PERSONALISED ASSISTIVE PRODUCTS

Managing Stigma and Expressing the Self

Susanne Jacobson

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pressing identity.

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1 Introduction

"Well, they stand out a mile, yelling out that this is a special assistive device. So, or well now that I'm an adult, it's pretty ok, but when I was a teen (.) My God! I didn't want anything like that. Because it was like <u>ugh</u> and then sort of the <u>special assistive device</u>, even the word sounds so hideous. I remember back then I had a crazy threshold, and maybe I still have it today, so that I don't want them. Like all that and then everything surrounding them, the image and the design and everything, so it's all sort of (.) <u>old</u> and, well I don't know, but mainly for old people and the like[.]" (Sally, one of the interviewed users, about what makes ready-made assistive products ugly. Emphases in the original.)

Many consumer products, such as kitchenware and tools, could be described as assistive in the sense that they are designed to enable users to perform various tasks and to reach goals.[1] Some products, like sports equipment, not only assist, but also enhance users' performance. Some are more generally body-related, while others, for example jewellery, may be directly attached to the body. Products' assistive capabilities are included in the definition of user experience in the standard for human-centred design for interactive systems (Finnish Standards Association SFS 2010, 3, 7), which is widely referred to also in industrial and strategic design. Depending on the function a product has for its user, all technology can even be rehabilitating (Anderberg 2005, unnumbered). In an ideal situation, being assistive could be seen as a built-in feature of all consumer products.

Although being assistive may be common to all products, some products are specifically categorised as assistive. An assistive product can be defined as "any product, instrument, equipment or technology adapted or specially designed for improving the functioning of a disabled person" (WHO 2001a).[2] It can be located inside, outside or distant from the body (Stineman 1998, 51) and be ready-made, modified or customised (Scherer 1996, 36)[3], like many other products. In accessibility technology research, Ladner (2010, 25) has suggested the term assistive redundant, because of the overall assistive role of technology, and proposed the term accessible instead.

What seems to distinguish assistive products from other products is the definition of their user: a person with disability. The user of assistive products is defined as a disabled or seri-

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1 In this research, products refer to industrially designed tangible objects, not, for example, services or user interfaces in ICT.

2 The definition used by WHO is a narrowed definition of the ISO 9999 classification of technical aids.

3 Scherer's description of assistive products derives from the American Technology-Related Assistance of Individuals with Disabilities Act of 1988.

ously disabled person who needs and uses assistive products (A Quality Recommendation for Assistive Device Services 2003, 30). What is characteristic to the definitions of assistive products is that many of them view disability as a medical condition, as a functional deficiency that needs to be compensated by extrinsic objects. For example, an assistive product is seen as repairing insufficiency caused by a medically diagnosed disease or disability (ibid., 29), rehabilitating disability and being assigned on the basis of medical grounds (Töytäri 2007, 11).[4] Assistive products seem to be "'fixing' people by diminishing disabilities" (Larsson et al. 2005, 2).

Ladner (2010, 26) points out that the mere adjective assistive refers to the physical function of a product to assist and to a user who needs that assistance. He claims that the word implies that a user is in need of something, dependent and not fully capable as a human being. From the viewpoint of users, a definition that highlights assistive functions can be very problematic. Because the notion of function can be considered normative (Searle 2007, 8), the sole product function to assist, which focuses on disability, can affirm the distinction and differences between disabled and non-disabled bodies and what is considered "normal". Product functions and physical properties, which enable users to carry out tasks independently, seem to be one of the key issues that cause dissatisfaction among users (see e.g., Brooks 1991, 1418; Hirsch et al. 2000, 77; Scherer 1996, 95). They can underline disability and override other parts of identity. Such one-sidedness can lead to stereotyping and stigmatisation.

One way to widen the scope could be to consider function not only referring to an individual, but also to the environ-

ment (see e.g., Anderberg 2005, unnumbered; DePoy & Gilson 2010a, unnumbered; WHO 2001b). Such a view can widen the conception of assistive products. Assistive products can be seen as standing in "the intersection of body and environment" (Brooks 1998, 10), and in an ideal situation, embodying qualities that fit both the properties of their users and the environment they are used in. The products can also be approached from the viewpoint of their actual purposes of use, and the activities and environments they make accessible (see e.g., Scherer 1996, 38–42) rather than considering separate assistive properties, which compensate bodily functions. Consequently, products that assist in tasks like hearing, seeing, communicating, moving, dwelling, playing, hobbies, working or studying (Salminen 2010a) can be identified.[5] When grouped like this, also accessible space can be conceived of as assistive product.

Whereas the focus on limited physical functions easily underlines users' disability, focusing on activities highlights users' ability. The activity focus can distance from special group thinking and stress that all people share similar, even identical, activities. Moreover, focusing on activities enables to view product use more holistically and acknowledge that some mainstream products can have potential for assistive purposes of use and some inclusive, even assistive, products may be useful for users who do not have disability.

Who are the current users of assistive products and what is the number of assistive products used? Statistics about the total amount of people with disability and the use of assistive products in Finland are inadequate. Nevertheless, it is estimated that 10% of the Finnish population are people with disability (Salminen 2010c, 13), which was 542,668 people at the end of

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4 In Finland, assistive products and services are part of medical rehabilitation (Töytäri 2007, 11). Local authorities, such as municipalities, are generally responsible for arranging medical rehabilitation (Health Care Act 1326/2010). For people in need of medical rehabilitation, assistive products that are assigned through medical rehabilitation are free of charge (Act on Client Fees in Social Welfare and Health Care 734/1992).

5 Assistive products can be grouped according to their level of technology as well. High-tech products are often powered by a computer and include electronic components, whereas low-tech products have mechanical operations. No-tech products do not have mechanical, electrical or computerised components. (Scherer 1996, 37.) In this research, the level of technology is of interest only in so far as it influences the product appearance and the associations product use creates.

2012 (Statistics Finland 2012c). The number of assistive products handed out by the municipality or joint municipal board to be used in medical rehabilitation was 399,584 in 2009, 415,678 in 2010, and 340,478 in 2011 (Statistics Finland 2012a).[6] When it comes to the accessible domestic environment, 9,082 clients had received reimbursement[7] for housing alterations or housing facilities and devices in 2009, 9,580 in 2010, and 9,655 in 2011 (ibid., 2012b). The statistics only show alterations that are funded by the municipality. People who have purchased assistive products or funded housing alterations themselves have not been included. Furthermore, due to accessibility regulations, newly built apartments are likely to require fewer alterations. The actual user group of assistive products or accessible domestic environment can be greater than the statistics show.

Based on the aforementioned estimates, the number of people with physical disability may appear small in comparison with the entire population of Finland. Compared with other consumer products, the number of assistive products in use may not seem large either. Both numbers are, however, likely to increase in the near future due to the demographic trend of population ageing. The number of potential users of assistive products is probably larger than the statistics reveal also because not all users who might occasionally benefit from assistive products are shown. This may be because the statistics do not recognise that disability is context-bound. Disability depends on the temporal-spatial context, which means that depending on time and space, everyone can experience disability (e.g., Freund 2001, 693; WHO 2001b; Papanek 1984, 68). Disability is contextual due to changing environmental factors and social contexts (Pullin 2009, 91) and situational in the sense that anyone can be disabled by such factors as varying lighting and noise conditions (Hannukainen & Hölttä-Otto 2006, 2). Even if a person had

congenital disability, its degree and the need for assistive products might vary. Regarding long-term illnesses, the diversity and level of disability may fluctuate considerably (Green 2009, 8).

The contextuality of disability means that also the need for assistive products is contextual. Current ready-made assistive products may not be adaptable enough to users' individual requirements. They do not necessarily take into account the fluctuation and variation of users' disability levels or the periods of time when users may not need any assistance. Instead, assistive products are often static and visible. They are mostly utilised "on-off", which means that they are employed and implemented either as such or not at all. Because of this, some people who could occasionally benefit from assistive products may not use them. The contextuality of disability affects not only the need for assistive products, but also how people with disability view themselves and are viewed by other people.

In the 1990s, when a new kind of a user-centred approach emerged in industrial and strategic design (Koskinen et al. 2011, 18), which eventually took into account various dimensions of user experience, also people involved in rehabilitation had awakened to the variety of consequences that using assistive products could create. Brooks (1991, 1417) pointed out that users' views on assistive products, and the social and psychological consequences of using them, had not been sufficiently examined, even though environments in general were studied also from the viewpoint of people with physical disability. Scherer (1996) studied how the emergence of assistive products affects users' lives and brought out some paradoxical implications: assistive products can simultaneously be experienced as widening and restricting use opportunities depending on whether they are evaluated from the viewpoint of their physical, emotional or social implications. Stineman (1998, 67–70) identified the image assistive products convey, and whether users experience that assistive product use changes the way other people and the society perceive and relate to them, as consequences that should be measured.

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6 The number includes assistive products for both long- and short-term use as well as products signed over to clients. The same assistive product can be handed out several times during a year.

7 Pursuant to the Services and Assistance for the Disabled Act 380/1987.

At the turn of the millennium, Pape et al. (2002, 17–18), who had studied individual meanings assigned to assistive products, presented that assistive products can help to increase participation and sense of control over disability. However, the authors concluded that the successful integration of assistive products also requires exploring meanings users assign to the products, users' expectations and anticipated social costs, and awareness of disability as only one aspect of oneself. A few years later, Hocking (2004) made an extensive study on the relationship between objects and identity in occupational therapy, but her focus was on historical and philosophical issues, not design. However, in her later study, she (Hocking 2008, unnumbered) had a more practical view, presenting that the meanings assistive products hold have been overlooked in efforts to match users and products.

Thus, the complexity of using assistive products is not unknown in the field of rehabilitation. In addition to research findings, frameworks for selecting assistive products (see e.g., Scherer et al. 2007) and for modelling, predicting and evaluating consequences of using assistive products (see e.g., Fuhrer et al. 2003; Lenker & Paquet 2003 & 2004; Jutai & Day 2002) have been developed. Some of them are characterised as user-centred (De Jonge et al. 2007). Also frameworks for user-centred assistive product design exist (see e.g., Poulson & Richardson 1998). Scherer (2002) has even suggested that a shift from people to person has happened during the 21st century in rehabilitation. Regardless of the developed models and frameworks, the adopted perspective could, nevertheless, turn out too one-sided. Pfeiffer (2002a, 6) has even made a harsh claim that research carried out in public health and rehabilitation is based on stereotypical assumptions about experiences of and living with disability and questioned its worth.

There were actually user-centred visions for the design of assistive products already in the 1980s: In the field of design, Papanek (1984, 134) called for engaging people with disability in the design of the products they use. Almost at the same time in disability studies, Zola (1982, unnumbered) encouraged us-

ers to throw themselves into designing and advised professional designers to allow for users' creativity and initiative. For some reason these views from two different fields did not merge and become established in the design of assistive products contrary to the development trends in the design of many mainstream products.

Design approaches such as Design for All[8], Inclusive Design[9] and Universal Design[10], which have been introduced to promote equality between people with and without disability, can, however, be considered one attempt to foster the application of user-centred practices in the design of assistive products. The inclusive design approaches aim at extending the reach of mainstream products for people without disability and for people with minimal, mild and even severe difficulties without losing commercial viability or mainstream design.[11] Adding more assistive features to mainstream products is seen as a way to include more users with disability in the users of mainstream products. (Hosking et al. 2010, 499.) Building upon the inclu-

8 Design for All (DfA), which predominates in the Nordic countries, means socially responsible and sustainable design. It aims at strategies that advance usability, attainability and accessibility of products, environments and services to a wide range of users. DfA relates closely to user-centredness and usability and reminds designers of the diversity of users and of designers' ethical responsibilities. (The Finnish Design for All network.)

9 Inclusive Design originates from Great Britain and the British Standards Institute defines it as "[t]he design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible … without the need for special adaptation or specialised design" (Inclusive Design Toolkit).

10 Universal Design is an American counterpart to DfA and Inclusive Design. It aims at products and environments that are accessible to as wide a range of users as possible. It is both a marketing tool and a design concept. At best, universal design results in solutions that minimise stigma and embarrassment. Universal design has seven principles, which aim at design that is useful, comfortable, accommodating, tolerant for errors, appropriate in sizing as well as easily understandable, communicative and marketable to users with diverse abilities and preferences. (The Center for Universal Design; Clarkson et al. 2003, 12–13, 319.)

11 Design for All, Inclusive Design and Universal Design have historical differences, but they share similar objectives of inclusiveness and are, therefore, referred to as "the inclusive design approaches" in this research.

sive design approaches, Pullin (2009, 93) introduces the term resonant design for design that meets requirements that are similar to people with and without disability. According to him, resonant design acknowledges the shared need, resonance, between people with and without disability and promotes design that is not just for either user group.

The aims of the inclusive design approaches make sense. Modifications that enhance functioning in the environment are advantageous for a wide range of people (e.g., Freund 2001, 693). Meeting the design requirements set by people with disability are particularly useful for other users when they are in extreme situations and can result in the best possible usability of products (Hannukainen & Hölttä-Otto 2006, 3, 20). There is also a point in attempting to change the image of assistive products through widening their user group. A product appearance that appeals to both people with and without disability could not only enable people with disability to identify with people without disability, but also the other way around: people without disability could be able to identify with the users of assistive products (Scherer 1996, 31). Broadening the appeal and the user group could eventually make assistive products also less expensive and less stigmatising (Hirsch et al. 2000, 78).

One way to realise this could be to include assistive products in a wider product category of wellbeing products as Larsson et al. (2005) propose. The authors (ibid., 1–2) claim that, currently, less attention is paid to assistive products' quality-of-life- and wellbeing-related features, even if assistive products' improvement of ability does not necessarily increase them.[12] Jokiniemi (2007) offers a concrete example of an assistive product that pays attention to the needs of both people with and without disability: audible traffic signals that are based on nightingale sounds. After studying the signals, Jokiniemi (ibid., 58–76)

suggests that even though they are assistive, they are experienced as less disturbing than the traditional audible traffic signals due their naturalistic sounds. As nature-based the nightingale signals are discreet and merge into the surrounding environment. What makes the idea particularly interesting from the viewpoint of potentially stigmatising product functions is that the signals can afford an assistive utility function to people with visual impairment and mostly an aesthetic one to others.

Regardless of their benefits and potential, the inclusive approaches have received criticism because of their risk of homogenising and ignoring individual variation and real life incompatibility (see e.g., Shakespeare 2006, 46–47). Some of that criticism also manifests itself in the findings of this research. Moreover, most assistive products are not designed to be inclusive, nor resonant, although there are product exceptions that attract both users with and without disability.[13] Inclusive design does not automatically include assistive products, which are still often thought to represent a more specialised design that solely focuses on physical requirements extending beyond mainstream and inclusive needs. Their user group is often considered marginal, which also maintains the category of assistive products as marginal.

Earlier research shows that the users of assistive products seem, nevertheless, to appreciate mainstream features: The most used assistive products are characterised as the same as or similar to products used by people who do not have disability, and they possess universal qualities that are typical of various consumer products. They are lightweight, portable, easy to use, compatible with other products, cost-effective, safe, reliable, durable and attractive. (Scherer 1996, 130.) Users value assistive products that enable equal access, because that allows them to do things as everyone else (Shinohara & Wobbrock 2011, 708). In that sense, assistive products can also support "normality" (see also Brooks

12 A similar dilemma has been detected in the design of patient clothing: the care environment should make people feel better and more able to recover, but it can be experienced as upsetting due to shabby, worn-out, ill-fitting clothing that lacks decency (Topo & Iltanen-Tähkävuori 2010, 1689).

13 For example, various kitchen utensils by Ergonomi Design Gruppen (now Veryday) and Good Grips® by OXO.

1991, 1422), but the way current assistive products appear is likely to influence the visibility of disability and how disability is viewed.

Issues such as social and ethical challenges (see e.g., Green 2009; Oishi et al. 2010; Rauhala 2007), cultural differences (see e.g., Ripat & Woodgate 2011), aesthetics and individuality (see e.g., Ravneberg 2009), and even assistive products' influence on self-concept and identity (see e.g., Hocking 2008) have recently been addressed, but some problems faced in the design of assistive products may, nevertheless, stem from erroneous assumptions or insufficient knowledge of users' preferences.

In the current practices around assistive products, user-centredness seems to be understood narrowly. It appears to concentrate on rehabilitation and phases, which follow the actual design such as the provision and prescription of assistive products. Design is rarely considered in tandem with these phases. If design is included, the focus appears to be on functional properties that emphasise accessibility and assistive purposes of use, which are contrasted to appearance (see e.g., Pippin & Fernie 1997, 101). Whereas most products also have other functions in addition to assistive ones, assistive products tend to be solely assistive. Furthermore, usability is often considered equal to user experience, even if it is only one part of it. Modification, customisation and personalisation that are typical of many consumer products, mostly concern ergonomics, particularly among assistive products for mobility.[14] Nevertheless, the products could also support users' overall ability, not only locomotion (Töytäri et al. 2003, 129).

One reason for these shortcomings might be that there has not been enough information on users' experiences of using assistive products in social contexts, in order to realise the need for product qualities of other kind. Users' independence may have

been the only objective.[15] The associations that assistive products create or the products' semantic qualities are seldom addressed. Parette and Scherer (2004, 217), who have studied the stigma of using assistive products, have remarked that research on the relationship between stigma and the use of assistive products is relatively new considering that the stigma of disability has been acknowledged for long. There is research on the stigma caused by assistive products and its relation to product abandonment (see e.g., Hocking 1999; Pape et al. 2002; Phillips & Zhao 1993), but as Gaffney (2010, 68) points out in her more recent exploratory paper, there still is little research on the reasons for and the consequences of the stigma caused by the use of assistive products. In use, assistive products can still strengthen and equalise their users physically, but weaken them socially.

This is not to say that being assistive or accessible would not be a hoped-for product feature. On the contrary, enabling users to function and independently carry out activities is a fundamental design objective. It does not make sense to design an assistive product that would not increase its user's ability to take part in her daily activities and those of her community. But, an assistive product does not perform well, if its user does not accept and use it, because of its appearance that is more likely to socially segregate than integrate. Solely fulfilling assistive functions is not enough. Also other functions are required.

Also product appearance can increase accessibility by helping a user integrate with the surroundings. Rather than ruling each other out, assistive and appearance-related product properties are complementary and could be taken equally into account in designing. Particular attention could be paid to considering how products are integrated into users' lives (Hirsch et al. 2000,

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14 Similarly in the design of accessible interactive systems, personalisation often only refers to the best possible usability of interfaces (see e.g., Burns et al. 2008; Cremers & Neerincx 2004; Petrie & Weber 2004).

15 In the disability context, independence can refer to a person's ability to perform practical tasks without direct help or to make decisions and be in charge of her life (Helgøy et al. 2003, 473). Because the focus of this research is in assistive products, which can be considered "tools for enhancing the independent functioning" of people with disability (Scherer 1996, 36), the emphasis is on the former. However, in this research, well-designed assistive products are also seen as a way of increasing the latter.

78). Assistive products could invoke positive connotations that enable users to "fit in", and to maintain roles (Pape et al. 2002, 7, 13, 17) and quality of life (Jensen 2009, 594). What needs to be remembered, however, is that a product's attractiveness is not solely influenced by a product looking good, but also by whether it appears functional and what it communicates about its user (Crilly et al. 2004, 576). Hussain (2011, 1437), who has studied Cambodian children's views on prosthetic legs, emphasises the meaning of cultural and social beliefs and attitudes, because those also affect the aesthetic experience of using assistive products.

At best, assistive product properties have been considered the very first premise to start from. Scherer (1996, 159–160) has presented a usability hierarchy similar to Maslow's hierarchy of needs, where lower-level criteria should be met before upper-level criteria. In Scherer's hierarchy, functional needs form the lowest level and are followed by needs that relate to product appeal, usability and performance. Even though the hierarchy was presented almost two decades ago, most current ready-made assistive products manage to meet only the lower-level criteria, whereas criteria like product appeal remain unmet. Yet, product appeal contributes to users' identification with their surroundings and can increase self-esteem and self-actualisation. It can be as important as physical accessibility in enhancing users' independence and participation. Perhaps the multiple criteria could rather be considered horizontal than hierarchical (see also Correia de Barros 2012, 7). What also creates pressure for viewing the product use more holistically is that disability in the context of use is complex. Assistive products are often employed in complicated situations. In addition to physical disability, the use situations may involve other issues that influence identity such as illness, ageing and unemployment.

People involved in the design of assistive products may not be aware of how users experience assistive product use, what users actually prefer, and for what kinds of purposes assistive products are used. Or, users and designers can have diverse interpretations of the experiences of using assistive products (Brooks 1991, 1419). Research on assistive products tends to be quantitative. The focus on measurable qualities and averages can lead towards losing individual variation that, however, could inspire design. Based on a case study of involving users in assistive product development, from an empirical ethics viewpoint, Rauhala's (2007, 99) findings reveal that an image may still prevail that people with disability would be more interested in assistive products' functional rather than aesthetic qualities. She suggests that such an image may have led to a technical problem solving focus where neither designers nor users had been properly involved in the case she studied. She (ibid., 22) suspects that, generally, there is not enough knowledge to meet users' preferences in the development of assistive products.

Even if issues that are relevant to design were addressed, the information may not be applied or directly applicable. The experts currently engaged in the design process may work too independently, in which case the information does not reach everyone involved. Or, some form of expertise may be missing. Another factor, which could hinder the application of design-related information, is that users are seldom systematically involved in the assistive product design process. Users may either be engaged too late when the design is already decided or not at all. They are rarely considered experts who could actively contribute to the design. Instead, users' lives appear "objects of intervention". Rather than appreciating users' autonomous agency (cf. Keinonen 2010)[16], the design of assistive products appears to emphasise the protection of users, which leaves them with few possibilities to influence. The role of a user is often seen as subordinate to that of a designer (cf. Jääskö & Keinonen 2006, 108–115). Nevertheless, the most potential way to realise that assistive products enhance users' self-esteem and quality of

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16 Keinonen has assessed the practices of user-centred design from the dimensions of protecting users from harm and appreciating users' autonomous agency.

life could perhaps be to engage users in various phases of the design process (Scherer 1996, 149). Without user-involvement, the information may not become concretised in assistive products, even if their developers had the knowledge.

Even though earlier research pinpoints several development needs for assistive products, it seems to rarely examine the problematics from the viewpoint of professional design and potential design solutions.[17] Research reports and design guidelines dealing with assistive products tend to be from the fields of rehabilitation and occupational therapy. In addition, the topic is touched upon in academic papers that represent, for example, psychology, social psychology, sociology, medicine and engineering. Professional designers are rarely mentioned, let alone involved. The specialists most often referred to are occupational and other therapists who adjust assistive products and medical personnel who prescribe them. Rehabilitation engineers and technicians are mentioned as people who develop and build assistive products. Various experts are included. Even though professional designers rarely seem to be involved, the making of assistive products is often referred to as *designing*.

In design research, which could offer the needed design viewpoint, assistive products are an emerging object of study compared to the aforementioned fields. Nevertheless, design researchers who at present study assistive products seem to be exploring the use of assistive products from diverse and fresh viewpoints such as assistive products' image and visual appearance (Bispo & Branco 2008 & 2009; Dankl 2009; Pullin 2007), assistive products' semantics (Rønneberg Næss & Øritsland 2005), the meaning of culture in product use (Hussain 2011), engaging users in design (De Couvreur et al. 2009; De Couvreur & Goossens 2010 & 2011), users' inventiveness (Correia de Barros et al. 2009 & 2010)[18], and the use of assistive products

in social interaction (Shinohara & Wobbrock 2011).

