Overcoming the Stigma Associated with Assistive Devices

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Abstract: This paper focuses on the stigma associated with current assistive devices. Through examples from literature on stigma and preliminary results from an ongoing empirical study, the paper presents how users experience assistive devices and how assistive devices become stigmatizing. Drawing from Erving Goffman's insights into the management of stigma, the paper explores the ways stigma related to assistive devices could be challenged from the viewpoint of design. The paper introduces how people with physical disabilities have tried to manage the stigma in order to have assistive devices that express their identities. The paper concludes with implications for design and suggests personalization as a means of overcoming the stigma associated with assistive devices.

Key words: Assistive devices, Design, Personalization, Stigma.

1. Stigmatizing Assistive Devices

1.1. Starting Point

During recent years, built environments that are accessible and attainable have been of general interest in Western countries due to their rapidly ageing populations. Such approaches as Design for All, Inclusive Design, and Universal Design have been introduced to promote equality and provide a wide range of users with inclusive products. Regardless of the various benefits of those ideologies, current assistive devices still remain marginal and are considered unsatisfactory and unaesthetic among users.

Users' views of assistive devices and the social-psychological consequences of assistive devices have not been fully examined, even though environments encountered by people with physical disabilities in general have been studied [1, p. 1417]. Brooks [1, p. 1419] claims that *"[t]here has been little systematic investigation into the relationship between assistive devices and disability as a social condition."* In occupational therapy, for instance, focus has traditionally been on the functionality and effectiveness of assistive devices [6, pp. 3-4]. Parette and Scherer [2, p. 217] also state that the relationship between stigma and the use of assistive technology has only begun to be studied, although the stigma related to disability has been acknowledged for a long time.

This paper focuses on the stigma associated with current assistive devices and explores the means for overcoming it from the viewpoint of design. Herein, assistive devices are any devices that promote users' independence in their daily tasks. The focus, however, is on such devices that assist in locomotion (Figure 1).

The users of assistive devices are referred to as 'people with physical disabilities' rather than 'the disabled' in order to emphasize the many-sidedness of identity.

Figure 1. Examples of traditional assistive devices to assist in locomotion.

1.2. Defining Stigma

The history of stigma dates back to ancient Greece where the term stigma was generated *"to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier."* In practice, stigmas in ancient Greece were cuts and burns on the body, and they informed about their bearers' slavery, criminality, or traitorousness. Along with Christianity, bodily stigmas became associated either with holiness or, from the medical viewpoint, physical disorder. [3, p. 11]

According to Goffman [3, p. 59], stigma symbols are contrary to prestige symbols. They are continuously available for perception, draw attention, and break up a coherent image [3, pp. 59, 124]. Stigma relates to perspectives rather than persons and concerns everyone depending on contexts and phases of life [3, pp. 163-164]. For Goffman, stigma means *"a socially constructed deviance label"* [4, p. 14]. This is also how this paper sees the stigma associated with assistive devices.

What we consider stigmatizing today may have changed since Goffman wrote his book about stigma nearly five decades ago. Post-modern conceptions of identity have not only affected our perception of the way identity is constructed, but the essence of stigma has likely altered as well. Simplistically, what was once considered as 'deviant' may be 'individual' today. According to Green [4, p. 34], who has considered the relevance of the concept of stigma, *"[d]iversity and difference are celebrated and prized in an 'anything goes' world in which uniqueness, innovation and irony dance around rules and traditions."*

Furthermore, due to individualism, reflexivity, and self-awareness, the body becomes significant and intertwines with the self: *"[w]hat one is and how one looks and presents oneself define who one is."* [4, p. 34] However, post-modern conceptions of identity construction seem not to have reached the design of assistive devices apart from the case of eyeglasses. In addition to associations and connotations that users experience as unfavorable, the stigma related to assistive devices arises from users' limited possibilities to express their identities.

1.3. The Stigma Associated with Assistive Devices

Even though assistive devices may be functional, they often become abandoned for other reasons [5, p. 125]. Hocking [6, p. 3] claims that abandonment relates to users' perception of themselves as disabled and to broader

issues of identity. For instance, some older people refuse to go outside their homes due to embarrassment about their reliance on assistive devices [7, p. 76]. If assistive devices that aim at mitigating disability become stigmatizing, they are likely to be rejected [3, p. 115].

