



Designing Out Stigma

a new approach to designing for human diversity

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Abstract

This paper sets out to present and discuss the “Designing Out Stigma” research project which focused on understanding stigma associated with products and on the repercussions of their use on the building of self-image.

This project set out from a theoretical framework whose main goal is the development of environments, products and services that promote social inclusion for everyone, no matter what their abilities. The project’s principles are as follows: people with disabilities have the right to participate socially on an equal opportunity basis, and it is society’s role, in general, and companies’, in particular, to ensure products and services exist that guarantee that participation; the existence of products that respond to the basic survival and mobility needs will not by itself guarantee the conditions required for effective participation in social life; products developed for elderly and people with disabilities must take into account the integration expectations of the people that use them; the stigma that is associated to disability cannot be solved by hiding it; hiding is based on the preconceived idea that a stigmatized person cannot be integrated in any way, thereby forever prolonging the stigma; the current ageing demographics in all societies across the globe calls for greater participation of the elderly and disabled people, not only as a basic citizenship right, but also as an economic and social sustainability need.

Introduction

It is an unmistakable fact that objects hold an important role in the construction of identity, acting as markers of a certain lifestyle. In this process of symbolic construction, to own a certain object entails more often than not a high social status. However, some objects can also carry with them stigma: owning them brings about a discrediting effect in the building of the owner’s identity.

For people with disabilities the use of objects employed to mitigate their impairment (such as a wheelchair or a walking aid) often acts as a symbol of stigma and reinforces prejudices towards the people who use them.

From Universal Design to Non-stigmatizing products

Contemporary democratic societies are built on the acknowledgment of the individual rights laid down in the Universal Declaration of Human Rights in 1948. Access to education, culture and leisure are considered a right of every human being. However, on a daily basis, persons with disabilities face social and physical barriers, such as attitudinal prejudice related to their disability, inaccessibility of buildings and other architectural infrastructure, as well as inaccessibility of products, information and communication tools.

The ageing of the world population leads us to believe that in 2050 34.5% of Europe's population will be over 60 years old or more, which means something like 230 million people [1], This ageing process will give rise to a steady increase in the percentage of disabled persons.

By acknowledging the role that products and environments play on social participation, Ronald Mace created in 1985 the concept of universal design [2] in order to describe a design approach that entails social justice and equity. It would be further developed as the design of products and environments that are usable by the largest number of people regardless of their age or ability [3].

A number of important authors [4] [5] [6] have shown, ever since, that the concept of equity in products and environments does not necessary lead to solutions designed to serve everyone. Today, this issue has been re-focused on the inclusiveness of these solutions, which is the core of the Inclusive Design concept.

Despite this theoretical evolution, the strategy of designing products that can be used by the largest number of people regardless of their ability continues to be championed, through the example of good practices as the main strategy for developing inclusive objects. At the heart of this strategy is the aim of eliminating the products' stigmatizing effect by dissociating them from the idea of disability - If everyone can use them, there is no stigma attached.

But we must bear in mind that this dissociating strategy is in fact a covering strategy, which leads to the perpetuation of stigma [7].

Despite the immediate efficiency that covering or hiding the disability can have to avoid stigma, it usually leads to a growing number of further concealments, which mean that the person will be under permanent stress. Covering cannot be seen as absolute either, because not everyone can conceal their disability.

From our perspective, the strategy of designing products that can be used by the largest number of people is only a partial solution for the stigma associated with objects designed for people with disabilities.

We must understand how the stigma arises from an object's usage, and find ways to compensate for it without the need to hide a person's disability. Such a solution is the only one which brings to bears the goal of real social integration, in which people can reveal their physical characteristics without stigma

Stigmatizing objects

If we are to understand the mechanisms that transform a particular object into a stigmatizing one, we must first analyze the nature of stigma itself as a social phenomenon. According to Goffman [8], we may speak of stigma when any person is considered diminished or inapt in relation to a full social acceptance due to some of her or his attributes.

In the case of people with disabilities the stigmatizing attributes are often emphasized by the use of objects that bring about the stereotypes associated to the lifestyle of its users. Thus, whether we are referring to the stigmatizing attribute itself – such as a physical impairment – or an associated object – say, a wheelchair – they both become symbols of the stigma, which, as one perceives them, trigger a specific set of preconceived ideas about the social role of that particular individual.

Often the presence of the stigmatizing object is enough to place a person in a certain category: using a wheelchair is enough for the user to be characterized as a motor impaired person, even if he isn't disabled at all.