Recently, also the stigma of using assistive products and how designers could influence it have begun to attract design researchers' attention (see e.g., Bispo & Branco 2008 & 2009; Vaes et al. 2012).[19] In Sweden, Olander (2011) has studied how young adult users with disability emotionally experience their assistive products and cope in a situation where they are forced to use involuntarily chosen products. She (ibid., 89, Article 2) has found that users either endure and accept the situation, avoid using the products, or come up with their own solutions such as redesigning the product's appearance or function. She (ibid., 105) concludes that designers and engineers should approach assistive product design not only from the utility perspective, but also from the viewpoint of users' desired identities. In her recent study on combining design and rehabilitation engineering, Correia de Barros (2012, 283) has brought up the need to study the features of assistive products which trigger stigma.

Some design researchers have also expressed provocative proposals in terms of product design. It has traditionally been suggested that assistive products could be "non-visible" (e.g., Scherer 1996, 131) and prosthetics, for example, more "natural-looking" resembling real limbs instead of sticking out as different and artificial (Hussain 2011, 1432–1433)[20]. However, Pullin (2007) has encouraged the design of assistive products to learn from fashion design. He (ibid., 1–3) proposes that instead of imitating the natural and making invisible products that fail in their invisibility, assistive products could project an image. He describes how this has already happened with spectacles that have become fashionable eyewear that frame the most personal part of the body. Similarly, orthoses like wrist splints could be designed to resemble pieces of jewellery, not medical equipment (Underwood 2005). It has even been suggested that the design

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17 In this research, professional design refers to design activity that is practised by professional designers who have received education in industrial or spatial and furniture design.
18 See also Jacobson & Pirinen 2007a & 2007b.

19 See also Jacobson 2010.
20 Hussain focuses on designing assistive products for people with disability in less-developed countries and proposes that the preferences for natural-looking prostheses might derive from cultural differences in viewing disability.

of assistive products could take advantage of how bling products fulfil a desired self-image and evoke feelings of pride (Olander 2011, 105). What is important from the user viewpoint is that attractive products that can be viewed as fashion accessories could be accepted more easily (Resnik et al. 2009, 84).

This doctoral dissertation introduces a case study of young adults' experiences of ready-made and personalised assistive products. Through literature on products' role in identification, a questionnaire on assistive device satisfaction, an Internet database about users' inventive product modifications, interviews with professionals who work with users, and interviews with users who have personalised their assistive products, the phenomenon of personalising assistive products is explored as a means of managing the assumed stigma caused by using assistive products. The findings are organised into a typology where users' experiences of both ready-made and personalised assistive products are grouped into types and subtypes, which describe the various functions assistive products can have. The stigma associated with ready-made assistive products is broken down into structured descriptive categories that provide further information on how users experience the stigma. Users' experiences of personalised assistive products introduce how personalisation can change the experienced and perceived stigma of assistive products into self-constructive and self-expressive positive symbols and, consequently, change the product image. Furthermore, the findings reveal how personalisation adds aesthetic, social and identity functions to products that have previously been considered having primarily assistive ones. The descriptions of the types and subtypes can be seen as strategic design information in the development and evaluation of assistive and inclusive products.

The dissertation is divided into five chapters. This first introductory chapter has so far led to the problematics of assistive products and offered an overview of some of the current approaches. The introductory chapter concludes with research objectives and questions.

The second chapter presents a theoretical framework and focuses on the role of products in identification. The social and material construction of the self, similarity and difference between people, and the emergence of roles, types and stereotypes are unfolded. The meaning of products in constructing and expressing the self is explored. Perceiving and interpreting products, various product functions and managing impression with products are discussed. Lastly, products that stigmatise and stereotype are explored. Light is shed on the nature and emergence of stigma, the assumed stigma of using assistive products, and people's techniques in managing stigma.

The third chapter introduces the adopted perspective, which views people with disability as inventive individuals in relation to their assistive products, and the case study approach, the collected empirical data and its analysis.

The outcome of the exploration of literature and the analysis of the empirical data is presented in chapter four in the form of a typology. The typology is based on users' experiences of ready-made and personalised assistive products and it is constructed around stigma, managing stigma and expressing the self.

In the concluding chapter five, discussion and key conclusions, the contribution and implications of the research and suggestions for further research are presented.

1.2 Objectives and Research Questions

The interest of this research is to study how young adults with physical disability experience the design of assistive products, whether assistive devices or accessible space, in their daily use. In assistive devices, the focus is on items that are visible in social interaction, that is, items that are employed in view. In accessible space, the focus is on home due to its importance in identity construction and semi-public nature in welcoming guests. The research aims at providing new knowledge particularly on the social and psychological consequences of using assistive products and, hence, filling the gap identified in previous research.

In users' experiences of assistive products, the focus is on

the assumed stigma of using the products and how users manage that. A particular interest is taken in the personalisation of assistive products. Instead of mere ergonomic adjustment, personalisation here refers to customising a product in a way that takes into account users' identity-related requirements and preferences. Personalisation is explored as a means of managing stigma. This preliminary hypothesis builds on the findings of an earlier user study I participated in, where some inventive people with disability had modified their domestic environment in order to have more suitable accessible and assistive solutions (see Chapters 3.1–3.2).[21] In this research, the interest is taken further in how young adults with physical disability have personalised their assistive products in order to make them express their identities and connote things beyond disability.

In personalised products, the focus is on qualities that can reduce the stigma associated with current ready-made assistive products. Ambiguous qualities that hide or surpass the assistive, presumedly stigmatising, appearance and associate the products with another product category than the original are considered particularly important. Furthermore, the research concerns mainstream products that are applied to assistive purposes of use, which is a form of product use found in the earlier user study, and how the interplay between product categories can affect the stigma of using assistive products. In that sense, the research touches upon inclusive design, but the focus is on assistive products as defined in the following paragraphs.

The research questions are:

- How do young adults with physical disability experience the design of assistive products in use?
- What is the stigma associated with these products?
- How do young adults with physical disability manage the stigma?

Young adulthood here refers to less than 40 years of age.[22] According to statistics on recipients and amounts of disability benefits, by the end of the year 2012 there were 7,277 such people[23], who had received disability benefits[24], 16–39 years of age in Finland (Kela 2012), which is circa 0.14% of the total population. The amount is likely to be larger, because not all young adults who use assistive products qualify or apply for the benefits and, therefore, show in the statistics.

Although there is a strong interest in elderly-related issues in the Western and Nordic countries, and even if some elderly people and children have similar disabilities and requirements for assistive products as younger people, only young adults with physical disability have been chosen for this research. Olander (2011, 1–2), who has also studied young adults with disability, presumes that young people constantly work with questions that relate to who they want to be or how they would like to be perceived. She supposes that using assistive products in such a situation can make the process of finding identity more vulnerable.

From the viewpoint of this research, such vulnerability is likely to place more emphasis on assistive products' appearance and identity-related qualities. Even though young people may be more preoccupied with finding their identities in general, the present-day young people with disability could be more self-confident in respect of disability than older generations who might still bear the stigma of disability. They could be more prone to express their identity through actions like personalising assistive products. It is, nevertheless, acknowledged that also elderly people and children with physical disability are potential users who benefit from individual assistive products. For chil-

21 Jacobson & Pirinen 2007a & 2007b. As its conclusions, the user study proposed pleasure, personalisation and empowerment as factors to be paid attention to in the design of individual accessible environments.

22 Many definitions of age exist, depending on whether the focus is on, for example, chronological or subjective age. The definition here, of young adulthood being less than 40 years of age, is based on views that consider middle age or middle adulthood to begin when a person is in her forties, being preceded by early adulthood (see e.g., Levinson cited in Marin 2001, 237).
23 Visual, auditory and intellectual disabilities excluded.
24 Disability allowance or care allowance for pensioners.

dren with disability, emotional and aesthetic needs are important because of the developing self-image (Hussain 2011, 1427). Thus, the findings of this research are likely to be useful for a wider group of people than the one studied here.

Similarly to Brooks (1991), for example, this research applies the term a *person with disability* instead of the term a *disabled person*. A person with disability is seen as implying that a person's identity consists of various qualities, whereas a disabled person suggests that there is only one, a disabled, identity. A view, according to which an entire person is seen as dysfunctional (ibid., 1417), is in conflict with the standpoint of this research. By physical disability, disability that affects a person's motor skills is meant here. Other disabilities like intellectual disability and hearing and visual impairments have been excluded to retain the focus. A person with physical disability is considered particularly prone to stigmatising experiences because of the use of more visible and obtrusive assistive products for mobility.

The terms assistive device and assistive technology are common in the assistive product literature. In this research, they are not, however, used as narrower and technology-oriented. Also the term assistive solution has been considered, but not used as too ambiguous. Instead, the term *assistive product* is chosen. It is used in order to emphasise that, as products, assistive products have as diverse purposes of use as any products. In addition, the term product stresses a design viewpoint.

The research focuses on assistive products that are designed to assist in locomotion and dexterity in tasks like moving, performing daily chores or dwelling. Other products like hearing, visual, and communication aids are excluded, because they are seen as less obtrusive due to their smaller size, in some cases hidden position, and their relation to possibly less visible bodily functions than mobility. Moreover, some visual and communication aids like spectacles and mobile phones can be considered mainstream and not bearing the potential stigma of special equipment. Since the interest of the research lies in the assumed stigma of using assistive products, the focus is directed at visible products that are employed in social contexts.

In this research, also accessible space is included. Accessible space means, among other things, wide enough door openings, low enough thresholds, various add-ons like ramps, handrails, grips, and stair or ceiling lifters, fixtures such as an electrically adjusted kitchen, and stand-alone products like a shower or a standing chair. Also materials, colours, patterns, contrasts and lighting can increase accessibility.

From the viewpoint of accessible space, a merely morphological division can be made where products like shower or standing chairs represent separate items of furniture and add-ons are examples of fixed furniture. Shower chairs and standing chairs and alike could be considered similar to mobility products, but a distinction can be drawn between products that are used at home as furniture and products that are carried with. Assistive products for mobility can be characterised as body-related or attached to the body and accessible space as forming a continuum with a building, which emphasises fitting in.[25]

One reason for including accessible space in this research is that accessible and assistive properties and a user's motor skills are interconnected. Accessible space has a similar objective of assisting someone in accomplishing a particular movement or task as separate assistive devices have. Space and devices both enable and ease users to perform tasks and often even simultaneously. It is sometimes difficult to separate individual assistive items from accessible space. Sometimes accessible space consists of diverse assistive components that together contribute to accessibility. A further reason for including accessible space is that particularly the domestic space can embody qualities that are meaningful to people from the viewpoint of their identity. The domestic space can have a similar function of constructing and expressing a user's identity as separate objects (see Chapter 2.2.2). What also supports the inclusion of accessible domestic space in the scope

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25 The division is influenced by Harni's (2010) classification of objects based on their morphological-functional properties.

of this research is that homes can be seen as open to visitors' evaluations, and to the emergence of stigma, and, in that sense, parallelled to social contexts of use.

Consequently, in this research, the term assistive products follows Gitlin's (2002, 110–111) division and refers to separate assistive objects like wheelchairs, walkers and reachers, but also to structural alterations made to the physical environment (e.g., widening doorways), special equipment attached to the structure of the physical environment (e.g., handrails), and material adjustment of the non-permanent features of the physical environment (e.g., clearing pathways and lighting adjustments).[26]

1.3 Positioning the Research

This research is positioned in the field of *design research* in *industrial and strategic design*. In studying assistive products' role in expressing and constructing their users' identities, the research interconnects conceptions of user experience, inclusive design and design semantics as presented in Figure 1. User experience refers to the diversity of factors involved in the product use (see Chapter 2.2.2), inclusive design, as unfolded in the first subchapter, to the design of products that meet various requirements set by a wide range of users, and design semantics to products' representational qualities (see Chapter 2.2.1). In the figure, the personalisation of assistive products is positioned in the intersection of these areas where issues of identity are a common focus.

Users' experiences of assistive products and the personalisation of the products are here largely approached by applying conceptions of stigma and stigma management. The applied conceptions derive from, or are strongly influenced by, Erving Goffman's (1963) insights. Personalisation is explored as a users' means of managing the stigma associated with assistive products.

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26 Gitlin includes in assistive products also environmentally-based behavioural modification (e.g., using task breakdown techniques or conserving energy in activities), but the focus of this research is on tangible objects.

Figure 1. The positioning of the research.
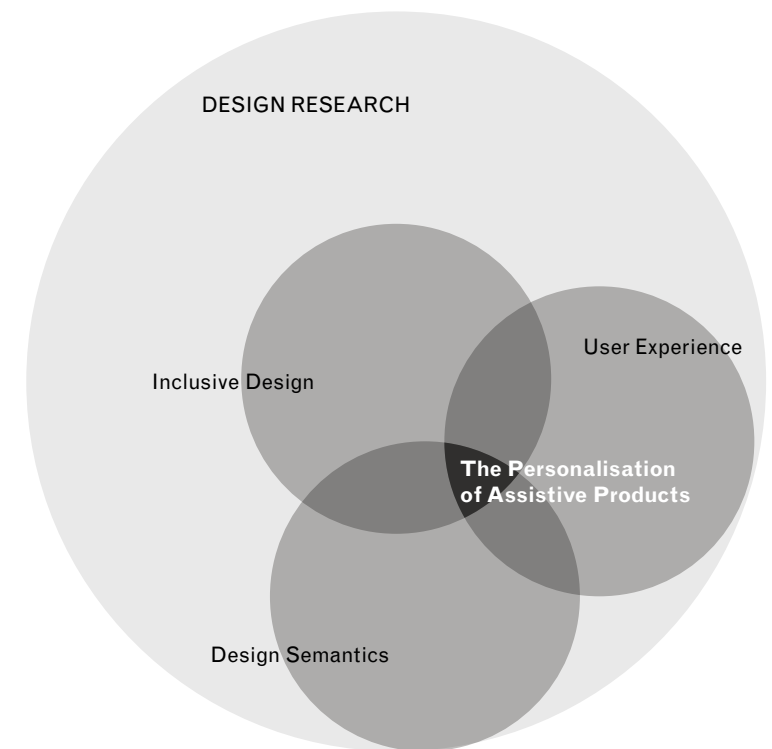
In his recent edited volume on locating and interpreting Goffman, Jacobsen (2010, 19) characterises Goffman's approach as "multi-perspectivism", which means that a same phenomenon can be approached from a variety of informative directions. Such approach is found particularly useful for this research, because as a case study of the personalisation of assistive products (see Chapter 3.2), this research focuses on potentially stigmatising products in social contexts of use, and utilises diverse data in describing the phenomenon and increasing understanding of it.

It is difficult to categorise Goffman. Jacobsen and Kristian-

sen (2010, 70–88) consider Goffman at least a symbolic interactionist, a functionalist, a structuralist, an existentialist, a phenomenologist, a critical theorist and a postmodernist. The standpoint of this research, and from which perspective also Goffman is here interpreted, derives from symbolic interactionism and social constructionism in the sense that products are viewed as carriers of socially constructed symbolic meanings. However, Goffman's functionalist viewpoint of normality (ibid., 75) is shared in the sense that although the world may have become more tolerant for diversity, norms and uneven opportunities that affect identity construction and expression still exist.

Due to its focus on the social construction of phenomena such as categorising people, Gordon and Rosenblum (2001, 15–16) have proposed the social constructionist perspective as useful to approach disability. In their literature review, the authors have, however, found its application infrequent compared with, for example, the studies of gender or sexual orientation. In disability studies, Shakespeare (1997, 217) has claimed that issues related to cultural and material representation and the meaning of disability have not been taken into account well enough, and the potential contribution of social psychology and anthropology has been neglected. In addition to Goffman's conceptions of stigma and its management, this research also applies insights from anthropologist Mary Douglas (2002) into classification in the evaluation of assistive products.

Because in the field of design, research literature on assistive products, particularly from the viewpoint of stigma and its management, is emerging and scattered, this research applies widely earlier findings from industrial and strategic design, fashion and clothing design, architecture and interior architecture, and even urban design. References are also made to earlier studies carried out within fields like occupational therapy, rehabilitation, social psychology and sociology. In outlining the problematics of assistive products, literature that has acknowledged the social construction of disability and, consequently, constituted to this research, has been prioritised.

2 Products in Identification

In this chapter, a theoretical framework that has helped understand the problematics of assistive products is introduced. First, the material and social construction of identity is discussed. Attention is paid to similarities and differences between people and to how roles, types and stereotypes emerge. A stereotype of disability and an ideal body type are considered to be background forces behind the problematics and, therefore, viewed as examples. Thereafter, the meaning of products in identification is discussed. The perception and interpretation of products, the functions of products, and the role of products in managing impression are presented. Finally, a special case, products that stigmatise and stereotype, is discussed. Conceptions of stigma and the assumed stigma of using assistive products are explored. The chapter concludes with notions of managing stigma, in which the focus is on people's concrete techniques.

2.1 The Materially and Socially Shaped Self

This research centres on products' role in expressing and constructing their users' identities. In this realm, conceptions of user experience, inclusive design and design semantics interconnect as presented in the previous chapter. Therefore, it is necessary to explore how identity is viewed. Research literature on identity is extensive and the conceptions of identity are plenty. Since the research focuses on assistive products and their presumed stigma in social contexts of use, the quest of applicable conceptions of identity has been guided by views that acknowledge the social construction of the world. From the viewpoint of identity construction, this means that even though people are unique and diverse as individuals, identity can be seen as socially constructed in the sense that interacting with other people influence identity. In social interaction, identity is defined, maintained, modified and redefined. (E.g., Jenkins 2008, 40; Berger & Luckmann 1966, 194.)

The question of how products contribute to social interaction (in which identity is constructed) is important for this

research, because personalisation is explored as a way of influencing how assistive products and their users appear in front of other people. Since interpretations people make about themselves, other people and society affect identity construction (Elliott 2008, 9), how people's interpretations of assistive products and their users influences users' self-images is also of interest here.

It needs to be noted that the terms *identity* and *self* are often used in parallel. For social anthropologist Jenkins (2008, 49), who has studied, for example, social groups and categorisations between people, common core features of identity and self include similarity, difference, reflexivity and process: selfhood can be understood as "an individual's reflexive sense of her or his own particular identity, constituted *vis-a-vis* others in terms of similarity and difference, without which she or he wouldn't know who they are and hence wouldn't be able to act". In this research, the terms identity and self are used as synonyms.

In the following subchapters, views on identity that consider the self as a combination of inner and outer factors and acknowledge the active continuous role of an individual in shaping her self with the help of material and social means are presented. These are considered potential in studying inventive individuals, who modify their material environment in order to make it more compatible with their identities. From the standpoint of this research, identity can be seen as characterised by the following key assumptions:

- Identity is a twine of personal and social, in which inner and outer are interwoven.
- Identity is flexible, variable, and continuously and actively [re]constructed from material (and social) elements.

The focus here is on material products. Social matters are discussed, when they touch upon how other people perceive and interpret a person and how that contributes to the construction and expression of a person's identity. However, also in social matters, the focus is on material products as triggers in perception and interpretation.

2.1.1 The Intertwined Personal Identity and Social Identity

In literature on identity, conceptions of personal identity and social identity are often discussed. Personal identity refers to the uniqueness of a person, what distinguishes her from other people, and social identity to a group of people who are in some way(s) similar (e.g., Jenkins 2008, 16-18; Goffman 1963, 11–12, 73–75). The distinction between personal and social identity is not, however, clear-cut. For Jenkins (2008, 37–38), personal identity and social identity are intertwined and neither of them is fixed, but reflexive. They are entangled with each other and formed in interaction. The main difference for him between personal identity and social identity is that individual emphasises difference and collective similarity, but they both are based on the interplay between similarity and difference.

Personal identity can be considered the primary source of self-presentation, which is expressed in using products and, particularly, in personalising them. Personalised products can be used in marking who an individual is, for distinguishing her from other people. Products can also be utilised for the purposes of social identity, in which case they also draw from the qualities of social identity. Social identity can be concretised, strengthened and directed through using products. Through the use of products, a person can associate herself with like-minded people. People can, however, simultaneously and in different ways emphasise similarity in one context and difference in another (Saguy & Ward 2011, 66–67). Therefore, the term identity is used here to refer to the twine of personal and social.

Even if personal identity and social identity were seen as entwined, a distinction can be made concerning how a person views her identity and how other people view it. Goffman (1963, 12) distinguishes *virtual social identity*, which concerns the assumptions and demands people have towards a person, and *actual social identity*, which involves the attributes the person actually has. What is meaningful for this research in this distinction is the possible incompatibility between how other people view

an individual and how she herself views her self. Of particular significance here is that products can add or even induce this incompatibility. Thus, products can contribute to identity also in negative ways. Instead of uniting, products can isolate users. Through the use of products, a person can become linked with particular identity types whether she experiences them as accurate or not. The fact that first appearances can indicate the category a person is anticipated to belong to (ibid., 12) is considered particularly important here because of the unfavourable associations using assistive products can create.

2.1.2 Flexible, Variable and Continuously [Re]constructing Identification

Since this research takes a stand that products contribute to identity expression and construction, views that do not consider identity predetermined appear relevant. Sociologist Elliott (2008, 8), who has explored identity from the theoretical viewpoints of symbolic interactionism and feminist and queer theory, asserts that rather than being stable and solid, identity is nowadays seen as "flexible, fractured, fragmented, decentred and brittle". He (ibid., 5) suggests that people structure their identities through managing, shaping and styling the self, and by interacting with other people, which shapes how people conceive themselves. These conceptions can be corrected, changed and developed (Csikszentmihalyi & Rochberg-Halton 1981, 3). The fact that identity can rather be seen as achieved than ascribed (Dittmar 1992, 12, 66) enables to explore how products contribute to achieving a particular identity.

Because identity is never final or settled, Jenkins (2008, 17) suggests it could be viewed as "a process of 'being' or 'becoming'". Consequently, he discusses *identification*. He (ibid., 5) sees identity as a continuous process of identification, which refers to something that a person does. Of particular interest to this research is the role of material in identification: with which products, and with whom, a person identifies through the product

use. The focus is not, however, on products as representations of wealth (cf. Dittmar 1992), but on aspects of identity more widely.

In identification, people can draw on all things that can be used, ranging from clothing, occupation and religion even to other people or pets (Jenkins 2008, 71). In addition, the self can be extended to body parts and organs (Belk 1988, 140). Considering products that are close to the body like assistive products, it is noteworthy that for people, identification is primarily embodied, from the viewpoint of the body (Jenkins 2008, 48). Green (2009, 34), who has studied the experience of long-term conditions like illness and disability, suggests that the significance of the body has increased due to phenomena that are dominating in the current western cultures such as individualism, reflexivity and self-awareness. According to her, the self and the body have become intertwined and how a person looks and presents herself defines who she is. She claims that diversity and difference are nowadays appreciated, and taste, style and possessions have become important in projecting, the self. She describes identity as "flexible and overtly selected", which she considers emancipating, because "you can be anyone you want to be" and the key identity markers that used to be important like birthplace, age or qualifications are less significant. Due to multiple choices, which are less constrained by traditions about how to be, and require ongoing review in synchronisation with constantly changing styles, Green (ibid., 39) considers identity rather self- than socially produced. Such a view can be seen as emphasising products in defining the self.

Even if identity was seen as a result of choice less dependent on other people (e.g., Branaman 2010; Green 2009), freedom to choose is not always inclusive. Not all people can construct or express their identities the way they wish, at least not by selecting and using products. For various reasons, one of which is lack of product choice, the users of assistive products form a group of people who do not have real choices. Furthermore, the use of assistive products can be experienced as labelling in social contexts, which emphasises the importance of other people's percep-

tions and interpretations in constructing and expressing identity.