Why are assistive devices experienced as stigmatizing, then? One reason could be that in their design mainly functionality and usability are traditionally in focus. Aesthetic qualities, for instance, appear to be a matter of lesser importance. As such, assistive devices become experienced as stigmatizing, which affects their users' assimilation into their environment [8, 9]. What the use of assistive devices symbolizes influences the meanings that are ascribed to them [10, p. 15].

Stigma can relate to both physical marks and non-physical characteristics, and there are various dimensions in stigma [4, pp. 14-15]. Disruptiveness, aesthetics, and concealability [4, p. 15] are central to the stigmatizing features of assistive devices. According to Green [4, p. 15], their degree depends on how obvious and apparent the stigmatizing features are. Such visible stigmas as physical disabilities or obvious assistive devices cause wider social disadvantages. Similarly, illness-related disabilities that worsen and become more visible receive more negative societal reactions. [4, p. 16] Through the use of assistive devices, attributes related to disability often become emphasized [1, p. 1418; 13, p. 2]. In one sense, assistive devices can "add disabilities" and make a person appear more disabled or differently disabled than she actually is.

Assistive devices are rarely designed by professional industrial designers, as other consumer products are. Instead, they are often designed by mechanical engineers and technicians. Brooks [1, p. 1418] claims that assistive devices are neither conventional nor desirable and they strain social interaction. Due to their role as replacements for more typical and desirable physiological functions and substitutes for routine abilities, they are not considered as symbols of valued social status [1, p. 1418]. Brooks [1, p. 1418] claims further that *"[v]ery rarely will an assistive device be an accessory that demonstrates personal choice, taste, or social fashion."* Again, eyeglasses are a well-known exception. Through the transformation from eyeglasses into eyewear, they have come into vogue [11, pp. 2-4; 12, p. 3].

In their exploratory papers, Bispo and Branco [13, 14] discuss the stigma related to current assistive devices. According to these authors [13, p. 2], stigma lies in the relationship between a stigmatizing attribute and what the surrounding environment considers 'normal' or 'common'. Hence, the same object can be either stigmatizing or non-stigmatizing depending on the context of its use. This is particularly apparent when assistive devices are brought from hospitals into private homes. Coarsely speaking, they transform homes into hospitals and residents into patients. In social interaction, assistive devices point to disability and elicit associations with medicine and social welfare [1, p. 1418]. As Bispo and Branco [13, p. 3] state, assistive devices that are experienced as stigmatizing are designed for hospital contexts and their formal codes.

According to Hirsch et al. [7, p. 77], designers should understand how and where assistive devices will be used, and, therefore, assistive devices meant to be used in homes should be unobtrusive and stylistically fitting. After all, such design drivers have been built into the design of other consumer products for a long time. Interestingly,

the design of other assistive-like products, as for instance sports equipment, is specifically based on their users' lifestyles.

Despite the diversity of the world of fashion, stigma has been recognized in the clothing industry [15] and patient clothing [16] as well. According to Iltanen [15], clothes that are designed to take into account the physical changes of the ageing body can construct social age in a negative way. Dankl [12], similarly to Iltanen, considers the ways in which material culture conveys the images of ageing. She claims that, for instance, walking canes are *"agents of being old"*. Even though maintaining self-image through the expression of social roles is important for patients in long-term care, current patient clothing tends to focus on patients' physical needs [16]. Assistive devices resemble clothing and accessories, but instead of 'finishing' a person's appearance, many devices stand out as distinct instruments.

Furthermore, stigma is generated through considering people with disabilities as a homogeneous group, the disabled. Pullin [5, pp. 89-90] claims that in the design of assistive devices more attention has been paid to clinical than cultural diversity. He remarks that people who share the same disability may not share, for instance, the same culture, taste, education, or priorities. Still, the same assistive solutions are offered to people with a particular disability despite their age or attitudes. Pullin [5, p. 101] continues that in addition to recognizing different abilities, diversity within any disability ought to be acknowledged instead of stereotyping people with the same disability.

2. Studying How People with Physical Disabilities Tackle Stigmatizing Assistive Devices

This paper draws from literature and preliminary findings from the author's ongoing doctoral research on personalization of assistive devices. The literature review focuses on Erving Goffman's [3] insights into the management of stigma. In addition, recent literature on stigma as a concept and the methods of challenging it is explored. The aim is to understand stigma in the context of assistive devices and conceptualize the ways of managing it.

