing impaired”, some others object to the word “impaired,” which they feel implies that a person is flawed, deficient or imperfect. Using an appropriate language is quintessential.

Choosing the right methods

In the project, we experimented with different methods for engaging deaf people in the design process. However not all of them were equally successful. Activities involving abstract thinking were less engaging, like the one focused on reflection on ways of accessorising the body performed in the first workshop. Drawing from this experience, it is advisable avoiding situations distant from the Deaf participants’ experience and imagery.

The mediation of interpreters

The co-design team has to include professional sign language interpreters to bridge the communication gap between the deaf/hard of hearing and the non-signing language users. The sign language interpreters are fundamental intermediary to create an atmosphere of empathy and collaboration. They have to be professional, skilled and certified.

Equivalence in participation

All stakeholders have to be equal partners in participatory design. In our project, some methods proved to be particularly successful in achieving equality like thinking-through-making during the second workshop. This stimulated creativity and joint reflection.

Encourage the role of leader

Even if in the co-design team there is not an assigned leader and the group dynamics are free-flowing, leaders can show up in different ways. In our project, a deaf person spontaneously took the responsibility of stimulating the activity showing integrity, empathy for others, and promoting joint reflection. This happened in particular during the second workshop, where a deaf person accepted to take the responsibility to drive the evaluation of the app. She was able to understand the main goal of the activity and act accordingly. This was tremendously successful. It is advisable to let deaf people drive informal evaluation activity to facilitate the participation of the other deaf participants.

Ethical challenges

Beside practical ethical issues concerned with co-designing with vulnerable people (e.g. managing the informed consent), there are other challenges related to the fact that researchers and designers may feel insufficiently prepared for dealing with disable participants. In our project we involved an ethicist who supported us in facilitating the activity by ensuring an appropriate use of time (sessions were in total not longer than two hours with several short breaks), selection on the sign language interpreters and space set up. This turned to be a precious support.

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