Furthermore, some parts of identity can be more stable than others. Jenkins (2008, 72) emphasises that selfhood is entangled with embodied identities as gender/sex, ethnicity/race and disability/impairment. Acknowledging that those identities are complex, he (ibid., 84–88) discusses *primary identification* referring to more consistent and axiomatic identities. For this research, it is relevant that physical disability could be considered primary identification, but a distinction can be made between congenital disability and disability that has resulted, for instance, due to an accident in later life. In the first case, disability is likely to have been incorporated more profoundly into a person's identity, which affects her self-image and, for example, the use of assistive products.

2.1.3 Identifying Similarity and Categorising Difference

In exploring potentially stigmatising products, issues of identifying with something or someone are central. Jenkins (2008, 13) proposes that people use identification in order to sort out themselves and other people both individually and collectively. He (ibid., 17) emphasises that similarity and difference are included in the concept of identity. They refer to the sameness and consistency between people or objects. Jenkins points out that the verb to identify is closely linked to identity: it concerns classifying people or objects, and associating or attaching oneself with someone or something else. An individual differs from other individuals, but the similarities of individuals within a group make them differ from the members of other groups (ibid., 73). The interest of this research is in products' role in identification, in indicating individuality and similarity, and consequently also in categorising users.

What was briefly touched upon in Goffman's virtual and actual social identities relates to identification with a particular group and being categorised by others. Jenkins (2008, 43), building upon Karl Marx's distinction between class for and in itself, distinguishes between a *group for* itself and a *category in* itself. The former means that a group identifies and defines itself and the latter that a group is identified and defined by other people. Consequently, he (ibid., 103–105) discusses *group identification* and *categorisation*. In-group identification includes out-group categorisation. Goffman (1963, 86) discusses cognitive recognition, by which he means "the perceptual act of 'placing' an individual, whether as having a particular social identity or a particular personal identity".

What is important for this research in group identification and categorisation is the fact that identity can be assigned by other people based on outward qualities, including products. Through categorical identification, a person can become placed in a social category and locked into "a uniquely distinguishing identity" based on a differentiating quality like appearance, voice, a name (Goffman 1983, 3) or a product. Hughes (2000, 557), who has studied how medicine has influenced the aesthetic invalidation of people with disability, claims that through social processes of "othering", people construct opposites, which constitute each other. He describes how the advantages of the one are the disadvantages of the other. Jenkins (2008, 108) points out that whereas group membership is a relationship between members, categorisation is not. People who are categorised by others may not even be fully aware of the content or implications of them being categorised. He (ibid., 106) describes how categorising shapes their group identity through "the categorising gaze of others" as well as the categorisers' own identification process.

Disability can be experienced both as belonging to a group and being placed in a category. Disability can be seen as an essential part of identity that a person with disability is

not necessarily willing to change. Pullin (2009, 102) presents how some people with hearing impairment, for instance, have a strong identity as deaf persons that they designate themselves as "Deaf with a capital D", by which they want to emphasise that deafness is a large part of their cultural identity: it is not "something to be cured". Disability can be seen as culture (e.g., Ripat & Woodgate 2011, 93–94), in which case it is an example of belonging to a group and sharing a group identity. Other people viewing people with disability primarily and solely as homogeneous "the disabled" without connection to their actual identities can be seen as categorising. It seems that people who have a strong visible primary identification tend to become categorised as a group. People with disability, for instance, are easily slotted into "a disabled category" even if they actively identified with another group, as in the case of athletes who have disability. Shakespeare (2006, 71) points out the difference between a badge and a label: the former is positive identification of people with disability as members of a disabled collective and the latter negative ascription of a group membership.

What is of interest for this research is how products influence group identification and categorising. In consumer research, McCracken (1986) has studied how cultural meanings are transferred to products and to their users. He suggests that products express and substantiate cultural meanings. They encode principles that distinguish cultural categories. (Ibid., 73–74.) From the viewpoint of social psychology, Dittmar (1992, 155) emphasises the role of material possessions in placing and evaluating other people in order to orientate and to form impressions and anticipate behaviour.

Assistive products can be viewed as opposites of mainstream consumer products, because the same particular qualities that form their product identity make them differ from other products. What makes them different from mainstream products reinforce their group. Through associations with disability, assistive products also reinforce their users as a group, people with disability, and their difference from the users of other products (see also Shogan 1998, 272).

Wrong Categories

Due to different qualities, some products may stand out among other products and also their users among other people. From an anthropological viewpoint, Mary Douglas (2002) has suggested that people construct meanings by classifying things. According to her, clear characteristics affirm the classifiwation system, but problems arise when something does not fit in it: Systematic ordering and classification involves rejecting elements that are inappropriate. Something can become anomalous, if it does not "fit a given set or series", in which case it clarifies the group it is not part of. (Ibid., 44, 47.) Jenkins (2008, 150–151), leaning on Douglas's insights into symbolic classifications and their boundaries, states that "[i]ssues of classification are always issues of identification". Disorder both spoils and affirms pattern (Douglas 2002, 117).

Although Douglas bases her conclusions on studying such topics as primitive tribes, rituals and religion, her ideas about "matter out of place" could also shed light on the reactions some assistive products seem to create. Douglas (2002, 45) proposes that people tend to perceive stimuli that are interesting and what is interesting is guided by a tendency to make patterns. She explains that in chaos, people aim at constructing stability and recognisability.[27] Something that appears contradictory becomes easily rejected, but if it becomes accepted, the assumptions according to which it is classified have to be modified. Douglas, however, admits that once something is labelled, the label easily guides later treatment. A product can act as a cognitive reference, which means that new products in the same category are likely to be compared with that product (Athavankar 1990, d21).

Some people can appear ambiguous compared to some other people and become labelled. Shakespeare (1997, 231), who

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27 In the field of design, among others Hekkert (2006, 160) has suggested that in order to perceive connections and make relationships our sensory system must detect order and unity.

has discussed the cultural representation of disability from the viewpoint of, for instance, Douglas's views on anomaly, suggests that people with disability are viewed as ambiguous. Deriving from Douglas, he describes how throughout history, reactions to disability have resembled the reactions of "primitive people" to anomalies, for instance, reducing, controlling and avoiding ambiguity or labelling it dangerous. Also some products could be viewed as ambiguous compared with other products. This research is interested in how using a particular product, an assistive product, can influence a person becoming perceived as ambiguous, even anomalous, and engage her in managing such impressions.

Naming as a key process in categorising people (Gordon & Rosenblum 2001, 6) is particularly apparent in the case of assistive products, because users who qualify for the funding of assistive products have to meet the set particular criteria and, in a sense, "become named". The qualification is based on categorising users. Gordon and Rosenblum (ibid., 8–9) claim that people with disability are squeezed into categories based on predefined identifiers in order to allow the benefits, even though the division between able and disabled cannot be considered definite. Naming also contributes to the categorisation of products. Naming is one of the reasons why this research discusses assistive *products*, instead of devices or technology, in order to underline the products' multiple purposes of use as brought out in the Introduction.

2.1.4 Roles, Types and Stereotypes

Like dimensions of classification and identification, also roles, types and stereotypes are ways of making sense of the world, enhancing predictability and understanding others (Jenkins 2008, 151–153, 189). Berger and Luckmann (1966, 45, 74) suggest that people mutually "type" each other in order to be able to anticipate others' behaviour, to determine their own behaviour and to adopt roles. The authors (ibid., 91) specify that through roles, people participate in the construction of the social world. Because many products are visible and embody symbolic qualities in social interaction, they can be helpful both in assuming particular behaviours and roles and in typing other people. Dittmar (1992, 93, 185) proposes that products influence, among other things, types of person, stereotypes of social groups, gender identity, perception, and social interaction and categorisation.

Even if typing can help make sense, it is not always comprehensive or even truthful. Sometimes a person can become identified, either by herself or others, solely with a socially defined type and become a representative of a particular role, which can be positive or negative (Berger & Luckmann 1966, 108).[28] For Jenkins (2008, 152, 189), simplification encourages identificatory stereotypes, which emphasise putative similarities rather than particularities and differences, and are "extremely condensed symbols of collective identification". Dittmar (1992, 147) discusses *categorical differentiation*, by which she means the exaggeration of differences between groups and the minimisation of differences between individuals in groups.

The problem with exaggeration is, according to Goffman (1963, 90–91), that when a person's public image is based on a few dramatic facts to describe the entire person, it can lead to stigmatisation, in which case a person's true image becomes superseded. Berger and Luckmann (1966, 185-187) claim that the emergence of profiled types like "cripple" can lead to label-

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28 Berger and Luckmann call this the reification of identity.

ling, when a person's identity is defined according to predefined criteria and the person is considered having only that identity. In the studies of deviance, Becker (1997, 33–34) has suggested that one status that is socially defined as deviant can override other statuses and become a master status, in which case a person will be identified first as deviant and, thus, the master status will become the determining one in the eyes of other people.[29]

Understanding that people can be placed and categorically identified according to attributes like age, gender, class and race solely based on bodily markers in social situations (Goffman 1983, 14), can also explain why some products seem to enhance identificatory stereotypes, if they have dominating characteristics that are common and specific to their users. Material possessions can act as stereotypical descriptors of socio-economic groups and be used for locating people hierarchically (Dittmar 1992, 153). The interest of this research is in assistive products' tendency to express and construct the image of disability. They can influence the institutionalisation of disability by enhancing stereotypes.

The Stereotype of Disability

People with disability are often defined by their physical or medical condition and categorised as a homogeneous group that is characterised by stereotypical qualities. Even though the focus of this research is not on disability, but assistive products, it is important to unfold related conceptions of disability in order to understand the imagery and meanings associated with assistive products as "disability aids".

From the viewpoint of people with disability who personalise their assistive products, some stereotypes of disability, and of people who have disability, come up more clearly than others. Although disability and the experience of it is not only a

tragedy, dependency, or a loss of productivity and ability, but "a natural part of life" (Pfeiffer 2002a, 8), disability is, nevertheless, often considered to be something to feel sorry for. This is not to say that disability or becoming disabled would not involve tragic elements, but rather to point out that viewing disability exclusively as a tragedy may be one-sided and misleading. It can present people as, for example, passive and unenterprising.

Another misconception that appears relevant here is that disability is often parallelled to illness while people with disability may be healthy (see e.g., Green 2009, 9). Even if disability was health-related, health tends to be defined narrowly. Losing health, or becoming disabled, is regarded equal with losing both quality and control of life. Edwards and Imrie (2003, 152), who have studied how different values are attributed to a disabled body, claim that a disabled body is seen as broken, incompetent, powerless, dependent and without subjectivity. Similarly, Pfeiffer (2002a, 14) describes how it is seen as in need "to be fixed". How disability is viewed influences how the users of assistive products are viewed. For example people who use a wheelchair may be treated as "patients, reliant on expert opinion" (Gaffney 2010, 71). From the viewpoint of people's inventiveness, also such a view can misrepresent people with disability as subordinate and not as competent individuals.

The stereotypical characteristics associated with people with disability are often exaggerated, unjust, and concern a person's entire identity and life, not just disability. They can extend from a person's appearance to her employment. Pfeiffer (2002a, 14) brings out stereotypes that present people with disability as, for example, helpless, pitiful, ignorant, confused, and unable to do things or learn. According to Gordon and Rosenblum (2001, 14), stereotypes assume that people with disability would not be, for instance, active, independent, competitive, adventurous, competent or intelligent. Such stereotypical qualities are in contradiction to the perspective of this research that considers people with disability active and inventive in modifying products.

The stereotypes of disability not only concern the skills of

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29 Becker (1997, 32) applies the concepts of master status and subordinate status introduced by sociologist Everett C. Hughes.

people with disability, but also how they appear in front of other people. Stereotypes can claim people with disability to be, for instance, ugly, embarrassing, without social grace, willing to be solely with other people with disability (Pfeiffer 2002a, 14), aesthetically deficient, unattractive, or unable to realise values and attributes that culture esteems (Gordon & Rosenblum 2001, 14). Such stereotypical qualities appear particularly misrepresentative from the viewpoint of personalising assistive products. Personalisation in the scope of this research (see Chapter 1.2) focuses on appearance, adjusting it and showing qualities that derive from identity. Personalisation can also be used for identifying with a group based on a shared quality other than disability. Consequently, people who personalise their products might be interested in how they appear in front of other people and, therefore, contradict the aforementioned stereotypical qualities.

Hughes (1999, 165) suggests that impairment can become socially constructed in "the non-disabled gaze" that both "disfigures" and identifies "disfigurement". He suggests further that through the medicalisation of impairment, people with disability become reduced to "an authoritative diagnostic category", synonymous with their conditions. Due to stereotypical qualities, physical disability can be turned into a master status or a profiled type that supersedes other identities of that person. A person who has physical disability can become primarily or solely perceived as disabled. Shakespeare (2006, 71) calls this "the phenomenon of identity spread". Particularly people with severe physical disability, who have difficulties in expressing their will, are more easily subject to attitude problems (Teikari & Björkman 2006, 62). Positive and negative attitudes have a significant effect on a person's identity and viewing immobility as normal contributes positively to the identity of, for example, a person who uses a wheelchair (Gaffney 2010, 71).

This research is interested in how products can strengthen the existing stereotypes or trigger the development of new ones. Some of the current assistive products are seen as influencing the non-disabled gaze and contributing to their users' reduction

into a stereotype. Due to the image of the products, people's reliance on them and need for other people's assistance can be interpreted as incapability of independent action. The image of a person using an assistive product like a wheelchair as dependent on others seems persisting today and particularly in health care (Gaffney 2010, 71).

How disability is understood has been explored through various models of disability.[30] Since the emphasis of this research is on products and the assumed stigma of using them, studies on disability and the stigma of disability have not been in focus. In certain contexts, however, it has been necessary to refer to the aforementioned models of disability in order to shed light on the underlying background assumptions of the stigma associated with assistive products. Some of the models of disability have aimed at changing the medical viewpoint, which has prevailed in attitudes towards disability.

By considering the stigma people with disability experience, when using assistive products, as socially constructed, and viewing the users as active and inventive in modifying assistive products in order to diminish the stigma, the standpoint of this

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30 According to Ladner (2010, 26), the five models predominent in the Western world are medical model, rehabilitation model, special education model, legal model and social model. From the social model, Pfeiffer (2002b, 234) identifies further a UK Social Model and a US Social Model. The medical model as well as the rehabilitation model and the special education model comprise the deficit model, which, however, is in conflict with the paradigms of disability studies (Pfeiffer 2002a, 4). The nine paradigms of disability are, according to Pfeiffer (ibid., 4–7), the social constructionist version as found in the US, the social model version as found in the UK, the impairment version, the oppressed minority (political) version, the independent living version, the postmodern, poststructuralist, humanistic, experiential, or existentialist version, the continuum version, the human variation version and the disability as discrimination version. Seelman (2004, unnumbered) distinguishes four models of disability: the traditional model, medical model, social model and integrative model.

research is in line with a social model of disability.[31] The social model of disability considers people with disability "part of the diversity of life, not necessarily in need of treatment, cure, or special assistance" (Ladner 2010, 27). Furthermore, the social model underlines, according to Sapey et al. (2005, 494), that the limitations people with disability face can also result from social responses to their disability, not only from disability. The authors specify that, in its consequence, disability refers to society's failure to take into account the diversity of users. In this research, this failure is concretised in assistive products that focus on disability and do not acknowledge various aspects of identity. Products contribute to negative social responses by visualising and emphasising disability. Good design is seen as a means of influencing attitudes, which could eventually have an effect on social structures.

The social model has, however, received criticism for neglecting the embodied, corporeal quality of the individual disabled body (see e.g., Edwards & Imrie 2003, 241–242; Shakespeare 2006; Vehmas 2009). From the viewpoint of assistive products, the criticism seems justified, because assistive products are body-related, some even parts of the body, and contribute to how their users' construct and express their identities, experience disability, and how they appear in front of other people. The body is an inseparable part of the experiences the use of assistive products creates. Due to its tendency to emphasise the reciprocal fit between the environment and its users, and the relational and situational nature of disability, also the Nordic relational model of disability (e.g., Shakespeare 2006, 25–26; Tøsse-

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31 Pfeiffer (2002b, 234) explains that in the US Social Model, which originates from the conceptions of Goffman, disability is seen as an "unexpected differentness" that enables some roles, whereas others become impossible. The model suggests that changing role expectations will end discrimination. Pfeiffer unfolds how research within the US Social Model analyses social roles and attitudes towards fulfilling them, whereas the UK Social Model analyses social structures and their impacts on people. He states further that the US Social Model advocates aim at changing attitudes and behaviours, whereas the UK Social Model advocates aim at changing social structures.

bro 2004, 3–5) is close to the views of this research. The focus of this research is, nevertheless, more on the ways in which assistive products, for their part, construct stigma in social interaction.

The Ideal Body

In addition to stereotypes of disability, also qualities connected with an ideal body can illuminate the imagery and meanings associated with assistive products. "The myth of perfect bodies", according to which people "can and should strive to achieve perfect bodies", dates back to the ancient Greek Olympians (Stone 1995, 413). Nowadays, cultural and commercial factors influence the self through images of ideal body types and strategies to achieve "perfect bodies" (Elliott 2008, 5–6). Hughes (2000, 560–561) presents that consumer culture problematises and provides solutions to problems leaving "no excuse for not looking good". According to him, diets, exercise, cosmetic surgery, prostheses, organ transplants and replacements are solutions to reconstructing the body.

Through diverse media, perfect bodies are visible everywhere. Hawkesworth (2001, 303–304) claims that idealised images of beauty and attractiveness are "a dominant and constitutive part of the built environment in late capitalist society" and used for regulating what is regarded as visibly acceptable and desirable. She claims further that marketing techniques promote images of "flawless physical appearance", which stand for a vision of youth, physical beauty, fitness, mobility and movement.

Bodies with disability can seem far from those ideal body types or perfect bodies present in media, and that can have various consequences. Pfeiffer (2002a, 4) argues that disability refers to "a value judg[e]ment that something is not being done in a certain, acceptable way". According to Silvers (2010, 4), the thought about "normal" equalling natural originates from the ideals of Romanticism. She describes how people who, for instance, function atypically or anomalously, appear "abnormal" and dangerous instead of being merely different and threaten

the lives of "the normal". This view comes close to the earlier presented Douglas's view on anomaly and people's reactions to it.

The problem with a view of this kind and aspirations to achieve perfect bodies is, according to Stone (1995, 416), that it prevents people from recognising that all people have limits to their abilities and, thus, reinforces the conception according to which only a minority of people are disabled. She claims that this alienates people from their bodies and maintains "othering". The level of othering can, however, vary. Some disabilities can be viewed as more disabling or stigmatising than others (see Ripat & Woodgate 2011, 88–90). Similarly, some assistive products can appear more special and others more mainstream when compared with other consumer products.

Nevertheless, Hughes (2000, 561) describes how the fashioning of the body can become defining and in the process of aestheticisation, lead to the stigmatisation and discrimination of people with disability. Wolfensberger (2000, 106) claims that people who have physical disability, or whose visible bodily characteristics are viewed negatively, are widely devalued in Western societies. But, disability is also viewed negatively and devalued in developing and less-developed countries as, for example, Hussain (2011) and Ripat and Woodgate (2011) have presented.

As products influence how people view each other, assistive products can contribute to the construction of the devaluation. In addition, they can maintain, enhance and even create the dichotomy between perfect and imperfect bodies. Rehabilitation, along with prosthetic medicine, can be seen as having used "the normal body" as a reference, suggesting that a body with imperfections is in need of hiding and correcting (Hughes 2000, 561). In addition to products' categorising consequences, also specific accessible routes, and facilities like public toilets marked with a picture of a wheelchair, can turn attention to disability (see also DePoy & Gilson 2010b, 58) and strengthen the difference of people with disability from people without disability. Meanings associated with normal and abnormal, disability and ability, and

categories like "the disabled", have also been created through statistics (Shogan 1998, 271).

When it comes to design, the matter is nonetheless complex and contradictory. Due to their assistive properties, assistive products enable and increase users' opportunities to function in the physical environment. Despite its potentially labelling markings, accessibility means a hoped-for progress in the design of, for example, public spaces, many of which have been, and still are, inaccessible to people with disability.

2.2 Constructing and Expressing the Self with Products

In this research, products' meanings for people are seen as socially constructed in the process of definition and interpretation, in "symbolic interaction" (Blumer 1998, 10–12).[32] The interest is here in designers' ability to influence those meanings. As manmade, products can be seen as differing from natural objects in the sense that their maker has influenced their creation and, therefore, also influences their interpretation (Csikszentmihalyi & Rochberg-Halton 1981, 14).[33]

Products are considered here material for defining, constructing, shaping and expressing the self (e.g., Csikszentmihalyi & Rochberg-Halton 1981; Dittmar 1992). They are seen as symbols, through which various aspects of identity can be communicated. They are used for expressing and reinforcing a user's identity, but also for evaluating other people by drawing on what they socially represent. (Dittmar 1992, 66, 79, 183.) Taking into account the focus of this research, assistive products, two conditions, however, have to be acknowledged. First, the ability

32 Blumer (1998, 10) specifies that an object, whether physical, social or abstract, is "anything that can be indicated, anything that is pointed to or referred to". In this research, the focus is on physical objects that have, for example, social functions.

33 Also many other things such as cultural conventions, other people (Csikszentmihalyi & Rochberg-Halton 1981, 87), price, advertisements, other people's opinions and previous experiences (Desmet & Hekkert 2007, 62) influence meanings.

of products to construct and express identity varies considerably. The offer of current assistive products is often limited and one-sided: there may not be enough variation for identification and the features tend to centre on assistive functions and accessibility. Still, assistive products carry socially shared meanings [of disability] that contribute to identity construction.

Second, even if a large variety of assistive products were available, users' abilities to take advantage of their possibilities are not the same. People may not be equally aware of all available products, or if they are, the choices available for them might be limited. Conditions such as disability may involve lack of financial resources, which affects the attainability of products. Jenkins (2008, 72) points out that "the accessories of identification" are not equally available, but instead various things systematically influence people's access to resources, in this case products. He also remarks that some identities can enhance and others diminish a person's opportunities depending on the context. As unfolded in the previous chapter, disability involves identities that are characterised by stereotypical qualities, which may influence the opportunities of people with disability.

In the following subchapters, the meaning of products in identification is discussed. Identification is viewed both as constructing identity and identifying with something or somebody through the use of products. The discussion includes how products are perceived and interpreted, and for what purposes products are used. Of particular interest is how products are employed in identity construction and expressing the self.

2.2.1 Perceiving and Interpreting Products

Through their physical properties, products convey information on their functions, uses and meanings, which users interpret (e.g., Boztepe 2007, 61; Crilly et al. 2004, 565; Vihma 1995, 48). In the field of design, Crilly et al. (2004, 552–553, 564–565) have suggested that users' cognitive responses to product forms involve aesthetic impressions, semantic interpretations and sym-

bolic associations, which are interrelated and influence each other. According to the authors, aesthetic impression can be defined as the sensation that results from the perception of the [un]attractiveness of a product, semantic interpretation as what a product communicates about its function, use and qualities, and symbolic association as what a product communicates about its user. From the viewpoint of design semantics, the product form can be seen as referring to technical construction and visual composition on the syntactic level, but on the semantic level, it is a means of interpretation with a reference to something (Vihma 1995, 65).

This research is not only interested in how people experience the use of products, but also how they are viewed by other people when using products, and what are its consequences. The fact that in perceiving and interpreting products, people can recognise metaphors, characters, conventions and clichés (Crilly et al. 2004, 566–568) as well as assign personality or expressive characteristics to products and assess products' personal or symbolic significance (Desmet & Hekkert 2007, 60, 62), can help understand both the nature of the stigma caused by using assistive products and the role of personalisation in diminishing it.