The empirical data referred to in this paper is based on an earlier user study that was carried out in Future Home Institute by the author and her colleague. The study was a part of the multi-disciplinary research project Erilaistuva asuminen [Diversification in Housing] funded by the Finnish Ministry of the Environment in 2006-2008. In the user study, five people with physical disabilities self-documented their daily life with probes (for probes, see e.g., [17]) for a week and were then interviewed based on the probes. The probe kit (Figure 2) consisted of a questionnaire for background information, housing history, question cards, a 'clock task', and a disposable camera. Participants' emotional and value-related issues related to home and its abilities to fulfill their requirements were asked in the question cards. In the clock task, the participants described the typical events of the day and evaluated their experiences of them. Finally, the participants were assigned to photograph their home and its immediate surroundings. For this paper and the author's doctoral research, the data is being analyzed further from the viewpoints of stigma and its management. The analysis is theory-guided and mainly derives from Goffman's [3] conceptions of stigma management. The focus is on the means that participants have employed in managing the stigma.

Figure 2. The probe kit for users' self-documentation.

For the moment, the user study is being complemented with theme interviews that are conducted with teenagers and young adults with physical disabilities. In the case of young people with disabilities, issues related to social identity and acceptance are emphasized. Along with Hocking [6, p. 6], Parette and Scherer [2, p. 219] claim, referring to Scherer's earlier study, that compared to older people, adolescents with disabilities are more concerned with their appearance and projected image.

The theme interviews focus on one of the key findings of the user study, namely, user innovations created by people with physical disabilities. The objective of the interviews is to study the means that young people with physical disabilities have employed to overcome the stigmatizing features of current assistive devices. Hence, one of the findings of the user study serves as a hypothesis that is explored deeper through interviews. As with the user study, the theme interviews are being analyzed from the viewpoints of stigma and its management. The data collection is in progress and, thus far, two theme interviews have been accomplished.

3. Means of Overcoming the Stigma Associated with Assistive Devices

Goffman [3, pp. 14, 57] distinguishes '*discreditable*' and '*discredited*' persons depending on how known about, evident, or perceivable their stigma is. However, he points out that even if stigma was immediately apparent, people often try to restrain its obtrusiveness. Their aim is to withdraw attention from the stigma and to sustain the spontaneity of social interaction by reducing tension. [3, p. 125] Current assistive devices and their stigmatizing features are often visible. In addition, they are prone to exaggerate or even misrepresent their users' disabilities.

The following sections present means of managing stigma in the context of assistive devices and introduce how users have pursued individuality and personality. The means are divided into three categories according to their way of dealing with stigmatizing features. The first category relates to disguising the stigmatizing features, the second to turning attention from the stigmatizing features to other features, and the third to transforming stigmatizing features into features that convey prestige or status. In creating the categories, Goffman's insights into the management of stigma are applied to the appropriate extent and complemented with some recent conceptions of managing stigma. In addition, illustrative examples are provided from the preliminary results of the ongoing data collection presented earlier.

3.1. Covering Tracks

According to Goffman [3, pp. 114-116], stigma symbols can be concealed or obliterated for instance through using disidentifiers or covers. In fact, there is a long history of concealing and covering in the design of assistive devices. According to Pullin [11, p. 5], discretion has been prioritized in the design of assistive devices, and it has been achieved through concealment. In the case of, for instance, hearing aids or prostheses, this 'realistic approach' has resulted in imitation of human skin that is often experienced as unpleasant and tacky [11, p. 8]. Bispo and Branco [13, p. 5] point out that all stigmatizing features cannot be covered.

However, concealing and covering can be realized with style as well. One of the participants of the user study, 'Ed', has paneled accessible thresholds with oak in order to make them blend into the overall oaken style of his home (Figure 3, left). Similarly, he has integrated the accessible space required for a wheelchair into the bathroom (Figure 3, right). This kind of 'fading out' [9, p. 320] or 'disguising' of stigmatizing features resembles designing more than concealing.

Figure 3. Ed's oaken thresholds (left) and integrated bathroom accessibility (right).

Sometimes the visibility and obtrusiveness of those qualities that are central to stigma are not only hidden, but even restricted. For instance, a person with a physical disability may refuse to perform certain physical functions in order not to reveal her disability. [3, pp. 126-127] Similarly, assistive devices are rejected if they focus attention on disability, exaggerate, or misrepresent it. One of the interviewees, 'Sally', refuses to wear special shoes, because they make other people think she has not only a physical disability, but a mental one as well. Furthermore, she feels some assistive devices are clearly designed for old people and she, as a twenty-something, does not want to be perceived as much older.