However, assistive technology can be stigmatizing in one kind of environment and considered “normal” in another. This happens because our perception of stigma is based on stereotypes of what's “common” in a given situation.

Most of the assistive technology identified as stigmatizing by their users in social interaction situations were designed for hospital contexts and are adjusted to the formal codes of such environments. The stigmatizing effect of these products is linked to the growing integration of people with disabilities in different social contexts, such as work, education or leisure environments.

When people with disabilities became socially integrated, they start dealing directly with the products' meaning and develop problems, such as feelings of embarrassment or shame.

All objects have meaning and we are conscious of it: that is the reason why we are so careful when we buy clothes, cars, or furniture for our homes - we expect that the people with whom we have relationships create an image of ourselves that is compatible with our true identity. When using a stigmatizing object a person has no control whatsoever over their projected identity.

A person cannot choose to use a wheelchair, he or she must use it due to his or her physical condition. This assumption leads to the fact that assistive technology is designed with little attention to options that the user could choose between. Indeed, the object's characteristics seem to address, directly and unquestioningly, only the user's ergonomic needs.

This design process, mainly centered on ergonomic issues, empathizes the disability and hides the individual history and preferences of each person, the most important aspects of expressing identity.

By designing products with no cultural value, assistive technology leads to the situation where its usage becomes a symbol of fragility and disease, with negative repercussions on both emotional well-being and the full social integration of their users.

Designing out Stigma

When we examine the state of the art, we clearly find that the development of non-stigmatizing products will contribute to the social inclusion of persons with disabilities. But despite the fact that the stigmatizing dimension of products is often mentioned in existing studies, most of the time the reference is indirect.

This research aims to contribute further to the study of the state of the art and reveal the mechanisms that shape non-stigmatizing objects.

So far the research has developed a method for evaluating existing mobility assistive technology, in order to systematize guidelines that lead to a more consistent approach to the design of non-stigmatizing solutions.

Mobility assistive technology was chosen because the specific product's stigmatizing character cannot be hidden and leads to an explicit conflict between the obliterating mechanisms of the stigma and the existing prejudices.

The examples presented below are part of a survey that aimed to find existing non-stigmatizing mobility assistive technology, in order to understand and illustrate the principles of non-stigmatizing product development.



Figure 1 (left) - Oscar Pistorius is a South African Paralympics' runner. He's the first person with a disability to be allowed to compete in the regular Olympic Games. He runs with the aid of Cheetah Flex-Foot carbon fiber transtibial artificial limbs by Ossur.



Figure 2 (right) - Still from the documentary "Murderball", by Dana Adam Shapiro and Henry-Alex Rubin, a film about tough, highly competitive quadriplegic rugby players. The dirty, smashed look of the aluminum coating signals the falls and bumps throughout the matches, which then underline the physical endurance of the players.



Figure 3 (left) - The Speedster is an agile, smooth, flashy, and very fast electric wheelchair. This chair has a list of features never before available in a standard electric chair package, such as custom 21" wheels and high torque motors.



Figure 4 (right) - Child walker designed under a research project at the Pontifical Catholic University and the Centro de Vida Independente of Rio de Janeiro. Made from materials such as bamboo, painted wood and colorful plastic, this walker almost became a toy.



Figure 5 (left) - Still from the movie "Planet Terror" by Robert Rodriguez, showing us a feminine action hero who has a machinegun in place of her right leg. In the movie this amputee girl is a sensual, "perfect weapon".



Figure 6 (right) - The flames on Dr House's cane, a character from the well-known TV show produced by FOX Broadcasting Company, led towards the shattering of the stigmatized image of what a cane should look like.



Figure 7 (left) - The CadWeazle wheelchair, designed for beaches and off-road terrain, has four EuroTrax balloon wheels which prevent it from getting stuck in any soft ground.

Figure 8 (right) - Luca “Lazylegz” Patuelli was born with a congenital condition called arthrogryposis and expresses his passion for dance and movement through breaking. He uses the LiteStix titanium custom forearm crutches, which are extra strong and light.

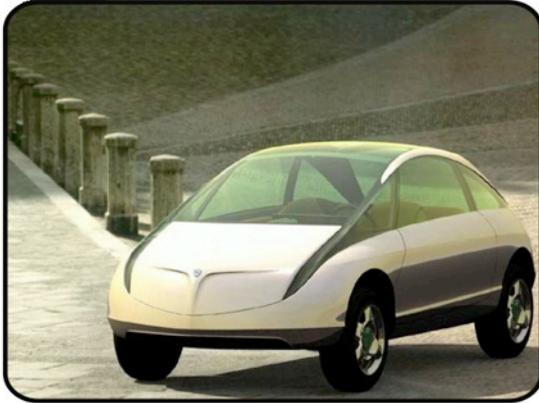


Figure 9 (left) - The Lancia Nea is a concept car developed to include the needs of older drivers that looks like a small sporty car.