Also the fact that products can evoke emotions (e.g., Hekkert 2006, 160; Desmet & Hekkert 2007, 61) can help explain the stigma users experience when using particular products. People can experience not only joy or pride when using a product, but using, and especially being seen as using, a particular product can also cause negative emotions and feelings like embarrassment or pity. Meanings are related to emotions also in the sense that people have "certain expectations about the consequence of owning or using products" like having an exclusive product (Desmet & Hekkert 2007, 62). For explaining the negative experiences that users may have when using products, it is illustrative that a particular product can be considered an enabler from the viewpoint of physical accessibility or an indicator of difference from the viewpoint of its social consequences, but in both cases, it can signal disability.

Malt and Sloman (2007, 86), who have studied the categorisation of artefacts, state that contexts and comparisons influence how products become perceived and interpreted. They (ibid., 105) note that a product can belong to more than one group and become parallelled to different products depending on time and context. Vihma (1995, 88) illustrates how the same object can be interpreted as a sales item in a commercial context, an exemplary work in a museum and a tool in a workshop. She suggests that contexts define the category according to which products can be sensibly interpreted and valued. According to Crilly et al. (2004, 565–566), a user may compare a product to the stereotype of its own category, to similar products in its own category or to products in other categories. In her semantic analysis of irons, Vihma (1995, 118) has also found that distinct features appear clearer when products are grouped into pairs and depending on the pair, congruent or deviating features come up more clearly.

Contexts and comparisons not only influence the perception and interpretation of products, but also products' value for users. Boztepe (2007, 58) proposes that context-related conditions like common behaviours, organisation of space, and socially and culturally shared meanings contribute to shaping user value. Therefore, the same product may have a different value for users in different contexts. The importance of the context of use is particularly apparent in the case of assistive products. Products that are originally developed to be used in environments like hospitals can become inadequate and attached with undesirable meanings in the domestic environment (Bispo & Branco 2009, unnumbered).

The interpretations of products may not always be explicit. Douglas (2002, 47) discusses ambiguity, by which she refers to different interpretations. In her example, she illustrates how treacle is neither liquid nor solid, but gives "an ambiguous sense-impression". An ambiguous pattern allows for more than one interpretation, which can be incompatible or compatible (Hekkert 2006, 164–165). Vihma (1995, 158), however, notes that in

order to be able to make an aesthetic evaluation of a product, it would be sensible to perceive it in a predefined category and to know its requirements.

From the viewpoint of cognitive psychology, Rosch and Mervis (1975) have studied how category prototypes are formed. Based on their analysis of superordinate and basic level semantic categories, the most prototypical objects seem to resemble most the other members of their category and least other categories (ibid., 598–599). Furthermore, among superordinate categories the authors (ibid., 582) have found that the more an item has common attributes with other members of the category, the more it will be considered a good and representative member of that category.[34] Interestingly, Rosch et al. (1976, 434) also describe how a deviant item, as a penguin in the category of birds, differs from the basic level category and is likely to be perceived first as "a member of its individual class".

From the viewpoint of design semantics, Vihma (1995, 57–58) refers to Athavankar's (1990) studies on the categorisation of design objects and discusses ideal or semantic types of products, which have characteristics that extend beyond their construction, technique or practical functions. Deriving from the experiments of Rosch on the representations the mind generates in categorising objects, Vihma presents how the amount of jugness, for example, reveals how close a jug is to its ideal type. She, however, notes that it is possible that a product can at the same time refer to its ideal type and some other characteristics. Athavankar (1990, d8–d9) proposes that the product form consists of perceptual clues, which define "the essence of the particular concept" such as the jugness of a jug. According to him, these clues are "semantic devices", which refer to the centrality or a core meaning of a particular form, a central member of a product category.

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34 For more information on superordinate, basic level and subordinate semantic categories, see Rosch & Mervis 1975, 577–591, Rosch et al. 1976, and Rosch 1978, 31–32.

What is relevant here is that designers can influence the ideal or central types of product categories. According to Papanek (1984, 21), designers can enhance "the chairness of the chair" by manipulating the relationship between what is expected from an object and how the object is configured. Also Athavankar (1990, d7) suggests that designers can exploit the flexibility, which people show in categorising, within product categories. In this research, it is assumed that also personalisation can influence product categories.

Perception and interpretation also influence naming. Malt and Sloman (2007, 89, 94–95) propose that products can be named based on their characteristics like form, function or both, but form and function tend to correlate in the sense that a similar form often refers to a similar function and vice versa. The authors (ibid., 100) claim that new variations of artefacts are seldom named uniquely unless differing from predecessors is explicitly intended: usually, existing names are just extended to cover the new variations. The claim seems reasonable regarding assistive products for mobility, because walking canes, forearm canes, quad canes and white canes are all canes. Meanwhile cross-country ski poles, alpine ski poles, Nordic walking poles and trekking poles are all poles, but although they functionally appear similar, they have different connotations. Rønneberg Næss and Øritsland (2005, 4) associate canes with "urban assistive products for old-fashioned, mobility challenged people" and poles with "outdoor sports activities" and people who are "young at heart and enjoy the outdoors". Use, purpose and form are entwined and a product's pragmatic and semantic dimensions seem to merge in interpretation (Vihma 1995, 55).

2.2.2 Product Functions

In addition to products' physical utility function, they can also have other functions. As proposed in the Introduction, one of the utility functions of many industrially designed consumer products can be considered assistive. Moreover, products can

have, for example, social, aesthetic (Crilly 2010), commercial (McCracken 1986, 71), experiential, enriching, inspiring and identity strengthening (Hekkert 2006, 168) functions.[35] The semantic function of a product relates to the way a product represents its purpose of use, expresses something, or refers to something when interpreted (Vihma 1995, 169).

Based on an extensive examination of how the concept of function has been classified in various disciplines, Crilly (2010) has constructed a "function matrix", in which different function classes are combined.[36] For this research, Crilly's (ibid., 330) conclusion that the concept of function can also be applied to non-physical and non-technical uses is central, because it allows to recognise and assess both functions that are currently predominating in assistive products and functions that are missing from them.

As this research centres on the stigma that using particular products may induce, products' representational qualities are of interest. Whether habits, ways of life, physical power, virtues like wisdom, justice and frugality (Csikszentmihalyi & Rochberg-Halton 1981, 21, 26–28), statements, assertions and expressions of attitudes (Vihma 1995, 88) or cultural categories like class, status, gender, occupation and lifestyle (McCracken 1986, 79), products stand for something. As material symbols, they cannot help representing and reproducing socio-cultural categories (Dittmar 1992, 69–70). How personalisation influences representations is of interest here. What, however, needs to be remembered is that different functions and meanings a product provides are not unconnected, but a product can be used for

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35 People, however, also use products just "for the sake of consumption" (Csikszentmihalyi & Rochberg-Halton 1981, 231).

36 In the matrix, classification according to purpose, effect or means results in physical, status, technical, social, ideological, aesthetic and non-aesthetic functions. Classification according to selection, intention or recognition leads to proper, system, design, use, service, manifest and latent functions. Each cell in the matrix represents a possible combination of the function classes, which can be redundant, directional, conflicting, ambiguous or productive. (Crilly 2010, 325–327.)

both utility and symbolic purposes. Dittmar (1992, 88–89) proposes that the meanings of material possessions for identity can be instrumental, that is, use-related and symbolic such as self-expressive and categorical.

In the field of design, product functions have been explored at least from the viewpoint of the experiences (see e.g., Battarbee 2004; Hekkert 2006; Jordan 2000; Jääskö & Keinonen 2006) and the value (see e.g., Boztepe 2007) that user-product interaction creates. For Jääskö and Keinonen (2006, 97), *user experience* encompasses, for example, the physical and operating environment, a product's novelty value, significance, and appearance as well as a user's personality. Battarbee (2004, 25), who has studied user experience in social contexts, defines user experience as "a commonly understandable, holistic, all-encompassing concept that includes the user, the product and the context of use" and "emphasises the importance of the emotional aspects of experience".[37]

From the viewpoint of affective experiences, Hekkert (2006, 160) and Desmet and Hekkert (2007, 59–61) identify three types of *product experience*: aesthetic experience, experience of meaning and emotional experience, which concern the gratification of senses, attached meanings, and elicited feelings and emotions when interacting with products. Boztepe (2007, 57) views *user value* as a result of the interaction between what a product provides whether formal, functional, tangible or intangible and what goals, needs, cultural expectations, physical context and emotions users provide. An illustrative example of

products, whose use has comprehensive consequences, is household products. For Csikszentmihalyi and Rochberg-Halton (1981, 184–185), they do not only have meaning as individual products, but are part of the gestalt of home for their residents. They indicate the activities that are appropriate for home, represent what the residents consider significant to possess and provide familiarity.

From the viewpoint of this research, two product functions appear central: utility function and another function that could be named *identity function*. The utility function relates to assistive products' accessible and assistive purposes of use and can be considered the primary function of all assistive products. It bears what Boztepe (2007, 59) calls *utility value*, which refers to products' "utilitarian consequences" like accomplishing physical (or cognitive) tasks and includes qualities such as accessibility. The identity function concerns the construction and expression of a user's identity, but it also creates value that Boztepe (ibid., 60) names *social significance*. Social significance means "the socially oriented benefits attained through ownership of and experience with a product" including "attainment of social prestige and construction and maintenance of one's identity". In this research, the currently overemphasised utility function and the less acknowledged identity function are considered contributors to the problematics of current assistive products.

The Identity Function Untangled

The identity function concerns products' ability to reflect, express, construct and structure the self. Products can represent the self and even become part of it. (See e.g., Csikszentmihalyi & Rochberg-Halton 1981, 16, 108–109; Belk 1988, 139; Claxton & Murray 1994, 422; Dittmar 1992, 43–47.) Since assistive products can also concretely extend a disabled body, their influence on identity can be more comprehensive than in the case of other consumer products. They are likely to become integrated into their users' body, identity and life more closely and extensively.

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37 There are several frameworks of user experience and Battarbee (2004, 38–52) groups them into person-centred, product-centred and interaction-centred. In his person-centred framework, which is based on the work of anthropologist Lionel Tiger, Jordan (2000, 13–14) presents four types of pleasures that people can have with products: *physio pleasure* refers to senses and physique and stresses the importance of environments' multi-sensory stimuli; *psycho pleasure* refers to the mind through challenging users' learning and problem-solving skills; *socio pleasure* refers to interaction with others (e.g., by enabling integration into society); and lastly, *ideo pleasure* refers to users' values and how the environment can fulfil them.

Regarding products as part of the self can be conscious or unconscious, intentional or unintentional (Belk 1988, 139), but some products can become part of a user's body and self more consciously and intentionally than others. For example assistive products are used out of necessity and often prescribed to users without choices (e.g., Rauhala 2007, 21; Olander 2011, 21). What is important here is that even if people were not aware of it, using products always has outcomes (Csikszentmihalyi & Rochberg-Halton 1981, 194). People can become "branded" even though there are no logos (De Poy & Gilson 2009, 64 & 2010b, 55).

As brought out in the Introduction, home is viewed in this research as a special context of products that construct and express identity. Csikszentmihalyi and Rochberg-Halton (1981, 123, 144) characterise home as "the most powerful sign of the self" and as a space, where its resident can develop, maintain and change her identity. Even though the authors state that home can shelter its resident from "ostracism or ridicule", and provide objects that define the self, parts of home are seen here as open to visitors' evaluations, which can affect a resident's identity.[38] Furthermore, parts of home can become exposed to products' negative qualities and consequences. For instance, assistive products, which do not fit home or with which users cannot identify, could be a threat to home's sheltering qualities.

Homes that are equipped with assistive products can appear contradictory for their residents and visitors. Csikszentmihalyi and Rochberg-Halton (1981, 101–102) describe how in environments like nursing homes for older people, the possibility that residents consider their furniture extensions of themselves

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38 Csikszentmihalyi and Rochberg-Halton (1981) specify that home is actually much more than a shelter. They compare home to church because "it is the place where ultimate goals can be cultivated, sheltered from the instrusions of public life". People turn physical environments into cultural environments. To adapt to it and to create order and significance, people continously personalise and humanise their environment. (Ibid., 122.) Through various kinds of investments, home begins to represent the accomplishments of its owner's self (ibid., 130).

that embody memories and experiences can be ignored due to the importance of hygiene. Still, the authors claim that particularly the self of elderly people tends to be structured around past (and also present) relationships that are embodied in objects and losing such objects may equal to losing parts of the self. Teikari and Björkman (2006, 61), who have studied the independent dwelling of people with disability in Finland, point out that self-determined living and a home that supports its resident's personality are fundamental for identity, independency, and the control of life and privacy also in housing for people with disability.

Assistive products may seem inseparable from their users, which can be experienced both positively and negatively. A user may want that for example a prosthesis performs and appears as if it was a body part and does not stick out. Sometimes an assistive product can, however, become so dominating that it does not leave room for its user's persona. Ravneberg (2009, 108), who has studied the public provision for assistive products in Norway, suggests that through smarter design, an item like a wheelchair can highlight the distinction between a user's body and a wheelchair, and positively influence a user's consciousness of her body and also identity.

From the viewpoint of the assumed stigma of using assistive products, which may socially isolate users, it is equally important that in addition to highlighting individuality and distinguishing from other people, products can also represent similarity and indicate group identity (Belk 1988, 152–153; Csikszentmihalyi & Rochberg-Halton 1981, 38–39; Dittmar 1992, 10–11; Mugge 2007, 32–33). Dittmar (1992, 62–63) conceptualises the functions of possessions as *intra-individual* or *inter-personal* instruments of self–definition, control and power. She (ibid., 124) proposes further an *actor perspective* for examining the significance of material possessions for identity expression and an *observer perspective* for making inferences about other people's identities based on their material possessions. Products can be used for assuming cultural values, integrating socially (Claxton & Murray 1994, 422) and for defining and constituting the world (McCracken 1986, 80).

What is central for this research in products' identity function is that products contribute to how a person is perceived, interpreted and responded to by other people (Dittmar 1992, 85–86; Vihma 1995, 88). And, how she presents herself to them and whether her presentation is accepted as part of her identity when viewed by others (Jenkins 2008, 71). Dittmar (1992, 11) proposes that products can act as "symbolic mediators between self and other". Products can contribute to the plausibility of a particular role as in the case of equipment that accompanies a professional role. The environment, of which products are part, can also reinforce identification with, for example, a particular person (Berger & Luckmann 1966, 174).

However, products can also signal conflicting information. Negative effects of using products can prevent from identifying with other people. Csikszentmihalyi and Rochberg-Halton (1981, 141) point out that conventional values that are attached to products and the opinions of other people may, nevertheless, sometimes tell more about a person than the direct interaction with products. In any case, how other people view product use can affect a person's self-image (Solomon 1983, 323).

McCracken (1986, 78–80) suggests that cultural meanings can be transferred from products to individuals through rituals like grooming. He describes how through grooming, products can be supercharged, their properties cultivated and as heightened transferred to their users. Through personalisation, which is an example of possession rituals, meanings can be transferred also from individuals to products. Thus, according to him, meanings are transferred from a product to a person and from a person to a product. Csikszentmihalyi and Rochberg-Halton (1981, 81) propose that through the process of refinement, objects that create emotions and thoughts can become symbolic and transmit their symbolic values to other objects, behaviours and persons. Some assistive products can represent values that are associated with disability. Whether users can transfer personal meanings from their identity to assistive products by personalising them, and influence the values that are associated with disability, is of interest here.

Products can have a function that comes with a collectively recognised status (Searle 2007, 12), but due to such product functions, properties and qualities which are experienced and perceived negatively, the status of assistive products is often weak. Goffman (1963, 59) suggests that social information communicated by a symbol can refer to prestige, honour or desirable class position. Even though commonly known as status symbols, Goffman prefers the term *prestige symbol*, which is also the term adopted in this research. He contrasts prestige symbols to *stigma symbols*.[39]

Prestige symbols can express a person's social status and be, for example, occupational symbols or class symbols. They can also express a viewpoint, lifestyle and cultural values. (Goffman 1951, 295–296.)[40] In addition to status, prestige symbols inform about how others are supposed to treat a person (ibid., 294; Csikszentmihalyi & Rochberg-Halton 1981, 29). A prestige symbol provides social significance that includes "attainment of social prestige and construction and maintenance of one's identity" as face saving acts, impression management and group belongingness (Boztepe 2007, 60). Through identifying with prestige symbols, a person can stand out from or above other people (Csikszentmihalyi & Rochberg-Halton 1981, 142).

Prestige symbols also involve power and control. Their status can be considered a form of power consisting of other people's respect, consideration and envy, that is, people who have a higher status are "looked up to". Prestige symbols can express users' "power to control others". Users can manipulate objects to their own purposes in order to maintain or even gain status.

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39 Goffman (1951, 295) emphasises the difference between prestige symbols and esteem symbols: the former refers to a position a person has and the latter to the way she fulfils it.

40 Goffman (1951, 298–299) explains that objects can gain status symbolic qualities in three ways: through intrinsic or natural restrictions and through their creators. Intrinsic restrictions involve expressive difference in reference to a recognised aesthetic or sensuous standard of judgement and natural restrictions refer to a limited supply. Objects gain status through rarity, expense, age or the attention of people who have status (Csikszentmihalyi & Rochberg-Halton 1981, 30).

(Csikszentmihalyi & Rochberg-Halton 1981, 29–31.) Person-alisation could be explored as a means of altering the status of a product and, consequently, also the status of its user.

Products are not only part of the self, but also instrumental in developing it (Belk 1988, 141). Csikszentmihalyi and Rochberg-Halton (1981, 28) suggest that in addition to representing the existing qualities of the self, material objects can generate qualities. Objects can be used for expressing "perceived possibilities" of the self. The authors (ibid., 53, 231) specify that products can expand or restrict the scope of people's actions and thoughts and, thus, what people can do, and be "instruments in discovering, furthering, and realising goals". Consequently, products can be used for both maintaining the present and structuring the future.

2.2.3 Managing Impression with Products

The way other people perceive and interpret us to be may differ from how we think we are. Goffman (1963, 12–13) proposes that there are discrepancies between virtual social identity and actual social identity, and a discrepancy can result from, for instance, a stigmatising attribute that reduces a person into what Goffman calls a "discounted" one. In consumer research, Solomon (1983, 324–325) has presented roles for products as responses and as stimuli: As responses, products are strategic communication tools used for communication when a role is mastered. When there are difficulties in performing a particular role, as in the case of stereotypes, products can be employed as stimuli. As stimuli, products "set the stage" for roles by matching behaviour.

In the construction of social roles and social images, a person's appearance is one of the important factors that contribute to a positive or negative image (Wolfensberger 2000, 115). Various "props" like clothing, furnishings and other personal possessions can be used in managing impressions (Leary 2000, 7245). People can exhibit different sides of themselves to other people also through the use of products (e.g., Vihma 1995, 88). Prod-

ucts can be used for revealing and enhancing desired impressions as well as hiding and fading undesirable ones. Products can reinforce an impression, but also consciously mislead.

In the field of psychology, Leary (2000, 7245) and Leary and Kowalski (1990, 34) have defined impression management, or self-presentation, as processes that people employ in order to control how other people perceive them. Leary notes that impression management may be tactical, sometimes deceptive, even manipulative, but often people just try to make sure they give an accurate impression of themselves, because personal characteristics are not always obvious to others. Branaman (2010, 247) concludes that self-presentation cannot be considered being only practiced by "fakes, con artists and narcissists", but also "those who fail to be seen by others as they see themselves" engage in self-presentation. Deriving from Goffman, Jenkins (2008, 42) suggests that people seek "to 'be' – and to be 'seen to be' – 'something' or 'somebody' or to successfully assume particular identities".

A broad definition of impression management involves both verbal communication about oneself and stylistic and non-verbal features of behaviour (Leary & Kowalski 1990, 40). Since the interest of this research is in the role of products in managing impression or presenting the self, the emphasis is on non-verbal communication. Impression management and self-presentation are used here as synonyms. A particular interest is taken in impression management, which is influenced by how people would like themselves to be or not like to be (ibid.), because assistive products may convey contradictory information on their users and engage them in actions that aim at more truthful information. Goffman (1959, 24–25) describes how people employ *preventive practices* to avoid embarrassments from what they express to be and what others accordingly expect them to be. If embarrassments take place, people employ *corrective practices* to compensate for them. Practices turn into *defensive practices* when they are applied to protecting own projections. When they are used for protecting someone else's projection, they are called

protective practices or *tact*. Defensive and protective practices are techniques to safeguard impression.

The fact that self-presentation can be seen as bridging the gap between a person's self-image and how other people see her (Branaman 2010, 247) could explain why some people personalise products. In addition to that, people's tendency to manage impressions when the impressions are relevant to social and material outcomes, self-esteem maintenance or identity development (Leary & Kowalski 1990, 38) can give a reason for personalisation. The impressions people manage may present aspects of their self-identity that they value most, go along with the expectations of their social roles (ibid., 40–41) and are believable to other people (Goffman 1959, 28). They can relate to abilities, attitudes, motives, status, emotional reactions and other personal characteristics (Leary 2000, 7245). All these aspects are involved in the use of assistive products and, in that sense, potentially open to management.

In the field of design research, Govers and Mugge (2004, unnumbered) have discussed product-personality congruence and product attachment. According to them, self-congruent products that are in some way(s) similar to a person's identity, provide "the symbolic function of self-expression" and allow a person "to show the world who she is". The authors claim that through this, the person also becomes more attached to the product. In consumer research, Sirgy (1982, 289) has suggested that people strive for positively valued products that maintain a positive self-image and, thus, have *positive self-congruity*. Because people also identify their self-images to others through brands, brands whose image is closest, most congruent, to their own self-images are preferred (Schenk & Holman 1980, 610).

Belk (1988, 159–160), who has studied the meanings of possessions, proposes that possessions as extended self help to present the self in a way that encourages feedback from other people. The self can be extended through, for instance, controlling and mastering or creating an object, and through knowledge and habituation of the object. He (ibid., 145) points out

that objects can extend the self also literally as in the form of a tool, or symbolically as a uniform when the symbolic object convinces its owner and other people that she is a different person with that object than without it.

2.3 Products That Stigmatise and Stereotype

2.3.1 Stigma

The history of *stigma*, as Goffman (1963, 11) unfolds it, dates back to the ancient Greek culture where the contemporaries generated the term stigma "to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier". Goffman describes how in practice, stigmas were cuts and burns in the body and informed about their bearers' slavery, criminality or traitorousness. He explains how along with Christianity, bodily stigmas became associated either with holiness or, from the medical viewpoint, physical disorder.[41]

In characterising potentially stigmatising products, the existing conceptions of stigma in general can also increase understanding about the nature and the emergence of product stigma. In their article on the social psychology of stigma, Major and O'Brien (2005, 395) characterise stigma as visible or invisible, controllable or uncontrollable, and as concerning appearance, behaviour or group membership.

While products like sports or professional equipment are less likely to group their users in negative ways, some other products can label and stereotype their users. In that case, the stigma is visible in the form of a visible product. In the case of stigmatising products, which are used out of necessity or which are not necessarily chosen by their users, stigma could also be viewed as uncontrollable. The stigma of products, which are car-

41 The definitions of the word stigma include examples like a scar left by a hot iron, a mark of shame or discredit and an identifying mark or characteristic; specifically: a specific diagnostic sign of a disease. The origin of stigma is in "Latin *stigmat-, stigma* mark, brand, from Greek, from *stizein* to tattoo". (Merriam-Webster.)

ried with, can be seen as appearance-related. As some products can substitute or enhance bodily functions, their stigma can also concern forms of behaviour. Stigma can include physical marks and non-physical characteristics (Green 2009, 14).