3.2. Creating Diversions

Stigmatizing features can be presented as signs of other features that are less stigmatizing [3, p. 117]. Stigma symbols may be worn voluntarily as well, or a 'disclosure etiquette', through which stigma can be revealed in a matter-of-fact way, can be employed [3, pp. 123-124].

In the case of current assistive devices, stigma is often visible in an unfavorable way and worn involuntarily. However, employing other eye-catching devices or accessories can turn attention from disability to other features. Another participant of the user study, 'Tina', stated that using a scooter as a substitute for a walker eases her interaction with the surrounding environment (Figure 4, left). The manifestly envious passers-by stop to admire her extraordinary vehicle without paying attention to her disability. Similarly, Sally has intentionally bought a

bright yellow kick bike. When interviewed, she described with content how children in particular, who are prone to stare at her disability, loudly admire her bike (Figure 4, right).
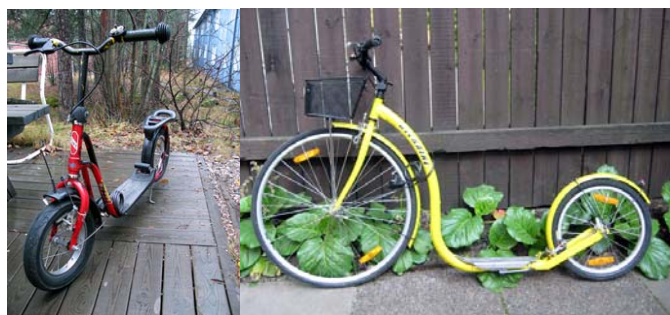

Figure 4. Tina's scooter (left) and Sally's kick bike (right) raise admiration.

3.3. Pride and Joy

Similarly to pieces of clothing, assistive devices both define and express their users' identities. In addition to masking and concealing, technology can be used for reshaping and presenting the self [4, p. 36]. Optimistically Green [4, p. 36] envisions that assistive devices can become more varied, bespoke, and personalized: *"[m]odes of dealing with disability thus become areas of choice – blank pages on which constructions of self and identity can be drawn."* At least, assistive devices can support 'coping efforts' that help to match social feedback and self-image [10, p. 17].

Pullin [11, p. 1] criticizes the current design of assistive devices for not projecting any image. He calls for fashion instead of discretion and challenges top designers to bring their perspectives to the field [11, 5]. Bispo and Branco [13, p. 5] also suggest promoting a new image of assistive devices; an image that can be controlled by users. Sally appears particularly design-conscious and wants her assistive devices to be of high quality and design. She is willing to pay extra for such devices, but they are difficult if not impossible to find. She is particularly concerned with having a stylish accessible kitchen. She has been dissatisfied with the existing accessible selection of products and decided to partially install bathroom fixtures in her kitchen (Figure 5). Bathroom cupboards are smaller and, therefore, within her reach. The combination of regular kitchen cupboards and smaller bathroom cupboards suit both her and her husband who does not have disabilities. Furthermore, Sally has spiced up her kitchen with design kitchenware where applicable. Thus, her kitchen has become both functional and an appealing center of attention in her home.

Figure 5. Sally's accessible design kitchen with bathroom cupboards.

According to Green [4, pp. 7-8], naming and defining is one attempt to change the public image of long-term conditions. She clarifies that long-term condition itself is a less stigmatizing term to cover various causes of chronic illness and disability. She lists, quoting Deborah Marks, positive naming and defiant self-naming. Positive naming emphasizes capacity and difference instead of limitations and deviance. Defiant self-naming is directed to the illness or disability itself and changing the stereotypes through the use of derogatory language. [4, pp. 7-8] An example of the latter is Mentalwear Ltd., a Finnish company that *"designs new and radical t-shirts which make a statement!"* The company aims at fighting prejudices related to, for instance, mental health in a humorous way (Figure 6). The company declares that its shirts are *"statements for tolerance"*. [18]

Figure 6. The Mentalwear shirts with a statement.

A slightly similar attitude can be found behind high-tech prostheses that turn disability into super-ability. The American award-winning athlete Aimee Mullins, who had both of her legs amputated below the knee as an infant, has set an astonishing example of this. She has numerous prosthetic legs of various designs, attributes, and heights. According to Mullins [19], a prosthetic limb is no longer a replacement of loss, but *"a symbol that the wearer has the power to create whatever it is that they want to create in that space"*. She continues that people with disabilities can become *"the architects of their own identities"*.