Figure 10 (right) - Tank Chair is an off-road wheelchair that can go anywhere outdoors. It overcomes streams, mud, snow, sand, and gravel, allowing disabled persons to get back to nature, and it can also climb up and down stairs.

All the examples presented above have something in common - a break which brings prejudices into question. The development of non-stigmatizing solutions requires us to develop objects that show the person behind the disability, emphasizing their cultural preferences and lifestyle, and exposing the prejudice as false.

The shattering of the stigmatized image seems to be more powerful as it runs contrary to prejudices, so using symbols of physical performance, sexiness, aggressiveness, speed, or outdoor and radical activities, seems to be the most effective way of creating non-stigmatizing products.

Take figure 1 as an example, by associating Olympic level sports with the common image of disability, it contradicts prejudices relating to physical fragility and ineptitude which are usually associated with disabled people. This relationship between contradictory symbolic elements shakes the preconceived perception of disability, thus generating a rupture in which prejudices are questioned and in which a new social image can be found for people with disability.

In figure 2 we have a still from the documentary film Murderball, which depicts the recent evolution of wheelchair rugby. In this movie the positive result of the objects that associate disability to sports is quite evident, the dirty, smashed look of the aluminum coating signals the falls and bumps throughout the matches, which then underline the physical endurance of the players, questioning our prejudices towards them.

Unfortunately, membership of an elite group of professional sports athletes is something accessible only to a few. Most of ordinary disabled citizens are left out of this equation.

Nonetheless the possibility is there, as images 7 and 10 show two wheelchairs that use outdoor lifestyle solutions as a powerful contradictory symbol to the prejudice that it is not safe for disabled persons to go off-road.

In order to guarantee an effective symbolic transformation of disability, the proposed new symbolic imagery must create an “argument” with the automatic perception of prejudice. If a product creates an impression that doesn’t fit our expectations about how a disabled person should look, then it exposes our prejudice and gives us the chance to change our minds.

This “argument” works not only at the level of the general population, changing the social image of disability, but also, and most importantly, at the level of the disabled persons, changing their self image, proposing new activities and social engagements and paving the way for an attitude of greater self confidence.

Methodology

The stigma associated to the use of an object is a rather complex phenomenon. On the one hand, it stems from the cultural meaning given to an object, on the other hand, it is related to the emotional response from the user.

A research model was developed with the intent of evaluating the way in which the construction of meaning is made in objects developed specifically for people with disabilities.

This model aims to respond to a difficulty inherent to the very nature of the study: the identification of a stigma symbol is an unconscious phenomenon, where emotional reactions and interpretations deeply rooted in cultural codes converge.

Such a constraint leads to the need to employ three different data retrieval methods, linked to the three levels of emotional response proposed by Donald Norman [9] - visceral, behavioral and reflexive - each complementary to each other, when the interpretation of the participant’s reactions are concerned:

1. Registering the attention focus of the participant, by monitoring it via eye tracking technology, capturing the image points that are being observed, and which provides us access to a precognitive level.
2. Evaluating the emotional impact of the image through association with a predetermined range of emotions.
3. Open-ended questions about the meaning attributed to each image – which provide access to the participant’s reflexive process.

The crossing of the data collected from these three levels of reaction will allow us to relate the attribution of meaning and the emotional state of each participant to the most relevant details of each object in his or her perceptive process.

In order to allow us to compare the results from the set of images thus far assembled, we cover: mainstream objects, products that are seen as excellent examples of universal

design, assistive technology, real and fictionalized contexts in which the disability(ies) can be approached in a non-stigmatizing way, and objects developed for disabled people through new imagery' perspectives.

Future developments

From technology compatible with the national industrial context, a small series of healthcare products related to several levels of discrimination, from canes to walkers, prosthesis and wheelchairs will be developed, so as to evaluate the non-stigmatizing dimension in a real context by Portuguese users with disability.

To that end we are counting on the cooperation of the Professional Rehabilitation Centre of Gaia, which will assure the project's compliance with the Portuguese social context.

The prototypes are the third stage of expected results of this research project, which in conjunction with the evaluation tool and the non-stigmatizing guidelines, are the foundations for future applied research projects on object-associated stigma.

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