Considering the abundance of factors that are involved in product use as discussed in the previous chapter, it is understandable that stigma is not limited to products' stigmatising features. Moreover, stigma can involve attitudes, discriminatory and stigmatising practices, services, legislation, media, and materials, experiences of actual discrimination and restricted participation, and be perceived and/or internalised (Van Brakel 2006, 309). Major and O'Brien (2005, 396–398) list that a visible stigma can lead to negative treatment and discrimination, expectancy confirmation processes, automatic stereotype activation, and identity threat processes. In its wide-ranging consequences, stigma can resemble many other product qualities, however, its consequences seem to be largely negative.

Green (2009, 13–14), who has studied the stigma of long-term conditions like illness and disability, suggests that the concept of stigma has broadened by the shift of focus from individual characteristics to larger scale political issues where power plays an important role.[42] She (ibid., 28) concludes that in recent sociological literature on stigma, "the spoiled identity viewpoint" has shifted to a more wider perspective that takes into account macro level phenomena as social oppression, discrimination and exclusion. The assumption that "one can infer internal worth from an external sign or characteristic" (Papadimitriou 2008, 700) is, nonetheless, relevant to this research, because from products people can infer positive or negative worth that is associated with wealth, social standing, education, talent, health and many

other things. The consequences of using stigmatising products extend from direct product interaction to responses from the surrounding environment.

How does stigma develop? Stigma does not appear in a vacuum. Various factors like culture, age, gender, power or affluence affect its development (Scambler 2009, 449–452). In addition, media contributes to stigma (Van Brakel 2006, 327). Link and Phelan (2001, 367–375), who have studied the development of stigma, suggest that stigma evolves from the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a power situation. Green (2009, 18) elaborates Link and Phelan's conception further and introduces othering instead of separation. She describes how people notice differences, label them, and labels then lead to negative stereotypes. She concludes that people with labels become "others", who are perceived as inferior, which results in discrimination, exclusion and loss of power.[43]

Because this research concerns product appearance, it is important to note that stigma is characterised by a perceived difference (e.g., Green 2009, 15; Major & O'Brien 2005, 395) that is experienced negative. People can feel deviant and stigmatised, if they think they raise negative attention, stick out (Scherer 1996, 132; Parette & Scherer 2004, 219). Jones et al. (cited in Green 2009, 15) have introduced various dimensions in stigma, of which disruptiveness, aesthetics and concealability appear central here. Green (ibid., 15–16) proposes that the degree of the various dimensions of stigma depends on how obvious and apparent the stigmatising features are and suggests that visible stigmas like physical disability or obvious assistive products cause wider social disadvantages. Similarly, illness-related disabilities that deteriorate and become more visible can receive more neg-

42 In recent literature, the health-related stigma is often explored in the context of HIV, AIDS or mental illness (see e.g., Scambler 2009; Van Brakel 2006; Heijnders & Van der Meij 2006). Even though physical disability does not necessarily result from or include illness, the health-related stigma has often been found here as the most appropriate conception due to its focus on the body and the occurrence of assistive products in both health-related conditions and physical disability.

43 Jenkins (2008, 98) points out, referring to the labelling perspective from the studies of deviance, that also positive valorised identities are internalised in the same or similar ways as negative stigmatising ones, and they can be viewed as labels with consequences.

ative reactions. Gamliel and Hazan (2006)[44], who have studied homes for elderly people, suggest that any form of individuality can, however, become deviant in a place that lacks privacy and personalisation, and in this research, anonymous homogeneity is considered one of the main reasons for the stigma caused by assistive products.

Even though Goffman (1963, 124) views stigma symbols as "continuously available for perception", he (ibid., 14, 57) distinguishes *discreditable* and *discredited* persons depending on how known, evident or perceivable their stigma is. He (ibid., 102–104) describes how the world of a stigmatised person is divided into people who know and people who do not know about her stigma. Furthermore, her world is divided spatially into places where the stigma has to be kept undisclosed, places that treat her as if she was qualified, and places with similarly stigmatised people where the stigma can be revealed. Goffman (ibid., 112) describes further how also time can be divided in the sense that a person stays close to the place in which she can "refresh her disguise". He calls this "the Cinderella syndrome" and describes how the person moves from "the repair station" only a distance that allows her to maintain control over information about her.

If physical disability is experienced as stigmatising, the use of assistive products can affect its visibility or obviousness to other people. An otherwise discreditable physical disability can turn into discrediting through the use of assistive products that focus on disability. Similarly, a visible physical disability could be turned from discrediting into discreditable due to a well-designed product. Thus, the visibility and stigmatising effects of a particular quality could be better controlled through design.

Even though the focus is here on physical products, it is important to note that stigma is social in nature. Instead of being a quality of a person, stigma emerges in a social context and, there-

fore, it is relationship- and context-specific (Major & O'Brien 2005, 395). According to Goffman (1963, 163–164), stigma involves a two-role (normal/stigmatised) social process, in which everyone participates depending on contexts and phases of life. He emphasises that normal and stigmatised are not persons, but perspectives. For Goffman, stigma means "a socially constructed deviance label" that "emerges as a result of social reactions to such [visible physical] attributes" (Green 2009, 14–15).

Fougeyrollas and Gray (1998, 24–25) present that in particular life situations, interaction between functional differences and contexts can result in discrepancies with norms. Stigma can be located in the relationship between a stigmatising quality and what the surrounding environment considers "normal" or "common" (Bispo & Branco 2008, 2). The identification of a stigma symbol can be unconscious. Emotional reactions to and interpretations of stigma are culturally bound. (Ibid., 2009, unnumbered.) What, however, needs to be noted is that a stigmatising context is often pervasive (Miller & Kaiser 2001, 74).

Views that acknowledge the social construction of stigma are of interest here, because through them also the stigmatising effects of products can be evaluated. Context of use can affect whether a product is stigmatising or non-stigmatising. An example of a former prestige symbol that has turned into a stigma symbol is a walking cane. According to Dankl (2009, unnumbered), it used to be "a sign of elegant gentlemen", but due to society's progressive tendencies it has become an image of ageing.

Within the studies of deviance, Becker (1997, 163) has suggested that deviance results from a process of interaction between people who make and enforce rules and people whose acts are labelled deviant when judged by the rules. It is important to notice that deviance differs from stigma in the sense that deviance is mostly associated with deviant, often immoral, behaviour, which may cause stigma. Instead of deviant behaviour, this research focuses on a stigmatising quality, but some of the views presented in the studies of deviance seem useful in the

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44 Gamliel and Hazan compared two kinds of homes for elderly people and found that in the more modest one, a new label based on, for instance, a resident's behaviour or attitude, could become her entire identity that made her differ from other residents.

exploration of stigma, because also they emphasise the social construction of difference that is experienced as negative.

Becker (1997, 20) identifies four types of deviant behaviour: *falsely accused*, *pure deviant*, *conforming* and *secret deviant*. Falsely accused and pure deviant are both perceived as deviant whereas conforming and secret deviant are not. Secret deviant behaviour corresponds to Goffman's discreditable in the sense that other people do not know of it. Secret deviance means being vulnerable to the discovery and persistence of deviance (ibid., 187). Pure deviant and also falsely accused bear similar stigma as the discredited for Goffman. Conforming behaviour appears "normal". From the viewpoint of this research, the division between visible and non-visible is central. If stigma is viewed as a continuum consisting of visible in one extreme and non-visible in the other, products as part of visual appearance can be considered a means of altering how a person is situated in that continuum. Products can conceal a visible stigma or reveal a non-visible one.

What we consider stigmatising today may have changed since Goffman wrote his renowned book five decades ago. Green (2009, 37) suggests that the way people with disability are viewed and view themselves today differs significantly from the way they did, for instance, in the 1970s. She suggests that people with disability have now better opportunities to participate in social and economic life.[45] She suggests further that people, who would have lived "hidden", now take actively part in social life.

The tendency of modern Western societies to emphasise individuality may not have influenced only how identity is seen, but also how stigma is conceived. Simply, what was once considered deviant might be seen as individual today. Oyserman and Swim (2001) have approached stigma from an insider's perspective and propose that the role of a stigmatised person may have

changed from a victim into an active agent, which means that a stigmatised person may not only avoid stigmatising settings, but also actively cope with them. That may also give some explanation to the personalisation of assistive products. Green's (2009, 34) view extends even further as she challenges the relevance of the concept of stigma and claims that diversity and difference are acknowledged and valued today differently than before. This may be the case among several products and clothing that contribute to appearance, but there still are products which are experienced and viewed as stigmatising.

2.3.2 The Assumed Stigma of Using Assistive Products

Leaning heavily on Goffman, Jenkins (2008, 39–40) suggests that the world we construct and experience can be understood as three interrelated "orders": the individual order at individual, embodied, level, the interaction order in relationships between people and the institutional order in "established ways of doing". All these three orders are involved in the use of assistive products. An assistive product is an integral part of its user's body and identity. In addition, whether successful or not, it is a means of identification and self-presentation in various social contexts. On the institutional level, an assistive product often seems to represent disability and the practices associated with it in society.

Stineman (1998) has assessed the consequences of using assistive products from the viewpoint of how the products operate and on which level they influence. According to her (ibid., 54), products that operate inside the body influence impairment and can reduce both disability and handicap, products that operate outside the body influence the surrounding environment and can reduce social and physical barriers, and products that operate outside but close to the body and influence disability

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45 Green validates this trend by the development of pharmaceuticals and assistive products that have provided people opportunities to participate in education and employment.

can reduce handicap.[46] Prostheses could be viewed as operating inside the body and assistive products for mobility, for example, close to the body. Accessible space and inclusive products can be viewed as operating outside, since they aim at providing not solely physical, but also social and economic accessibility. In addition to being accessible and assistive, they can be characterised as adaptive, because they aim at meeting diverse requirements set by various users.[47]

What seems to be specific to assistive products is that they tend to become rejected and abandoned more often than other consumer products. Pullin (2009, 125) claims that even if assistive products performed technically well, many of them become abandoned. Ravneberg (2009, 106) suspects that people discard and dismantle assistive products or "keep them in closets", because they are not satisfied with their design, they mismatch, they make users lose self-confidence and feel uncomfortable, and they do not fit age, sex or lifestyle. Also users' skills to use technology, attitudes towards technology, the user-centeredness of service (Salminen 2010b, 19), users' motivation to employ the products, the severity of users' disabilities, the quality of other product options, and the experienced benefit of using the products (Scherer 1996, 117) have an influence.

The use or abandonment of assistive products is hereby affected by several factors, but the characteristics of users, products and the environment where the products are employed (Scherer 1996, 118; Salminen 2010b, 18–22) are central for this research. Scherer (1996, 119–120) suggests that a supportive and rewarding environment and pride to use an assistive product increases

product use. She specifies that if a user has a low self-esteem, she experiences the product use embarrassing, the environment discourages, prevents or makes the product use awkward, the product may be avoided, abandoned, or used only partially or reluctantly.

In the intersection of users, assistive products and the environment, stigma seems to be one of the key reasons that affect whether the products become used or rejected (e.g., Goffman 1963, 115; Pape et al. 2002, 17). Salminen (2010b, 19) presents that assistive products can stigmatise their users, because people tend to classify each other according to outward appearance: some people experience that the use of assistive products labels them as disabled, which may restrict their use of those products. Similarly, some elderly people have difficulties in accepting assistive products, because the products may be viewed as representations of old age (e.g., Dankl 2009; Hyysalo 2010).

How users see assistive products, is influenced by what the use of those products symbolises (Pape et al. 2002, 15). Meanings are primarily determined by psychosocial and cultural factors like the costs and benefits of using the products (Cook et al. 2010, 42). In the field of design research, Bispo and Branco (2009, unnumbered) have proposed that through the process of signification, the use of current assistive products becomes a stigmatising symbol that has negative effects on both the emotional and the public image of the user. The authors claim that the stigmatising effect of assistive products creates "a double negative role" for people with disability: in addition to a visible, identifiable sign that emphasises social discrimination, the stigmatising effect results in feelings of shame, low self-esteem and exclusion. In this sense, the stigma of assistive products can simultaneously be perceived and internalised.

Brooks (1991, 1418), who has studied users' responses for assistive products, claims that due to the products' role as replacements for more typical and desirable physiological functions and substitutes for routine abilities, they are not considered to be symbols of valued social status. She claims further that

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46 Impairment occurs at the intersection of body and mind, disability at the intersection between either body and physical world or mind and society (depending on whether a person has a physical or a psychosocial or cognitive disability) and handicap at the intersection of physical world and society (Stineman 1998, 52–53). Consequently, impairment could lead to disability and disability to handicap depending on, for example, assistive products.
47 Scherer (1996, 36) characterises products, which are designed for the mainstream, but adapted in order to be useful also for people with disability, as adaptive equipment.

assistive products are neither conventional nor desirable, and they are stressful in social interaction. According to Pape et al. (2002, 17), assistive products are associated with dishonour, disgrace and embarrassment. Assistive products that are intimate to the user's body, such as mobility or breathing aids, have been claimed to have a particular effect on social identities and relationships (Brooks 1998, 4). From the viewpoint of this research, the fact that specifically mobility products like wheelchairs and walkers are often experienced as stigmatising (Hirsch et al. 2000, 77; Stineman 1998, 57), and also abandoned most often (Phillips & Zhao 1993, 41), may explain why some of the products become personalised by their users.

Whether induced by stigma or other factors, the abandonment of assistive products has various consequences. It may decrease users' functional ability and independence, increase costs, and deteriorate health. From the assistive product allocation viewpoint, the abandonment represents an ineffective use of funding. (Scherer 1996, 116.) In the following, the design emphasis on utility function, products' poor appearance and lack of congruence with the self, products as signs of disability, and the power various stakeholders exercise by allocating assistive products are explored as potential contributors to stigma. The contributors are considered alongside the abandonment of assistive products. The stigma caused by assistive products is materialised also in their abandonment.

The Emphasised Utility Function

In the design of assistive products, utility functions seem to have been prioritised over other functions that contribute to user experience and user value.[48] Scherer (1996, 95) has claimed that in the design of assistive products, considerations such as users' social and emotional needs are almost excluded for the sake of

physical aspects.[49] This can be problematic from the viewpoint of what the products represent or symbolise, because as Vihma (1995, 178) has pointed out, products can be interpreted as metaphors, even though design that emphasises technology or functionality might not take into account their metaphoric references.

By providing accessibility, assistive products aim at connecting users not only physically, but also socially to the environment. The social function appears to be recognised, albeit not applied to practice. Accessibility that centres on utility function does not necessarily guarantee access to social interaction. Instead, it can become a stigmatising hindrance that isolates users, if it focuses attention to users' disability and emphasises difference. A comparable issue has been recognised within some protective equipment: Vihma (1995, 137) has found that the design of bicycle helmets is sometimes dominated by protective aspects resulting in labelling products. Similarly, the design of assistive products seems to be driven by assistive features that contribute to stigma. However, bicycle helmets and assistive products differ in advertising. Whereas helmets are presented as elegant sporty accessories (ibid.), the advertising of assistive products tends to emphasise assistive physical aspects.

Current assistive products can be considered representing both practical and engineering styles. In practical style, the parts of a product correspond to its utility functions and in engineering style, a product is "defined by production and technical details such as joints and seams of moulds" (Vihma 1995, 114). The forms, colours and graphics of assistive products often serve solely assistive functions. Furthermore, those attributes appear to be separate. They do not seem to complement each other in the sense that they would form a whole. Materials are chosen to be durable, but not necessarily appealing. Technical properties and usability are often emphasised. Assistive products can, neverthe-

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48 See also Jacobson & Pirinen 2007a & 2007b.

49 Similar issues have been identified within patient clothing: even though maintaining self-image through the expression of social roles is important for patients in long-term care, the current patient clothing tends to focus on patients' physical needs (Iltanen & Topo 2005).

less, influence user experience and evoke emotions, even if user experiential qualities were not paid attention to in design.

Eger and Drukker (2010) propose six qualitative phases of product development for consumer products: performance, optimisation, itemisation, segmentation, individualisation and awareness.[50] Even though assistive products are not mass-market products, some of the phases, and especially their characteristics, that is, newness, functionality, product development, styling, number of competitors, pricing, production, service and ethics (ibid., 48), seem to characterise the current state in the design of assistive products quite well. The design of assistive products can be seen as having reached the phases of performance and optimisation, perhaps even itemisation, in terms of their technical performance, ergonomic aspects and issues of reliability in use and safety, but signs of segmentation or individualisation seem absent or at the least rare. However, the last phase, awareness, seems to have been taken into account in the form of ethical aspects that are likely to derive from the strictly regulated health-care context of assistive products.

The reason for the early product phases could be designer-related. Assistive products are rarely designed by professional designers as many other consumer products nowadays are. Instead, they are often designed by engineers or technicians. Larsson et al. (2005, 2) have made a rather harsh claim that in engineering design, issues concerning overall quality of life can be "heavily under-prioritised", particularly in the design for people with disability. Also appearance-related aspects such as style may be

secondary, which can result in poor choice for users. From the viewpoint of expressing identity, the limited selections and assortments of assistive products leave users with few possibilities. In that sense the stigma of assistive products could be considered designed.

Not only in design, but also in the evaluation of assistive products utility functions can be emphasised. The during- and after-use consequences of assistive products may not be properly assessed. Simpson (2010, 51) claims that the long-term consequences of using assistive products are rarely evaluated. Instead, he suggests, scientists and engineers evaluate products as part of the research and development processes and clinicians when they are fitted for their users. Such evaluations are necessary, but they may not be sufficient, because the social consequences of using assistive products like stigma emerge in actual contexts of use in process of time.[51]

One reason for the insufficient evaluation of assistive products could relate to research methods. Quality and satisfaction measures are claimed to be difficult to define and subjective measures are thought to cause reliability issues and to not allow enough generalisation (Simpson 2010, 54). The problem is that users' individual experiences that arise through various product functions in different contexts of use may not show and become applied in design, if they are measured in large quantities in laboratory settings, or if they concern only quantitative information in the first place (see also Hyysalo 2010, 95–96). Also qualitative measures in actual contexts of use would be needed.

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50 In the performance phase, the focus is on improving primary functionality, the optimisation phase extends the focus on ergonomics and issues of reliability and safety, and in the itemisation phase, also product aesthetics becomes a concern. The first three phases concentrate on improving functionality, reliability, ergonomics and safety. In the segmentation phase, extra features and accessories are developed and the design focus shifts to emotional and expressive qualities, in the individualisation phase, products are tuned to individuals and design strategies such as mass-customisation and co-creation are adopted. In the final awareness phase, also ethical concerns become of interest. (Eger & Drukker 2010, 49–52.)

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51 Similar findings have also emerged in research on health technologies. Hyysalo (2010, 109–112, 173–178) has found that technical features and features related to manufacture are salient in the design of wristcare devices and also influence the evaluation of the devices. According to him, the actual use-related consequences emerge in use. Health technologies are not in the scope of this research, but like patient clothing, they can increase understanding of similar problems faced in the design of assistive products.

The Poor Appearance

Based on the qualitative product development phases introduced in the previous section, the emphasis on utility function can mean that assistive products' appearance is of minor concern in product development. The aesthetic function appears to be rarely taken into account in the design of assistive products and many of the products could be characterised as too large, clumsy and noisy. Also their smell can be unpleasant as in the case of prostheses. Assistive products do not seem to follow the style of those consumer products that are currently favoured in society: Brooks (1991, 1418, 1422) claims that an assistive product is very rarely "an accessory that demonstrates personal choice, taste, or social fashion". She claims further that neither it is considered convenient or a source of pride.

Product appearance influences and can even prevent using assistive products. Whereas assistive products, whose characteristics users perceive positively, are more likely to become employed (Wielandt et al. 2006, 36), products that look unusual and do not meet their users' needs become unused (Parette & Scherer 2004, 219; Scherer 1996, 132). Ugly assistive products are more easily rejected despite their necessity (Salminen 2010b, 20). In the institutional clothing used in hospitals and residential care, it has been found that even small details like a too tight rib of a tracksuit can ruin the value of the product (Topo & Iltanen-Tähkävuori 2010, 1688). Cook et al. (2010, 41) claim that poor design, despite good intentions, is a major problem that affects the abandonment of assistive products.

Among assistive products, lack of variety is mostly associated with appearance. From the viewpoint of utility functions, products are often tailored according to invididual ergonomic requirements, which they may meet well. But, their appearance is less likely to allow for similar customisation. Lack of variety in appearance-related qualities can enhance stigma by maintaining a one-sided image of users. Furthermore, aesthetic and social functions seem to be interrelated and consequential in the sense that the [un]aesthetic values of assistive products may contribute to stigma, which, for one, affects social identity and social acceptance.

There are, however, contradictory findings regarding the influence of choice on product abandonment. Whereas assistive products are claimed to be abandoned if users have more potential product options to use (Scherer 1996, 117), also evidence that implicates that the abandonment of assistive products would not always be significantly related to alternatives to choose from has been found (see Phillips & Zhao 1993, 41). On the one hand, the importance of appearance and product options may relate to the stage when assistive products are employed. In later stages, as a user has learnt to master a product, appearance may become more important. On the other hand, the concern of the product's image is higher when the product is employed for the first time. Users want to control the images they convey about themselves, and when choices are available, users become also interested in the product appearance. (Pippin & Fernie 1997, 100–101.)

The Insufficient Identity Function

The abandonment of assistive products also relates to users' perception of themselves as disabled and to broader issues of identity (Hocking 1999, 3). Salminen (2010b, 20) suggests that users rather accept a pleasant-looking product because it also supports an able self-image. Because an assistive product easily becomes part of its user, a strong contradiction between a product and its user's personality may prevent the use of the product (Töytäri et al. 2003, 152). From the viewpoint of this research, assistive products' ability to construct and communicate their user's identity (Hocking 2008, unnumbered) is central. Many of the current assistive products seem to maintain solely a "disabled role" or a "disabled reality" that people with disability are not necessarily willing to accept as their main, or only, identification.

Belk (1988, 159) proposes that people discharge or neglect

products when they no longer fit their self-image, in which case either the self-image has changed or the product image has changed. Also changes in the environment or culture influence. The incompatibility between users and products may, however, also have more profound consequences than the non-use of products. Csikszentmihalyi and Rochberg-Halton (1981, 16) claim that objects that hinder the pursuit of goals may also hinder the development of the self. The use of assistive products can create a discrepancy between how other people perceive a person and how she herself experiences her identity. This can, however, depend on the environment where the products are used and on the user's role in it. In an unusual environment the meaning of products that relate to identity can become emphasised. In a hospital, for instance, a person's furniture, clothing, voice, make-up, hair and movement differ from what they would be outside of the hospital (Album 2010, 358).

Govers and Mugge (2004, unnumbered) suggest that self-congruent products can express aspects of the self and product-personality congruence can influence the product attachment. That can further prevent the abandonment of products (Mugge 2007, 20). The fact that many assistive products are allocated through health centres and hospitals as second-hand can be one reason for their abandonment. At least it can hinder attachment with the products. Douglas (2002, 197) has proposed that when users' identities are recognisable in products, they can become unattractive "dirt" to others as possessions. Belk (1988, 152) suggests that if "the disgust" of others' possessions may depend on how recognisable the identities of the previous owners are in them, the disgust of a person's own possessions may depend on how unrecognisable her own identity is in them. Second-hand assistive products may carry traces of their previous users, which could prevent their current users from becoming attached to them. As for new assistive products, users may not recognise themselves in them either, if they do not provide features to identify with.

Assistive products carry meanings not only to their users, but also to the users' surrounding environment (Miller Polgar 2010, 21). It is essential for meaningful communication that people with disability are able to construct a reality that can be shared with other people like family, friends, personal assistants and professionals who are involved in their daily lives (Brooks 1998, 3). The fact that assistive products can be seen as "objects encountered and interpreted in personal and social contexts" (Hocking 2008, unnumbered) also influences the emergence of stigma.