4. Personalized Assistive Devices

This paper has focused on the stigma associated with assistive devices. Through a literature review on stigma and preliminary empirical findings, the paper has attempted to describe stigma related to assistive devices and the means for challenging it. With the aim of filling the gap in the research on assistive devices, users' experiences with assistive devices and how users have tackled the stigmatizing features of devices have been presented. The research is still in progress; thus the following implications for design are speculative.

The paper has approached the research problem from the perspective of stigma management. It has provided a fresh angle on empowered people with disabilities who have taken up the challenges related to assistive devices. Therefore, this viewpoint is contrary to the medical model that considers people with disabilities as passive victims [20, p. 7]. Rather, it is in line with the minority group model according to which social, political, and built environments create disability [20, p. 8; 1, p. 1418].

Based on literature and preliminary empirical findings, assistive devices arouse associations and connotations users experience as unfavorable. Assistive devices tend to emphasize disability instead of ability and allow users only limited possibilities to express their identities. In the design of assistive devices, the diversity of users with disabilities has not been fully acknowledged, and more attention is often paid to devices' functionality than to

aesthetic qualities. As such, assistive devices strain social interaction and may become rejected. Hence, the aesthetic individuality of assistive devices appears essential from the viewpoint of users.

In line with the conceptions on stigma management, the empirical findings reveal that some people with physical disabilities have taken control of the situation and aspired to individuality through personalizing their assistive devices. In personalization, three means of overcoming the stigma associated with assistive devices have been identified: disguising stigmatizing features, turning attention from stigmatizing features to other features, and transforming stigmatizing features into features that convey prestige or status. However, from the viewpoint of design a new challenge emerges as current assistive devices enable personalization only up to a certain point.

How to allow for personalization in the design of assistive devices, then? One way of accomplishing this could be to leave design 'open' [21, p. 8]. Users could finish incomplete designs according to their individual preferences. This kind of 'tuning' is, after all, already possible with many mainstream products. However, the problem is that assistive devices are often not owned by their users, but borrowed from, for instance, hospitals and health centers. As such, they have to remain returnable and reusable.

Another way of allowing personalization is mass-customization (for mass-customization, see e.g., [22]), again an already established approach within mainstream products. For instance, an accessible platform could be complemented with various modules of which some fulfill users' lifestyle-related requirements [8, p. 166]. In addition, assistive devices could be assembled according to pre-selected, mass-produced parts of which some are related to aesthetic qualities. The advantage of this approach is that most assistive devices are already ergonomically customized according to individual body measurements. At simplest, adding identity-related qualities would only widen the existing selection. Both mass-customization and leaving design open or incomplete would tackle the stigma that arises from the unilateral design of assistive devices and, therefore, users' limited possibilities to express their identities.

In the case of assistive devices, stigma is connected to a physical object. The particular physical qualities of that object express a one-sided image of its user, which not only relates to but also affirms a given stereotype. Even though assistive devices have certain physical qualities, their stigma arises from the social interaction in which they are used. Their physical qualities are interpreted and associated based on their shared meanings. Through design, however, new meanings and associations can be created and the emergence of stigma intervened. Through personalization, a previously visible stigma symbol can be turned into a positive prestige symbol. A personalized assistive device can even make the above-mentioned disclosure etiquette unnecessary through redirecting or even avoiding the focus. In addition to having assistive devices that express their users' identities and even help to construct them, personalization empowers users.

This paper has focused only on design. Most assistive devices are assigned to users by societal and governmental institutions such as hospitals, health centers, or social services. The process involves multiple stakeholders and is both rigid and slow to change. Since stigma related to disability and stigma associated with the use of assistive devices are interrelated, they can, however, affect the decision processes [2, p. 222]. If assistive devices are

likely to be rejected, they ought to be in decision-makers' interest. In the design of new, innovative assistive devices, political decision processes and thus the availability of devices to users ought to be considered as well. In addition to the design of assistive devices, research on mechanisms that are involved in the allocation of devices is required in order to ensure the requisition of new kinds of devices. The emergence of new assistive devices does not guarantee users' access to them.

5. Acknowledgements

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Figure 1: Apuvälinekuvasto 2010, Liikkumisen apuvälineet sivut [Catalogue of Assistive Devices 2010, Pages for Assistive Devices for Locomotion] copyright Respecta Oy. Available at http://www.respecta.fi/uploads/p8d2ilnh18vg.pdf (accessed 12 March, 2010)

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