Visible Signs of Disability

A person communicates through bodily expressions in the presence of other people (Goffman 1963, 59).[52] Assistive products are often body-related at least in two ways: they are attached to the body and they perform bodily functions. Brooks (1991, 1417) considers assistive products "cues to social roles", because they are closely related to the body and personal functions. What assistive products, however, currently communicate seems often to be solely attached to their function as disability aids and directed towards their users' disability.[53] Furthermore, stereotypical assumptions about the users of assistive products are often exaggerated, one-sided and even erroneous, which means that their cues may enhance the products' stigmatising effects. Edwards and Imrie (2003, 247) claim that the inattentive design of the built environment devalues the disabled body and draws attention to the limitations of the body.

Assistive products could be viewed as bodily expressions of collectively shared meanings of disability. They convey information on how disability and people with disability are viewed (e.g., Anderberg 2005, unnumbered; Brooks 1991, 1418 & 1998, 4).

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52 Goffman calls this kind of information social.
53 Some assistive products like white canes for people who have visual impairment, however, provide information that can also protect their users (see also Shinohara & Wobbrock 2011, 710).

Along with the use of assistive products comes all that is associated with disability. Assistive products contribute to what is understood by disability, what disability means. If disability is seen as "an ill-fit between embodied experience and diverse environments" and, therefore, the body and the environment as "equal vestibules leading into the category of disability", as De-Poy and Gilson (2010a, unnumbered)[54] have proposed, assistive products contribute, as part of the material environment, both to the ill-fit and the category.

An assistive product not only informs others that its user has a disability, but it often reveals even the kind of disability and how severe or permanent it is (Brooks 1991, 1418). When it comes to other consumer products, similar intimate or "impairing" qualities would not be paraded unless intentionally. On the contrary, Csikszentmihalyi and Rochberg-Halton (1981, 26–27), for example, suggest that some products are chosen to represent their owner's power. Instead of power, assistive products often address users' supposed frailty. The frailty associated with disability and, therefore, also with the use of assistive products, can be physical, intellectual, social or financial. All of them can be represented in the use of assistive products. As visible signs of disability, assistive products can become the focus of attention instead of their users, and barriers of participation that reinforce stigma, which can isolate users from their environment (Miller Polgar 2010, 20–21).

Assistive products not only point to disability, but also have a tendency to "falsify" or "add" it. Assistive products can lead other people to believe that the users of assistive products do not meet "usual expectations" (Stone 1995, 418), or that people who have a physical disability are disabled also in other respects (Sapey et al. 2005, 495).[55] Papadimitriou (2008, 700) considers a

wheelchair both "the symbol and object of stigmatisation": people who use a wheelchair are devalued and they have an inferior status, because they are thought to have attributes as dependence, helplessness and uselessness because of the wheelchair. She states that by becoming a defining characteristic, a master status, such a symbol of inferiority may portray its user as an object.

Assistive products make disability concrete not only to other people, but also to the person with that disability. How other people perceive disability affects the experiences of people with disability (Pullin 2009, 130–131). Through being observable and appearing inseparable from users, assistive products influence their users' self-perceptions (Brooks 1991, 1418). The stigma of disability also affects whether people acknowledge their own disability or not (Stone 1995, 418). For instance in the case of progressive conditions, Pape et al. (2002, 15) suggest that assistive products may symbolise "the nearing of the end" or "the serious implications of the disablement process".

The health-care viewpoint is apparent also in assistive products. Brooks (1991, 1418) considers assistive products "subjects of medical prescriptions or social-welfare intervention", which elicit associations with formal systems like health care and medicine. Also their design can be seen as associating them almost invariably with medical equipment, even though some of the products are used for similar, even identical, purposes of use as other consumer products. Vihma (1995, 97) has proposed that a product can be interpreted as referring to a particular environment based on a shared similarity, like in this case, a piece of medical equipment to hospital.

Assistive products seem to be not only designed and evaluated according to their utility functions, but also marketed the same way. Typical of the first product development phases proposed by Eger and Drukker (2010, 49), the promotions of assistive products are often realised through fairs and brochures delivered in retail shops instead of focusing on individual customers, products' users. Commercials tend to address professionals (Ravneberg 2009, 109). Actual contexts of use and product

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54 De Poy and Gilson base this view on their Disjuncture Theory, which locates disability at the intersection of the body and the environment.
55 Becker (1997, 33) remarks that it is similarly thought that one deviant act increases the probability that a person who commits it becomes regarded as deviant also in other respects.

qualities that would enable people to identify with the products seem to be missing. Users are often presented as patients in the context of health care, which positions them as different, even inferior, in comparison with other consumers present in media.[56] How disability is viewed is also present in marketing. Brooks (1998, 5) presents that assistive products would be "highly advertised and socially valued products", if disability was "a highly desirable characteristic". The way assistive products are currently marketed is likely to maintain the products' stigma and to contribute to the stereotypical images people have of their users.

Prescribed and Assigned

The users of assistive products have little, if any, control over their products. First of all, the products are employed out of necessity. Furthermore, users are not actively and systematically involved in the design process and they do not always have the chance to choose which products to use. Someone else may select products for them (see also Olander 2011, 21). Ravneberg (2009, 103) describes how the Norwegian state-regulated market for assistive products, which is similar in many other countries including Finland, "secures good solid products at a reasonable price, but deprives users of choice and control". Users may prefer products that exist, but which are not available through the public sector. Teikari and Björkman (2006, 62–63) suggest that due to financial reasons, there is a tendency in Finnish municipalities to arrange extensive "package deals" that are supposed to fix the housing problems of people with special requirements. The authors note that the "one size fits all" strategy does not, however, acknowledge the different quantitative and qualitative requirements of, for instance, young people with disability, peo-

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56 Also in their analysis of the catalogues presenting, for example, clothing used in the nursing environment, Iltanen and Topo (2005, 52–54) found that discreet, but explicit references are made to users' illness and weak ability to function.

ple with intellectual disability or elderly people.

Scherer (1996, 116) has proposed that the single most significant reason for abandoning assistive products is that the products do not meet users' needs or expectations, because users' opinions and preferences are not considered when choosing the products. When considering, for instance, a wheelchair, a user should have the possibility to choose various properties like colours and materials (Töytäri et al. 2003, 151–152). According to Csikszentmihalyi and Rochberg-Halton (1981, 17), one of the preconditions for products to be able to reflect and shape the self is that they are chosen and discarded. Being able to influence product properties can also increase product attachment, because a user "invests effort", whether time or attention, in a product by customising or personalising it (Mugge 2007, 96, 101, 115).

In the case of assistive products, lack of control is often associated with dependence. Pippin and Fernie (1997, 96–97) have shown that also feelings of being dependent relate to stigma. Spafford et al. (2010, 592) describe how some people with visual impairment do not want to be seen with assistive products and viewed or treated as disabled, because they experience the use of white canes as "signs of dependence" and "a source of embarrassment or stigma". The relation between dependence and stigma is also apparent in patient clothing as some clothes, like overalls to prevent inappropriate behaviour, can be very stigmatising and infantilising (Topo & Iltanen-Tähkävuori 2010, 1687).

Stakeholders involved in the design and allocation of assistive products can "assign" their users as disabled and contribute to the social construction of disability. Brooks (1998, 5) suggests that through their collective views and interactions, assistive products can become public expressions of whether disability represents "an ordinary life occurrence" or "a condition that is associated with multiple disadvantages". Similarly, Gaffney (2010, 71–72) states that rehabilitation can enhance associations of assistive products and "the sick role" and, thus, contribute to

the stigma of the products and the establishment of the products as "social symbols of incapacity".

Jenkins (2008, 198) has brought out how organisations like health centres, hospitals and social services can identify people and make the identifications last by actions like allocating resources. He (ibid., 191–192) claims that assessment through which, for example, the resources of public housing are allocated, involves stereotypes. As a result, there is "a spatial arrangement of public housing" where people's worth varies according to where they live and where people are placed to a particular place according to their identified worth. Similarly, assistive products can be viewed as "arranging" users into users who are thought to have particular qualities and resources.

In disability studies, DePoy and Gilson (2009, 2010a & 2010b) have critically brought up designers' role in creating disability through poor design and marketing. They (2010b, 55–60) state that disability is "a phenomenon of design and branding" resulting in "disability by design". Assistive products assign identity and manipulate from the viewpoint of both their users and people who view them. The authors claim that the products brand their users as disabled through their design and distribution outlets. In addition, they position users with disability as "a target market segment ripe for commodification and economic exploitation" (ibid., 2010a, unnumbered). The brands in the field of assistive design can be seen as directing users to their constricted product selection, which could be considered to be a form of manipulation. Shakespeare (1997, 230) remarks that in addition to media, also charity can reinforce "a subordinate position" for people who have disability.

2.3.3 Managing Stigma

Goffman (1963, 101) suggests that a stigmatised person learns the normal point of view, learns that she does not qualify for it, learns to cope with others' reactions to her disqualifications and learns to pass. According to him (ibid., 125), socialisation may be

concluded with a disclosure, in which case a stigmatised person accepts and respects herself as she is and does not feel the need for concealing her stigma.

This may not always be the case. Edwards and Imrie (2003, 250) present how some people with disability may employ "forms of bodily self-censure" that derives from "embarrass[ ] ment, awkwardness, or feelings of discomfort of perceived corporeal status". That may also explain why stigmatising products become critically viewed and evaluated. Ripat and Woodgate (2011, 90), who have studied disability and assistive products from the viewpoint of culture, propose that also inconsistent and incongruent meanings, which are assigned to assistive products by different groups and cultures to which a person belongs, may cause considerable internal conflict. Stigma can even become threatening, if it exceeds a person's resources to cope with it (Major & O'Brien 2005, 402).

As this research considers people with disability active and inventive in relation to their assistive products, views that emphasise people's attempts to cope with stigmatising qualities and their consequences are of interest. Many of them, however, seem to focus on intangible strategies, which concern among others adapting behaviour and attitude in social and societal relationships (e.g., Rogers & Buffalo 1974), therapeutic and educational actions from individual to governmental levels (e.g., Heijnders & Van der Meij 2006) and stress management techniques (e.g., Miller & Kaiser 2001). In order to explore personalisation as a way of influencing the stigma caused by assistive products, more concrete views that extend to controlling stigmatising qualities are needed. The focus is, thus, here on tangible, "hands-on" techniques that are applicable in the context of assistive products. The interest is in voluntary, conscious techniques that people, who experience stigma, can employ when expressing the self in social contexts. Of particular interest is the role of products in managing stigma.

Goffman (1963) has probably most notably discussed the management of stigma. He (ibid., 58) describes how people,

whose stigma is not apparent, may try to prevent its disclosure and pass as "normal". He defines *passing* as "the management of undisclosed discrediting information about self". Even if many assistive products which are experienced as stigmatising are often apparent, passing can shed light also on the reasons for personalising them. Personalisation can be explored from the viewpoint of "mainstreaming" assistive products, that is, trying to make them appear more like other consumer products and, consequently, also trying to make their users appear like any users of any products. Personalisation can be considered a way of adjusting the obtrusiveness of a visible stigma. Goffman (ibid., 69–70) specifies that the management of stigma occurs mainly in public life between people who are acquaintances or even strangers. He suggests that people with physical disability, for example, may employ techniques that help handle strangers, move past tactfulness, and distance on a more personal level beyond disability.[57]

The perceived visibility of a stigmatising quality does not necessarily determine the selection of stigma management techniques, then. Goffman (1963, 125) actually proposes that discreditable and discredited people often share similar, even identical, techniques to manage stigma. But in this research, the starting point is a visible stigma caused by the use of assistive products. It is assumed that poorly designed assistive products can emphasise and even reveal an otherwise less visible or invisible quality. Likewise, it is assumed that well designed, or personalised, assistive products can help manage or even prevent the emergence of stigma.[58] This research explores assistive products' ability to support users' attempts to adjust their social image and self-image (Pape et al. 2002, 17).

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57 Goffman refers to the process of "breaking through" introduced by sociologist Fred Davis.
58 I have earlier (Jacobson 2010) proposed that disguising stigmatising product qualities, turning attention or "creating diversions" from them to other qualities, and transforming them into qualities that express pride and joy by personalising products could diminish the stigma caused by using assistive products (see also Vaes et al. 2012).

Hiding and Covering

Considering the high visibility of assistive products, stigma management techniques, which aim at diminishing obtrusiveness, can become easiest at stake. Hiding is probably the most common means of managing both visible and non-visible stigma. Goffman (1963, 125–126) suggests that people with a visible stigma may engage in activities that prevent the stigma from "looming large". He introduces *covering*, through which people aim at reducing tension, withdrawing attention from the stigma, and sustaining interaction spontaneous and focused on its official content in social situations. According to him, the stigma management techniques employed in passing are similar and sometimes identical to covering, because "what will conceal a stigma from unknowing persons may also ease matters for those in the know". Goffman continues that "[m]any of those who rarely try to pass, routinely try to cover". Various disidentifiers or covers may be used as a means of concealing or obliterating stigma symbols (ibid., 114–116).

Assistive products can be manipulated and even rejected in order to manage stigma. People may cover assistive products or their assistive properties in order to make the products blend into the style of their homes instead of sticking out as "institutional-looking" (Hirsch et al. 2000, 77).[59] Shinohara and Wobbrock (2011, 709) introduce people who could "pass as having no disability" when not employing any assistive products.

In the design of assistive products, there is a history of hiding and covering. Pullin (2007, 5) brings out how discretion that has been achieved through concealment has been prioritised, but it has not, however, always been successful. He (ibid., 8) describes how the kind of "realistic approach" in products like hearing aids and prostheses has resulted in imitation of human skin, which may be experienced as unpleasant and tacky. Ravneberg (2009, 107), on the contrary, describes how her in-

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59 See also Jacobson & Pirinen 2007a & 2007b.

terviewee, who is hard of hearing, prefers "flesh-coloured instruments", because they visualise her disability less than colourful ones. Ravneberg remarks that the hearing equipment market has traditionally signalled through flesh-coloured products that hearing loss actually is something to hide.

Hiding and covering are not exclusive to people with disability or to the users of assistive products. Becker (1997, 168–170), for instance, discusses people who commit deviant acts and resort to covering up or hiding.[60] Iltanen (2007, 112) has found that middle-aged women may cover with clothes traces of life and ageing like scars, injuries and illness, because in view they would raise feelings of discomfort, insecurity and shame created by the disclosure of their imperfection. She presents that middle-aged women may also hide from clothes features that raise old-age-related associations. According to her, covering traces that relate to characteristics like age may also need appropriate revealing.

Hiding could, thus, require counterbalancing or manoeuvring. Goffman (1963, 126) brings out people's concern for the standards associated with stigma when covering. He illustrates this with an example of a person who, in addition to a visual impairment, also has a cosmetic defect in her eyes. The person may choose to wear dark glasses to hide the defect in spite of then revealing her visual impairment resulting in "a case of revealing unsightedness while concealing unsightliness".

Also Ravneberg (2009, 106–107) presents an interesting case, which could be seen as a form of hiding or covering. She introduces people with disability who choose to use worn-out assistive products instead of those with smarter designs. She describes how in "the patient market" of public services, the former are seen as representing temporality, independency and non-disability, but the latter permanence and dependency, be-

cause patients seldom get "the coolest" products. By employing old products, which are associated with temporary disability, users could hide more severe disability.

As discussed, assistive products in the scope of this research are not used alone in privacy, but in view and as part of social interaction. In Goffman's (1963, 127) opinion, the most interesting expression of covering relates to the organisation of social situations where particularly people with physical disability reconstitute their behaviour in order to avoid interference with etiquette and communication by minimising the obtrusiveness of their stigma. From the viewpoint of this research, it is important that products can be helpful in adjusting social situations and behaviour, because that can help explain personalisation. An illustrative example of this could be fitting assistive dishes and cutlery, which enable people with disability to participate and follow dinner etiquette.

Fading Out and Disguising

In earlier studies, I have found that "fading out" or "disguising" can be seen as a more appealing way of covering products' assistive properties.[61] In addition to covering, fading out or disguising resembles designing, because it involves not only hiding unpleasant features, but also replacing them with more pleasant ones, which fit the overall design of the context of use. The aim is not solely to manage stigma, but also to express something about a user's identity and that of her home.

In terms of fading out and disguising, prostheses offer an interesting example of managing stigma. A prosthesis, meaning "addition" in Greek, used to be an ancient medical art that was dedicated to the amelioration of physical stigma (Hughes 2000, 561). Nowadays, prostheses are versatile and enable various functions from daily tasks to demanding athletic performances.

60 Becker (1997, 61) has studied marihuana users in the presence of non-users and considers secrecy, that is, keeping others form discovering, as a means of social control. He (ibid., 73) unfolds how marihuana users cope with "the stereotype of the dope fiend".

61 Jacobson & Pirinen 2007b, 320 & Jacobson 2010, 6 (see also Vaes et al. 2012, unnumbered).

In addition to such active prostheses, there are also passive prostheses that are mostly used for cosmetic purposes. (Kruus-Niemelä 2010, 150.) Some of the prostheses used by the American award-winning athlete and model Aimee Mullins, for example, through which she can alter her height or finalise her outfit, can be viewed also as cosmetic prostheses, which convey identity-related information. Similarly to assistive products, also prostheses are customised and personalised by users, and users' ideas engaged in design (see e.g., The Open Prosthesis Program).

Goffman (1963, 117) proposes that stigmatising attributes can be presented as signs of other attributes that are less stigmatising. He (ibid., 123–124) describes how stigma symbols may be worn voluntarily or a "disclosure etiquette", through which stigma can be revealed in a matter-of-fact way, can be employed. Goffman (ibid., 126–127), however, points out that sometimes the visibility and obtrusiveness of those features that are central to stigma are not only hidden, but even restricted. He illustrates this with an example of a person with physical disability, who may refuse to perform certain physical functions in order not to reveal her disability. He also mentions "assimilative" techniques, like changing a name, which are common among minority ethnic groups.

In addition to disability and the use of assistive products, stigma management techniques also concern other visible physical characteristics that may be experienced as stigmatising. Saguy and Ward (2011, 68) suggest that obese people can apply various strategies, of which some are assimilationist and others more radical. Hawkesworth (2001, 310–313) describes how adults with severe acne can lessen their awareness of stigma and the emphasis of body-related values through time-space tactics: depending on the phase of their acne, they delay and postpone meetings, withdraw from companies they think do not like them, and prefer solitude, lack of light and dark places. Avoidance is utilised as a means of reducing anxiety in social situations. Obesity and acne are out of the scope of this research, but they can increase understanding of people's means of managing visible body-related stigma.

Drawing Positive Attention

Not all stigma management strategies are based on concealing. Green (2009, 7–8) presents naming and defining as one attempt to change the public image of long-term conditions. She points out how a long-term condition itself is a less stigmatising term to cover various causes of chronic illness and disability. In disability studies, Marks (cited in Green 2009, 7–8) specifies two strategies: positive naming and defiant self-naming. Mentalwear Ltd., a Finnish company that designs t-shirts that are "statements for tolerance", aims at fighting prejudices related to, for example, mental health in a humorous way (Mentalwear). The products of the company could be viewed as examples of defiant self-naming. Also the stereotypical images of ageing can be dealt with humour and mockery (Iltanen 2007, 77–79). Gamliel and Hazan (2006) have found that collective gossiping that affirms identity can be a means of turning the stigma of old age into positive among residents in an elderly people's home.

Saguy and Ward (2011, 54, 66) bring up how some obese people affirm their obesity instead of disclosing, and draw attention to a visible stigma instead of refusing to cover it, by *flaunting*[62]. The authors describe how people come out proudly as obese, reject cultural attitudes that consider obesity unhealthy, immoral, ugly or otherwise undesirable, and affirm and valorise characteristics that are stigmatising and highly visible. They aim at defining the meaning of their body and assigning new cultural meanings and practices for it. Wolfensberger (2000) has introduced the concept of social role valorisation, by which he means "upgrading" devalued social roles to more valued ones.[63] According to him (ibid., 120), medical equipment and prostheses as well as hospital-looking rooms are examples of imagery

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62 Saguy and Ward apply the concept previously introduced by legal scholar Kenji Yoshino.
63 Rauhala (2007, 41–42) has applied Wolfensberger's conception of the construction of social imagery in interpreting how people with disability were viewed in the project she studied.

associated with "the sick role". In valorising the role, he suggests that, for example, rooms could look like ordinary rooms and medical equipment and prostheses less sterile, less mechanical and more attractive. If assistive products carry positive meanings to both their users and the surrounding environment, the products are likely to become an integral part of their users' lives (Miller Polgar 2010, 21).

Designing Stigma Out

Even though technology and design can be viewed as "mediators of disability" that strengthen the old disabling structures, they can also break down old structures and create new ones (Anderberg 2005, unnumbered). Green (2009, 36) suggests that in addition to masking and concealing, technology can be used for reshaping and presenting the self. Optimistically, she envisions that assistive products can become more varied, tailored and personalised, "areas of choice – blank pages on which constructions of self and identity can be drawn". Design can be viewed as a way of managing, even valorising, stigma, which may explain why some mainstream products are used for assistive purposes of use, or why some assistive products are personalised.

The fact that the references of products can strengthen, but also change a culture's traditional values in order to meet new requirements set in a new cultural situation (Vihma 1995, 88) is central from the viewpoint of the stigma caused by assistive products, because that gives design a significant role in diminishing stigma. Through design and branding, bodies and environments can be redesigned and rebranded to produce compatibility and goodness of fit (DePoy & Gilson 2010a, unnumbered).

Designers not only materialise established cultural meanings, but also contribute to the creation of new ones. Designers can mould social perceptions (Athavankar 1990, d14) and influence values and attitudes through design (Olander 2011, 105). Volonté (2010, 120) suggests that the role of designers has widened to include inventing new ways of social communication

for products, which he claims is important, because communication has become the main source of identity, satisfaction and self-realisation for people. For him (ibid., 127), designing means modifying the world, in which a designer's task is not only to change the physical environment, but also "the experience of people and therefore the processes of signification that they enact". The alteration of physical environment evokes "new acts of signification" in the user. Volonté specifies that to design is to produce material situations that are potentially meaningful. According to him, the responsibility of a designer is to open and close new possibilities for communication in various life situations and, thus, the production of identity.

If design can provide assistive products with new ways and possibilities of communication, refresh their potentially outdated brands, change cultural values that are attached to them, and enable meaningful user experience, designers are not only able to influence the visibility of stigma, but also manage or even prevent its emergence. The prevailing image of assistive products and what the products represent are, however, strong.

Various ideas for designing out the stigma caused by assistive products have been presented. Stineman (1998, 69) has proposed that assistive products could be viewed as accessories, tools or machines instead of props and expressions of physical limitation. Pullin (2009) has toyed with the idea of top designers and couturiers also designing assistive products.

Also more specific design guidelines have been developed. Bispo and Branco (2008, 2) have encouraged paying attention to "the social expectations of what the so-called normal characteristics" of objects are and how assistive products currently differ from them. The authors (ibid., 4–5), who have applied Goffman's concepts of discredited and discreditable persons, have suggested that for people whose stigma is not visible, possibilities to cover or disclose stigmatising characteristics could be provided and for people who have a visible stigma, symbols that shatter the stigmatised image and promote a new one controllable by the user. Vaes et al. (2012, unnumbered) have pro-

posed reshaping the social and societal context where stigmatising products occur, reshaping products and their meanings, and empowering users who use the products. Stockton (2009, 3–5) has introduced many ways, through which the de-stigmatisation of assistive products could be achieved: through products' educational qualities, by utilising advanced technology, by applying mainstream characteristics, by adopting stigmatised characteristics in mainstream products, by providing assistive products with functional desire that appeals to other users as well, by altering product forms in a way that also alters rituals of use, by disassociating products from stigma by repositioning the existing brand, and by associating products with positively perceived brand values.

Also the inclusive design approaches have recognised stigma as a risk. In order to minimise the possibility of an individual being perceived as unequal, Kaletsch (2009, 67–71) has introduced an eighth principle, "Perception of Equality", to the Seven Principles of Universal Design.[64] The eighth principle concerns the stigmatising features associated with current products. Except for justifying the need for the principle through illustrative examples, the idea seems not to have been carried further in practice. Also Olander (cited in Olander 2011, 3, 85) has recognised the narrow focus of the Seven Principles and expanded them with "Emotional Universal Design Principles". Her principles concern the avoidance of segregation and stigmatisation, equitable choices, appealing design to all users, and enduring behaviour. Building on Jordan (2000; see Chapter 2.2.2 above), they provide users with pleasure on physical, social, psychological and ideological levels (Olander 2011, Article 1). By acknowledging the need to pay attention to users' self-images and how other people view them in the design of inclusive products, the first principle relates to the aims of this research.

DePoy and Gilson (2009, 64) point out that not only designing, but also branding represents and shapes such things as values, ideas, identities and cultures. The authors consider brands "design stories that unfurl and take on meaning" as shared by multiple creators. Advertising has a substantial effect on meaning creation and transfer as well. McCracken (1986, 75) unfolds how cultural categories, which correspond to the assumed meaning a user seeks from an advertised product, can also be found in advertisements. The way, and to whom, assistive products are currently promoted significantly affects the image of the products. The fact that the advertisements of assistive products often emphasise the health-care context of use reasserts the products' role as disability aids.

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64 The Seven Principles are Equitable Use, Flexibility in Use, Simple and Intuitive Use, Perceptible Information, Tolerance for Error, Low Physical Effort, and Size and Space for Approach and Use (Clarkson et al. 2003, 13).

3 The Personalisation of Assistive Products as a Case Study

The approach of this research rests upon an assumption that many people with disability are active and inventive in modifying their assistive and accessible physical environment. This is described in the following subchapter with relation to how research on assistive products has traditionally viewed users with disability, and how some novel approaches that are in line with this research view them. The latter subchapters present the case study approach, the collected empirical data, and the analysis of the data.

3.1 Inventive People with Disability

Anyone can possess at least some levels of design ability (e.g., Cross 2007, 38–39, 49).[65] This view has been adopted in the Finnish industrial design education that has fostered the involvement of users through user-centred approaches like co-design. At best, users can be seen as what Keinonen (2010, 23) calls "augmented lead users", who are, among other things, highly competent, present, social, active, communicative and critical in relation to design. However, particularly in the design of assistive products, users' active role is not established yet. This may derive from the conceptions of disability present in the assistive product field in general. For instance, Gaffney (2010, 71) suspects that rehabilitation staff may focus more on users' incapacities than their strengths. Similarly, Ravneberg (2009, 105) suggests that particularly in the public provision of assistive products, the focus can be on the "malfunctioning" of the body. Views that emphasise users' disability instead of their ability may slow down the application of the user-centred approach.

Access may often mean the use of assistive products, even personal assistance, but Ladner (2010, 27) proposes that people

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65 Cross specifies that non-professional design usually means selecting already designed products instead of designing new ones. In this research, non-professional design is considered any modification or customisation of products for the purpose of better suitability. The focus is on identity-related product qualities.

with disability do not necessarily need to "be taken care of or have decisions made for them by others". Even though the users of assistive products are often considered on the basis of their disability, also other views exist. Gitlin (1998) has proposed a theoretical career path of first-time users of assistive products. In the career path, a user progresses from a novice user in hospital to an early user, an experienced user, and an expert user at home in process of time (ibid., 129). The accumulating experience concerns the use, acceptance and mastering of assistive products, and various factors which influence them. Papadimitriou (2008, 701), who has studied the learning of mastering a wheelchair and becoming, through that, newly abled, encourages considering disability as a situated accomplishment, something a person can do, not what she is, instead of viewing it as "a master status or all-encompassing state of being". Concerning the independence of people with disability, Helgøy et al. (2003) have recognised the super-normal, the independent living activists, and the powerless and resigned based on their relationship with the service system. Even though none of the authors discusses users' expertise from the viewpoint of inventive use or modification of assistive products, they acknowledge users' skills and expertise.

Green (2009, 24) notes that disability theorists have criticised the prevailing "personal tragedy" perspective for considering people with disability passive, dependent and deviant and argued in favour of what people with disability can do, which, however, general society may not enable them to do. Also Livingston (2010, 59) suspects that people who do not have disability may underestimate the willingness and ability of people with disability to make contributions to society. In reducing health-related stigma, Heijnders and Van der Meij (2006, 353, 361) propose that people could be empowered to take a more active role.

Scherer (1996, 149–150) considers users an ideal choice for prototyping assistive products, because they are motivated and many of them can have technical insight. She suggests that users who participate in the design process can encourage other users to use assistive products and such "peer modelling" is a

further benefit of user participation. This research considers users potential also in the early phases of the design process. The view is not customary in the current design of assistive products. Although people with disability have participated in the evaluation of assistive products, their participation seems to be cursory with respect to the entire design process. It seems rare, for instance, in the early phases like in ideating. Examples of more profound user involvement are, however, emerging also in the design of assistive products. Livingston (2010, 60), for example, brings out CanAssist, which is a model, where people with disability are considered team members in design.[66]

Also the fact that people with and without disability can have common interests is starting to gain ground in the assistive product field. Cassim and Dong (2003, 535–536) have introduced young "critical users", who help designers to take account of the whole user needs spectrum, but also offer, according to the authors based on their young age and active social engagement, a consumer profile that shares a similar lifestyle, cultural taste and aspirations with designers. It needs, however, to be kept in mind that neither designers are a homogeneous group of people. Hosking et al. (2010, 498) discuss "boundary cases", which they define as "people on the borderline of exclusion, frustration, or difficulty", who could be considered when representing diversity. According to the authors, these people can "readily expose design opportunities that benefit a wide range of other users" and eventually foster the reach of products. These kind of opportunities are in line with the aspirations of the inclusive design approaches.

The potential of users' inventiveness has also been recognised in the development of health technology. Hyysalo (2010) has studied users' contribution to innovation and how that can be integrated into the development processes of wristcare tech-

66 Also Lewis and Matsuoka (2010, 66–67) introduce various benevolent organisations such as Yoky Works (USA), the Tetra Society of North America (USA), the Neil Squire Society (Canada), Remap (United Kingdom) and the Technical Aid to the Disabled of New South Wales (TADNSW) (Australia) that develop customised assistive products together with volunteers.

nology. Kilbourn and Buur (2007) have studied users of home haemodialysis as skilled practitioners and introduce the concept of "enskilment", which refers to a process of skilful usage and manipulation of objects. Enskilment can be situated bodily learning, environment structuring or sense making. Enskilment occurs through the use of products and designers could provide products with interaction that supports it. (Ibid., 2, 8.)

Recently, also the design of assistive products has been approached from the viewpoint of inventive use such as exploring stroke patients' do-it-yourself products (see e.g., Correia de Barros & Duarte 2009; Correia de Barros, Duarte & Bulas Cruz 2010; Correia de Barros 2012). Also some wheelchair users have turned out to be active in fashioning and altering their products in order to make them more appropriate (see Ravneberg 2009). In a prior study I participated in, von Hippel's (2005) lead user theory was applied to people with disability.[67] According to that study, if ageing of the population is considered a [mega] trend, people with physical disability could be taken as lead users in situations encountered by elderly people due to similar physical challenges (see also Helminen 2008, 96–97). The participants of the study proved to be innovative in modifying their domestic environment. Through ordering custom-made solutions, personalising mass-produced solutions, designing solutions themselves and innovating new ways to use existing solutions, people aimed at accessibility that connoted lifestyle-related qualities beyond disability.

In Hannukainen and Hölttä-Otto's (2006) research, people with hearing or visual impairment turned out to be potential lead users in the development of mobile devices. The results rest on the assumption that the requirements of users with disabil-

ity in ordinary situations can resemble those of ordinary users in special or extraordinary situations. Larsson et al. (2005, 3–4) have presented applying von Hippel's theory on lead users as potential in the design of wellbeing products, of which assistive products could be seen as a part. The authors argue that some problems involved in design can be identified as "wicked, fuzzy, or messy", which can lead to major difficulties in uncovering what users' needs are and how those ought to be addressed. In addition, they claim that in relation to wellbeing, there are various unmet needs. The authors present such circumstances as favourable for innovation.

Brooks (1998, 9–10) predicted in the turn of the millennium that the relationship between professionals and consumers would change in rehabilitation: through Internet, information about assistive products, which was previously only accessible to rehabilitation professionals, would be more open to other users as well. According to her, users could become more professional and professionals consultants, who bring order and accuracy to the vast and proliferating amount of information.

In design, also users could be seen as consultants, who share their experiences of using assistive products and provide designers with design suggestions. In wayfinding, for instance, people with visual impairment can have views on removing obstacles in their environment (Jokiniemi 2007, 54). In addition to concrete product improvements, people with disability hold experience-based information that can be valuable. It is likely to be emphasised due to the demographic trend of population ageing. Through co-operation between designers and people with disability, information that relates to the context of use can be utilised and transferred into practice.[68] According to Borisoff (2010, 111–112), technology innovation might enable people

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67 Jacobson & Pirinen 2007a & 2007b. Von Hippel (2005, 22) introduces "lead users" who differ from other inventive users: lead users are "at the leading edge of an important market trend(s), and so are currently experiencing needs that will later be experienced by many users in that market". Furthermore, lead users "anticipate relatively high benefits from obtaining a solution to their needs, and so may innovate".

68 Von Hippel (2005, 66–67) claims that a significant part of the need- and context of use related information required in innovation processes is distributed among users and difficult to combine with the information held by producers. He (ibid., 148) suggests that need-related innovation tasks could be outsourced to users.

to create own novel solutions that fit their specific wants and needs and foster innovations and, therefore, companies should crowdsource their communities in the development of new assistive products.

Engaging people with disability in product design is not solely a matter of developing better and more inclusive products. Green (2009, 41) considers most important in the empowerment of, for example, people with long-term illness, that "it is based upon and reinforces selfhood", and even though the self is affected by illness, it is not lost.[69] User involvement is an ethical issue. Rauhala (2007, 106) proposes that people with disability could be considered "equally benefiting and contributing partners" instead of considering their participation "a charitable cause".[70] In addition to acknowledging users' expertise, considering users equals reminds of the ethical issues involved in engaging users in the development of products in general.

Although the focus of this research is not on users' or companies' innovation strategies, it is assumed that people with physical disability are potentially inventive users of assistive products and their inventiveness could be beneficial in the development of assistive products. Here, inventiveness refers to personalising or customising ready-made assistive products, or employing mainstream products for assistive purposes of use. In both cases, users have tackled the parts designers are claimed to have neglected, the stigma of assistive products and the products' identity-related qualities, and created products, which express their selves and connote other things than disability.

Mugge (2007, 108–114) has identified seven dimensions[71] of personalisation, which concern the degree to which a product is personalised by a user, the amount of physical effort required in personalisation, the number of times a particular product can be personalised, whether a user or a designer initiates personalisation, whether a product is personalised for utility- or appearance-related goals, whether personalisation occurs before purchase or use or during use, and whether personalisation is deliberate or indeliberate due to effects like patina. Of those, the dimension concerning utility- or appearance-related goals appears here most relevant, because it directs attention to the tension and imbalance between assistive products' overemphasised utility function and other functions, and can help understand the role of personalisation.

Both the terms personalisation and customisation are used in this research: personalisation refers more strongly to products' identity-related qualities, to adding "a personal touch" (Mugge 2007, 96) while customisation can mean constructing a tailored whole from single ready-made parts. What is common to both is their aim to individual solutions.

3.2 The Data Sets

The focus of this research is in individual user experience. The interest is in how young adults with physical disability experience the design of assistive products in use, what is the assumed stigma of using these products, and how young adults have managed the stigma. In finding answers for them, also why users have personalised their assistive products is of interest. Case studies are particularly suitable when questions of this kind are involved, the studied phenomenon and the circumstances that have led to it are previously unknown, and the focus is on

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69 Green (2009, 51) refers here to "The Expert Patient Programme" established in the United States and introduced to the UK Department of Health, in which people with long-term conditions act as tutors for patients in enhancing their self-management skills.

70 Ethical issues are also encountered in the current patient clothing as it provides users with only limited possibilities to exercise agency (see e.g., Topo & Iltanen-Tähkävuori 2010).

71 The dimensions are Mental Effort, Physical Effort, Flexibility, Initiation, Goal of Product Personalisation: Utility or Appearance, Personalisation Moment, and Deliberateness.

contemporary events (e.g., Laine et al. 2007, 10; Yin 2003, 5). What can further make a case study a useful approach in this research is that case studies can elicit information on groups (or viewpoints) that might not be otherwise brought out (Peltola 2007, 125). In collecting data, I have aimed at openness typical of qualitative research. I have striven for data that would enable examinations from various viewpoints without tightly restricting to a specific one (Alasuutari 1999, 84) and give answers to my research questions.

As brought out in the Introduction, research is limited on users' experiences of assistive products, particularly on the social and psychological consequences of product use. More research has been carried out on the stigma of disability than on the possible stigma caused by assistive products. The personalisation of assistive products is a phenomenon that has not been studied as a users' means of managing stigma. Because of its unexplored nature, it could be seen as a unique case, whose description is valuable in itself (Koskinen et al. 2005, 161; Stake 2005, 445). The reasons for and consequences of personalisation are likely to be complex and wide-ranging, and uncovering them can surely benefit from an approach that takes advantage of various methods and diverse data.

This research could be characterised as what Cunningham (1997, 402–403) calls an intensive case study and Stake (2005, 450) an intrinsic case study. In such a study, the aim is to develop a deep understanding of a case and its context, and the goal is explanations or interpretations that can take the form of a history, a description or an interpretation. Through them, Koskinen et al. (2005, 265) suggest, the characteristics of a particular research subject can be made understandable. According to the authors, understanding unfolds from rich details and from the fact that similar findings arise from diverse data. Consequently, Laine et al. (2007, 9) view a case study as a research approach or a research strategy consisting of several methods and types of data rather than a single method.

In this research, the phenomenon of personalising assistive products is approached by combining insights from various directions, by finding methods and data that could comprehensively answer the research questions. The empirical data sets consist of a questionnaire to shed light on users' satisfaction with and experiences of using assistive products and circumstances that could lead to personalisation, an Internet database to show the occurrence and variety of users' product modifications, to introduce them on a more general level, and to increase understanding of both the assumed stigma caused by assistive products and the role of personalisation in controlling it. In addition to them, interviews with professionals have been included in order to find out out whether and how stigma and product modifications are visible in their work, and interviews with users in order to focus on personalisation, how and why it happens, on an individual level.

In addition to literature and the empirical data, understanding has been gained through various encounters with people who are operating in the field, through activities such as visiting trade events on assistive products, networking, and by presenting the research in other key events organised around the topic in the course of the research process. In its search for examples of personalisation and aims for describing them, this research has taken advantage of a data collection approach, which resembles what Mäkinen et al. (2013, 8) call "mountaineering", that is, traversing upwards towards rare research subjects who have sought after characteristics. Each data set has increased information on the research problem and source by source an understanding of it has been gained.

Similarly to Olander's (2011, 27) characterisation of her research, this research can be seen as resonating with unique and regular occurrences rather than with qualitative and quantitative measures. The purpose of the mix of data is to complement, test and give a wider context of interpretation to the findings of each other. The questionnaire, the database, the interviews with professionals, and the interviews with users are discussed in detail in Chapters 3.2.1–3.2.4.

In qualitative research, hypotheses typically arise as the research advances, for instance, in collecting or analysing data (Koskinen et al. 2005, 32). As brought up in the Introduction, this research builds on an earlier user study, where five adults with physical disability self-documented their everyday life with "probes" during one week and described their experiences in an accessible domestic environment.[72] The probe method was chosen due to its ability to reach single findings that might not be discovered by other methods or that might "disappear into averages".[73] Consequently, inventive persons with disability, who had modified their domestic environment in order to have more suitable accessible and assistive solutions, were found (see Chapter 3.1).

In addition to the aforementioned finding, earlier research on the stigma of using assistive products and theoretical assumptions about managing stigma all contributed to the hypothesis about personalisation as a means of managing the stigma associated with assistive products. Through case studies, existing ideas and theories can be tested, validated, widened and specified (e.g., Laine et al. 2007, 19; Peltola 2007, 112; Peuhkuri 2007, 135; Yin 2003, 28). The case was chosen according to what Peuhkuri (2007, 148) characterises as an interplay between theory and empirical data, where the research topic and its boundaries as well as theoretical issues are gradually specified.

In the following subchapters, the methods and empirical data are reported in detail. Instead of a chronological order, I have chosen to present them in an order that describes how they

gradually increase understanding of the research problem, narrow the focus from common to particular, and provide answers for the research questions.

3.2.1 A Questionnaire on Assistive Device Satisfaction

The objective of the Quest[74] 2.0 questionnaire is, according to its developers Demers et al. (2005, 3, 7), to evaluate users' satisfaction with assistive devices and related services, and to offer health-care professionals an instrument to measure users' satisfaction.[75] As a clinical tool the questionnaire provides practitioners with real-life benefits of assistive devices and as a research instrument it provides researchers with comparable satisfaction data (Demers et al. 2002, 101).

The Finnish National Institute for Health and Welfare (THL) collected data with the Quest 2.0 questionnaire several times during 2006–2009 in Finland. The data I received in June 2010 is in the form of an electronic workbook. It is a compilation of questionnaire answers from interviews carried out by various health-care organisations. The answers are from 757 respondents (412 women, 338 men, 7 unlisted) 3 to 94 years of age. The respondents live in different places in Finland. The evaluated assistive devices include assistive devices for mobility.

The answers in the received compiled workbook concern eight factors of satisfaction with assistive devices and four factors of satisfaction with assistive device services. The factors consist of assistive devices' dimensions (size, height, length, width), weight, ease of attaching and adjusting parts, safety and reliability, durability (strength, resistance), ease of use, comfort and pleasantness, and appropriateness (how well a device meets its user's requirements). In addition to them, the factors include the process through which a respondent has received her assistive

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72 Jacobson & Pirinen 2007a & 2007b. The study was part of the multidisciplinary research project Erilaistuva asuminen [Diversification in Housing] funded by the Finnish Ministry of the Environment (2006–2008). The probe consisted of a questionnaire for background information and housing history, cards with experience- and value-related questions, a paper "clock-face" for marking typical everyday events and for evaluating emotions the events had evoked, a disposable camera with instructions to take photographs of the environment, and two open questions about problems encountered in the environment and what kinds of solutions had been ideated in order to solve them. The probes were discussed together with the participants in individual interviews.
73 For more information on probes, see, for example, Mattelmäki 2006.

74 Quebec User Evaluation of Satisfaction with Assistive Technology.
75 With relation to the questionnaire, I use the original word device instead of product to emphasise that the questionnaire does not include accessible space.

device, the maintenance and repair of the device, the guidance she has received from professionals, and the follow-up. Each respondent has been asked to numerically evaluate all factors with a five-level scale, where value 1 means "not satisfied at all" and value 5 "very satisfied", and then share her experiences regarding the factors in her own words in a comments row. According to the developers of the questionnaire Demers at al. (2005, 7), the aim is to recognise reasons behind user satisfaction and dissatisfaction.

In addition to the answers concerning respondents' satisfaction with an assistive device and its services, there is background information on users' age, gender, place of residence, and who has funded the evaluated device. Moreover, respondents have been asked to name the brand and the model of the device and how long it has been in use.

I browsed the entire electronic workbook, but since the interest of this research is in young adults, and from the outset also teenagers even if none of them volunteered for the interviews (see Chapter 3.2.4), questionnaire answers from respondents of 13–39 years of age have eventually been included in the data. Because the further interest is in respondents' subjective experiences, only open answers have proven relevant, that is, the answers from the comments row, where respondents, or their personal assistants or also parents in the case of teenagers, have specified in their own words their numerical evaluations. The open answers are mostly short, one-line descriptions and elaborate on users' satisfaction with their assistive product in terms of the aforementioned features. Consequently, the data included in this research consists of open answers given by 82 respondents of whom 39 are women, 42 men and 1 who did not mark gender. The included products consist of 27 powered wheelchairs, 20 manual wheelchairs, 20 mobility scooters, 7 orthopaedic shoes, 5 standing frames and 3 walking frames or walkers, and their length of use varies from 1 month to over 12 months.

Stigma or personalisation are not directly addressed in the questionnaire, but through various factors of satisfaction the questionnaire provides answers for how users experience the use of assistive products. Some of the experiences may relate to stigma, especially those concerning products' dimensions, comfort, pleasantness and appropriateness. The questionnaire can shed light on the background forces behind the stigma of current ready-made assistive products, and reasons for personalising them, by giving an overall impression of users' satisfaction with their products. It can illuminate the phenomenon of personalising assistive products.

3.2.2 The Internet Database of Tips and Tricks

In addition to users' experiences of using assistive products, and the stigma associated with the products, I have explored product modifications. In order to find answers to how users might manage the stigma, I have complemented the data with an Internet database on users' inventive solutions.

The Swedish Spinalis Foundation maintains a database called Spinalistips[76]. It consists of "tips and tricks" for assistive products, adaptations and individually designed solutions from people with spinal-cord injury, which are presented as photographs and a variable amount of written text. The written texts are provided by users or people who have filled the database on their behalf like personal assistants. The written texts include descriptions of ideated products, information on who has ideated and funded them, and in some cases also comments. When collecting data, I also browsed other available Internet pages, which concern users' inventive assistive products. The Spinalistips database proved to be most extensive and diverse, and also most representative. It consists of users' inventive assistive product modifications and many of them are products for mobility or other visible assistive products used in public. I considered it best relating to the scope of this research.

The role of the database in this research is twofold. I have

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76 http://www.spinalistips.se/ retrieved October 2010 and June 2011.

explored the database from the same viewpoints of stigma and its management as the other data sets (see Chapter 3.2.5) in order to gain an understanding of the contents of the database, and to complement the other findings. The Swedish examples in the database have been considered comparable enough with the Finnish questionnaire and interview data due to the cultural, societal and geographical similarities between the countries. Later, a research assistant has used the database for reviewing a grouping (see Chapter 3.2.5) that I developed based on both the findings from the empirical data and literature. His task was to view the grouping against the database in order to evaluate how it holds also in a larger context and how it could be developed further.

As I was exploring the database in October 2010, there were altogether 1,015 tips and tricks from 58 people, of whom 14 were women, 38 men and 6 unknown genders, for assistive products, adaptations and individually designed solutions. The division and amount of the tips and tricks was the following: communication 86, mobility 160, carrying, moving, and handling 115, self-care 170, eating and drinking 33, looking after health 106, housing 342, household tasks 117, caring for household 25, assisting others and childcare 16, work, employment, and occupation 52, economic life 2, recreation and leisure 168, travelling 42, planning activities and tasks 3, and personal assistance 44. From those, I chose 483 to start with. I rejected the original division into categories, because I wanted to start the analysis afresh and proceed with criteria set by the focus of the research.

The key criterion for the chosen products was that users themselves have ideated them, hence, products ideated by others including personal assistants were excluded.[77] In addition, I considered the chosen products fundamental from the view-

point of stigma. Consequently, products that are used in social situations, or in spaces at home that are also used by other people like visitors, have been included. Intimate products that are used either alone or privately with personal assistants like toiletries have been excluded due to their context of use that does not involve similar visible social stigma as products employed in public. However, storing or carrying intimate products has been included if it happens in social settings. Mainstream products that cannot be identified as particular assistive products, like a fan or an air conditioner, have not been included, although they could make users' daily tasks easier. However, mainstream products that are applied to assistive purposes of use that differ from their original purpose have been included. After all, users' inventiveness has been the key criterion. Some of the tips and tricks are techniques that people employ in order to ease bodily functions like moving from a wheelchair to a car, but they have been excluded, because the focus of the research is on tangible product modifications. Some of the strategies could, however, be seen as resembling what Gitlin (2002; see Chapter 1.2 above) calls environmentally based behavioural modification and considers assistive products.[78]

As the research assistant started his analysis in June 2011, the total amount of tips and tricks was slightly larger. From those, he qualified products that were personalised, created or applied by users according to the scope of the research. Based on those criteria, he chose altogether 634 products according to my instructions.

The database represents both men and women, but in most cases, their personal details like age or occupation have not been listed. Therefore, the database may include product modifications from people who are 40 years of age and older. They have been included, because the inventiveness of people has been considered more important than age.

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77 Products include assistive devices and accessible space as defined in the scope of this research (see Chapter 1.2). Consequently, clothing, for example, is excluded.

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78 See also "new methods of task performance" (Correia de Barros 2012, 175–179).

While the questionnaire provides a wider context where the personalisation of assistive products might occur, the database reveals the actual occurrence of users' inventiveness. It reveals the need for modifying products, which may stem from the experienced stigma of using the products. The database displays a myriad of modifications, through which users have aimed at more suitable and individual assistive products. The modifications can increase understanding of the stigma users associate with some ready-made assistive products, and also the role of modifications in managing the stigma.

3.2.3 Interviews with Professionals Who Work with Users

In order to narrow the focus from the more general level provided by the questionnaire on assistive device satisfaction and the database on product modifications, and to gain additional perspectives on the studied case, I also decided to perform two kinds of interviews. Yin (2003, 89–91) suggests that interview is "one of the most important sources of case study information" and it is rather a guided conversation than a structured query and can be open-ended, focused or a survey. I have carried out focused interviews with professionals who work with users and more open interviews with users (see Chapter 3.2.4).

In order to find professionals to be interviewed, I approached organisations which operate in the interface with users of assistive products. Due to the small size of the assistive product field in Finland, the key organisations were relatively easy to identify. I contacted by telephone and e-mail four of them, which I considered representing the field widely. With two of them I had collaborated already in the beginning of the research when acquiring user data: the one had provided the questionnaire and the other helped in the recruitment of young adults. In addition to the four larger organisations, I also contacted a smaller operator in order to enrich the sample by bringing out an additional perspective. All contacted organisations were willing to participate and express their views.

In the chosen five organisations, altogether eleven professionals, who either directly work with users or have access to users' experiences through data such as research material, participated in the interviews. Three of the interviews were with individual participants and two were group interviews. Three professionals participated in the first group interview and five in the latter. By calling the interviewees professionals, I refer to their professional expertise and in order to distinguish between the two kinds of interviews I have carried out in this research. I do not consider the information the professionals have provided superior to that I have received from users, who I also consider experts (see Chapter 3.2.4) in relation to their personalised products.

The organisations, where the interviews took place during three weeks in the beginning of 2013, are located in the capital area of Finland. Some of them, however, operate nationwide. In the interviews, I was interested in knowing whether, and how, the stigma users associate with current ready-made assistive products, and the personalisation they may carry out, are visible in the professionals' work. I wanted to shed more light, from a different and more focused angle than those of the questionnaire and the database, on the phenomenon of personalising assistive products. Characteristic to the case study approach, I have also utilised triangulating methods, and complementing and testing findings, by including in the data also interviews with professionals.

The Interviewed Professionals

AVAS Apuvälineet[79] is an enterprise of two employees and has a small-scale production of assistive products. The manufactured products mostly include assistive furniture for learning and schoolgoing, but also other assistive products like bathroom equipment. For this research, it is of greater interest that the

company also repairs, maintains and modifies existing products according to users' individual requirements. Since the company operates in close connection with users and focuses on adjusting products into more individual, I considered it a good source of users' experiences and individual preferences. I interviewed the owner and managing director of the company who meets users, but also participates in the construction and modification of assistive products. Due to to his all-round role, I considered him experienced in users' requirements.

In order to also have a view from a larger assistive product provider, I contacted a company called **Respecta**[80] that offers, according to its webpage, "Finland's broadest and most comprehensive selection of assisting devices and related services", which are "well-researched and individualised". The company has eight clinics for assistive products and three other sales outlets in Finland. The professional I interviewed is a prosthetist orthotist specialised in leg prostheses, silicone products, supportive insoles and the repair of cosmetic hand prostheses. Even though prostheses have not been in the scope of this research, I considered the prosthetist orthotist's viewpoint enriching the interviews with professionals after briefly discussing the topic with her on the phone.

In addition to the assistive product providers, I have aspired to collect experiences from people involved in the public provision of assistive products more widely. I have wanted to better understand the process, of which most users of assistive products in Finland are part. I contacted the **Assistive Device Centre**[81] in the Hospital District of Helsinki and Uusimaa that is in charge of assistive products and services in special health care

within the district.[82] The participants in the group interview were a manager, two physiotherapists, an occupational therapist and a specialist in the maintenance of assistive products. One of them has experience of children's assistive products and others of adults' assistive products mostly for mobility.

Since the **National Institute for Health and Welfare**[83] (THL), which is a research and development institute under the Finnish Ministry of Social Affairs and Health, carries out research on assistive products widely, I already contacted it in the beginning of my research. In addition to access to the questionnaire on assistive device satisfaction (see Chapter 3.2.1), I interviewed three members in the Disabilities and Society team[84], which is part of the Health and Social Services Development Unit. The team aims at advancing accessibility and studying and developing services related to disability and assistive products. The interviewed people included a senior researcher focusing on research on assistive products, and also disability and ability to function wider, a development manager who is responsible for the development of assistive products and assistive product services, and a senior planning officer specialised in assistive product classifications.

In the beginning of the research, I also contacted the **Finnish Association of People with Physical Disabilities**[85] (FPD) in order to explore an organisation, which co-operates closely and in various contexts with people with physical disability. FPD is a national organisation that represents the interests of and provides services for people who have musculoskeletal disabilities. It is an umbrella organisation consisting of 160

80 http://www.respecta.fi retrieved 1 March 2013.
81 http://www.hus.fi/default.asp?path=1,32,660,40816 retrieved 1 March 2013.

82 The Hospital District of Helsinki and Uusimaa (http://www.hus.fi retrieved 1 March 2013) comprises five hospital areas in the province of Uusimaa. The Helsinki University Central Hospital is nationally responsible for treating severe and rare illnesses and ones calling for special expertise and technology.
83 http://www.thl.fi/en_US/web/en retrieved 10 April 2013.
84 http://www.thl.fi/fi_FI/web/fi/organisaatio/rakenne/yksikot/pake/vammaisuus_ja_yhteiskunta retrieved 1 March 2013.
85 http://www.invalidiliitto.fi/portal/en/ retrieved 13 January 2011.

member associations and 33,000 individual members. In order to learn the viewpoint of a professional who co-operates particularly with young people with physical disability, I arranged an interview with the Youth Action Coordinator of "**The Web**"[86], which is the FPD's Youth Cooperation Group. The Web involves five non-governmental organisations for physically disabled people: the Finnish MS Society, the Finnish Rheumatism Association, the Finnish CP Association, the Finnish Neuromuscular Disorders Association and the Finnish Association of People with Physical Disabilities. The Web offers young people possibilities to organise events and actions.

The Course of the Interviews

The interviews with professionals were structured and compact. They lasted from 30 minutes to 1 hour depending on the amount of interviewees present. In the interviews, I had three focused questions relating to the stigma of assistive products, the personalisation of assistive products, and development ideas concerning the current assistive products. I recorded all the interviews. From each interview, I made a summary based on the recording and interview notes. I sent each organisation a summary of the interview for the professionals' approval in order to make sure I had made accurate interpretations.

Even though the interviews with professionals I carried out cannot be considered such elite interviews, for example with top managers, as Koskinen et al. (2005, 112–123) discuss, they called for some similar procedures. In one of them, I needed to contact the management in order to get a permission to interview individual employees. This seems to be particularly important in health-care organisations perhaps due to the strong ethical code that guides their work in general. Also a more fact-oriented approach (ibid., 115–116) than in the interviews with users, for instance, was required. The shortage of time, which is

typical for elite interviewees (ibid.), was also characteristic of some professionals I interviewed. There was a time limit in the interviews, which required more profound preparation such as focused questions.

3.2.4 Interviews with Users about Personalised Assistive Products

In order to understand the personalisation of assistive products on a deeper individual level, and to reach first-hand experiences and consequences of using assistive products, I approached people who use potentially stigmatising products. Miller and Kaiser (2001, 83–84) have pointed out that research frames where people who do not have stigma try to play the role of people who have stigma are common in research on stigma and its management, but the authors have criticised the frames because non-stigmatised people may not have coping techniques to stigma.

The interviews with professionals were compact and benefited from a well-structured method with focused questions. With users I aimed at a method that I could guide without controlling too much. I combined open-ended and more structured approaches in order to allow the interviewees freedom of expression, but also to get answers for questions that could have been avoided due to their delicacy if not directly asked. Consquently, I carried out semi-structured interviews, which Hirsjärvi and Hurme (1982) call thematic interviews. They, as a softer research method, take into account diversity and aim at reaching nuances and conveying interviewees' true thoughts and experiences (ibid., 182). Moreover, semi-structured interviews are particularly suitable when intimate or sensitive topics are covered (Metsämuuronen 2003, 189). With semi-structured interviews, I aimed at discretion that would allow enough openness in probing a delicate topic. I tried to approach the interviewees as informants, or even as experts, rather than as respondents in order to gain their trust and willingness to participate and to emphasise the user-centred perspective.

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86 http://www.seittiweb.org/index.php/english retrieved 5 March 2013.

The questionnaire and the database aim at understanding personalisation on a general level. The interviews with professionals provide a narrower, the professionals', viewpoint on the subject matter. In the semi-structured interviews, the focus is sharpened on individual nuances and variation among users. The interviews with users can be seen as a special focal point within the phenomenon of personalising assistive products.

Constructing the Interviews

In semi-structured interviews, constructing hypotheses is not obvious, but depends on the research problem, earlier research and theoretical assumptions (Hirsjärvi & Hurme 1982, 40). As presented above (see Chapter 3.2), both earlier research on users' experiences on assistive products and the theoretical frame on managing stigma enabled to construct a preliminary hypothesis about personalisation as a means of managing the stigma associated with current ready-made assistive products. Through interviews with users, I aimed at acquiring a deeper understanding. The objective of the interviews was to uncover the interviewees' experiences of using ready-made assistive products and personalised assistive products. Particularly, the aim was to get first-hand information on the assumed stigma of using assistive products, how users deal with the stigma, and what is the role of personalisation in that.

The interviews were constructed around five themes: assistive devices and accessible space the interviewees currently use, the evaluation of ready-made assistive products (including devices and space), personalised assistive devices, personalised accessible space, and mainstream products used as assistive products. Each theme consisted of questions to keep the interview on course. The themes and questions were evaluated in three rounds. In the first round, three fellow researchers representing the fields of interior architecture and cultural anthropology evaluated the themes and questions. The revised version was evaluated by two experts in the fields of design semantics

and sociology in a second round. In the third round, themes and questions were transformed into the form of an Internet questionnaire and piloted with representatives of the actual target group, young people with physical disability. Based on the evaluations, the themes and questions were specified. I aimed at questions that are comprehensible, and since they dealt with intimate issues, the language appropriate.

Finding the Interviewees

Already in the beginning of the research, as unfolded in the previous chapter on interviews with professionals, I contacted the Finnish Association of People with Physical Disabilities (FPD) and became acquainted with the Youth Action Coordinator of The Web, FPD's Youth Cooperation Group. During 2009–2010, with the assistance of FPD, its member associations and The Web, I searched for teenagers and young adults (less than 40 years of age) with physical disability to be interviewed. During the time, recruitment advertisements were announced on several occasions. The main recruitment channels were Internet, e-mail lists and magazines. In addition, I tried to reach participants through the interviewees by applying snowball sampling (see e.g., Goodman 1961, 148). I asked for the interviewees' acquaintances who could be suitable for this research. I also asked the interviewees to inform their networks, such as a patient organisation, about the research. As they had volunteered, I considered them potential in also persuading other participants.

Regardless of my attempts, it turned out surprisingly difficult to find participants. Already when piloting the research questions in the form of an Internet questionnaire, I had noticed that it was difficult to attract respondents. At that point, I decided to discard an early idea of only carrying out an Internet questionnaire. I had thought that the Internet would be a good channel to reach young users of assistive products, but it did not prove promising. Instead, I decided to interview users.

Many things may have affected people's willingness to par-

ticipate in the research. I was pursuing rather exceptional users after all, users who represent a special case. Perhaps those who had personalised products were not interested in participating or did not themselves qualify their products for design research. Perhaps they did not want me to intrude into the privacy of their homes, which I, however, considered necessary in order to gain a proper understanding, especially of the spatial modifications, but also of aspects influencing the context of use. Furthermore, it was apparent from the recruitment advertisements that the research topic dealt with intimate issues, which could have restrained people from participating.

Teenagers seemed not to be interested in the research, at least not in public. I would have expected particularly teenagers, who tend to personalise items like clothing and footwear, to also personalise assistive products. Apart from some brief mentions on The Web's Facebook wall, only one teenager showed interest in the research to the Youth Action Coordinator. However, later she did not reply my e-mail. One of the young adults I interviewed thought, remembering her own adolescence, that teenagers could struggle hard with disability-related identity issues and, therefore, might not participate in this kind of research. According to the Youth Action Coordinator, teenagers have not been active participants in The Web either. Similarly to the interviewed young adult, also he supposed that if teenagers are not actively involved, identity-related issues could be an explanation.

Five people, who were willing to participate in the research, contacted me through e-mail based on the recruitment advertisements. Four of them qualified, one did not due to her older age. One of them had also participated in the earlier user study, seen my recruitment advertisement and decided to volunteer. In addition to him, I decided to contact another person who had participated in the user study, because I considered her qualified also for this research. I was already familiar with some of the products the two participants had modified in inventive ways.

The five participants, four women and one man, 24–39 years of age, live in different parts of Finland. I interviewed all of them personally in their own homes. The aim was to understand where they live and the overall context of their assistive product use. I considered this important due to the significance of home in identity expression and construction (see Chapter 2.2.2). A further account for interviewing in homes can be found in Rauhala's (2007, 118) notion that it can be difficult to understand the position of a person who has disability without a personal contact and a visit to her home.[87] She (ibid., 126) concludes that the developers of assistive products should make meaningful contacts with users in environments where users with disability "can best display their competence and project favourable images of themselves" like in users' own homes and with users' own tools.

I also wanted users' assistive products to be present in the interview in order to get a good impression of the products and to ease discussion on them around a delicate topic. In design research, interviews on the meanings of products, where products have been used as stimuli in interviews, have recently been carried out by, for example, Ahde-Deal (2013) on jewellery and Paavilainen (2013) on design objects in private homes.

The Course of the Interviews

The interviews started by asking the interviewees about experiences of using current ready-made assistive products. I was interested in what kind of attention using assistive products had attracted in social contexts. I was interested in possible experiences of embarrassment and shame. Through the questions, I strove for understanding the quality of the assumed stigma associated with the products.

Thereafter, I focused on personalised assistive products, whether assistive devices or accessible space. In addition, I was

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87 The participants in Rauhala's research had severe disability. Since this research includes also the personalisation of domestic space, it was essential to visit the participants' homes even though the majority of the participants did not have severe disability.

interested in mainstream products that had been employed for assistive purposes of use. I wanted to know how and why users had personalised their products, and to understand what kinds of experiences personalised products create and whether they differ from the experiences of using ready-made products. The attempt was to understand if and how personalisation affects stigma. I also asked each interviewee to imagine an assistive product of her dreams and a dreaded assistive product. Lastly, I asked what kinds of development ideas the interviewees have for the design of assistive products. The interviews ended with collecting background information. At the end of three interviews, I rewarded the interviewee with a small gift, because I felt she had had extra trouble like given me a ride to a station or been flexible with the schedule.

Both verbal and non-verbal communication is present in interviews. The flexibility of semi-structured interviews can make reliability and the qualification of conclusions problematic. Hence, thorough recording of information, particularly contradictory information, is necessary. (Hirsjärvi & Hurme 1982, 50.) All interviews were recorded. The shortest interview lasted approximately 55 minutes and the longest 1 hour and 40 minutes. The remainder were on average 1 hour and 20 minutes. Even though the interviews were semi-structured, and also produced information that was not related to the research, the focus on products kept the interviews compact. The recording of the interviews enabled me to pay attention to products that were present during the interviews and to observe the interviewees while interviewing. It was possible to make notes about the situation while the actual interview was recorded on tape. Due to that, the interviews became flexible and flowing. I could get impressions about the interviewees and prepare descriptions that highlight their individual preferences and situations in life.

The Description of the Interviewees

In the following descriptions, and in later chapters on the results with quotations from the interviews, the interviewees are addressed with false names. Instead of anonymous alphabetical or numerical codes, I prefer to refer to them as persons in order to emphasise human-beings and individuality. In addition to their names, other identifiable personal details like names of family members, place of residence, workplace and possible medical condition have been concealed.

"**Alex**", with whom I had become acquainted during the earlier user study in 2006, is 39 years of age and working full-time in the field of information technology.[88] He has a Bachelor's degree. He lives in a newish apartment building with his wife and two small children in a suburban residential area in a large city in southern Finland. Alex's disability is severe and he uses a powered wheelchair. He has personal assistance all day. In addition to the powered wheelchair, he has a shower chair, which he also uses for travelling and some personal assistive products to aid in his daily tasks. He has several powered wheelchairs. One of them has special wheel rims, while another is for his hobby, floorball. He has complemented his wheelchairs with a small bag for his personal belongings and he calls it a "man purse".

His home, which is in the first floor, is accessible for a wheelchair, which means that, for example, light switches are positioned low enough, thresholds are lowered, there is a slope to a balcony, most doors are sliding, and the front-door and its inner door are both electrically operated. He also has an electrically adjustable bed, which is made by inserting a hospital bed inside a mainstream bed frame.

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88 In the earlier published articles, Alex was named Ed, which was also a false name. After getting to know him better during the interview I made for this research, the name Ed began to appear strange, as if it did not portray him anymore. Therefore for this research, I decided to change it to another name, Alex, which I think represents him better.

Alex describes himself as extremely aesthetic. He wants his assistive products to be stylish and context-fit. They need to fit the style of the home. Alex seems to be very conscious of the design process of assistive products and the shortcomings faced in it. He is willing to make the effort to find or customise a perfect solution. According to him, all his assistive products are customised in one way or another. He has also applied and modified mainstream products wherever possible. He has, for example, a mainstream carpet, which is particularly suitable for an electric wheelchair. Most furniture in his home is mainstream furniture, which have been customised in order to be accessible for him.

"**Carla**" is 33 years old. She has vocational education and she used to work first in beauty and then in the nursing sector. She is on disability pension and retired from her work. However, she is actively involved in organisational activities. She lives with pets in a row house in the rural area of a medium-sized town in western Finland. She has a partner who lives in another town. Carla has an illness that causes various fluctuating symptoms like muscular weakness, a bad sense of balance and fatigue. Depending on the day, Carla's condition and need for assistive products vary. A personal assistant, who is also present in the interview, helps her 18 hours a week. Carla uses a mobility scooter, a manual wheelchair, a walker, a cane and no-tech devices to aid in her daily tasks like in reaching. Because of her varying perceptive skills, she also has several notes of paper, particularly in her kitchen, in order to help her independent functioning. Even though she describes herself as a "hamster", who gathers all kinds of things, she tries to organise them, because she does not remember if something is hidden or out of sight.

Carla is waiting for a visit from a surveyor to evaluate her need for accessibility modifications to be made in her apartment. She already has, however, made some modifications. For instance, a handgrip has been installed into the bathroom and with the help of her personal assistant she has made her desk suitable for a standing position. Accessibility means also enough room for her.

Carla has a unique bold style of her own and, according to her, she is recognised in her neighbourhood. She has decorated almost all her assistive products with tribal stickers and related things that are common among motorcyclists. They are consistent with her clothing and overall style. In addition to the biker symbols, colour is an important quality for her. In the interview, she brings out how the personalised products positively influence her self-esteem and other people's reactions.

"**Laura**" is a 24-year-old student at a university of applied sciences and in the time of the interview she was in practical training. She studies social and health care, but has earlier also studied business administration. She lives with her husband in a rented country house in a small town in southwestern Finland. The landlord lives in the main house next door. Laura is congenitally paraplegic and uses a manual wheelchair. She also has a folding shower chair, a standing support and no-tech devices like reachers to aid in her daily tasks. In her apartment, there are accessible thresholds and space to move with a wheelchair. Both her kitchen and bathroom are accessible, for example the cupboards are lowered, but not electrically adjusted. Her husband has made wheelchair accessible slopes to front- and back-doors.

Laura describes herself as active, sporty and young. She considers herself "mobile" in the sense that she wants to be on the move. She appears self-confident and knows what she wants. She emphasises in the interview that disability is an essential part of her self and she does not want to hide it. Nevertheless, she seems to be as concerned about her looks as many young women. She uses a customised sporty manual wheelchair with special aluminium wheel rims. She is very proud of it and compares it to a "pimped" car. She has been able to choose the colour of the wheelchair, which is black, and its special carbon fibre material.

"**Sally**" is 27 years old, has a Bachelor's degree, and is on maternity leave from her work in the field of marketing. She lives with her husband and an infant child in a loft apartment in the downtown area of a large city in southern Finland. She is short in stature, which causes restrictions in reaching and bend-

ing down and pain. Instead of a traditional assistive product like a walker, Sally uses a mainstream kickbike as a mobility aid. She does not want to look old and fragile, but young and pert. Her kickbike is bright yellow and she tells how it awakes positive reactions in her environment. Sally also uses canes, various no-tech devices like kitchen utensils, sock and zipper aids, and reachers to aid in her daily tasks, and orthopaedic shoes. In her apartment, she has an electrically adjustable accessible kitchen, an accessible bathroom and several childcare furniture that are accessible for her. She has found various mainstream products like kitchenware, which also meet her specific requirements.

Although Sally is short in stature, she and her husband have wanted to have a loft apartment with exceptionally tall walls located in the attic of an old apartment building. There are various tailored spatial solutions that fit both her and her husband who does not have disability. In addition, she has positioned some furnishings and objects low enough for her. Sally seems to be very design-conscious and wants her home to be of high quality. In the interview, she makes clear that she does not want to compromise over that. Particularly in the kitchen, she has various products that could be characaterised as high-end design.

"**Tina**", the other participant with whom I had become familiar earlier, is a 32-year-old woman who is on study leave from her work in the commercial sector. She has already gained a Bachelor's degree, but wants to have another from a different field. She lives in a student commune in a suburb of a large city in southern Finland. She has her own room, but she shares a kitchen and a bathroom with a couple of other students. The apartment is located on the first floor of a small apartment building. In the interview, she mentions that she does not enjoy living there.

Tina is short in stature, which causes arthrosis, restrictions in her joints' mobility and pain. She has applied mainstream products to assistive purposes of use. She uses a sport kick scooter as a mobility aid instead of a walker. It is important for her that the scooter is an ordinary piece of sports equipment. She

has made slight functional modifications to it to be able to use it as a mobility aid. The scooter is originally meant for children and she has altered its looks by removing some decorations and by painting some of its bright colours black so that it does not look childish. Tina also uses forearm crutches and orthopaedic shoes. In addition, she has various no-tech devices to aid in her daily tasks. Since she lives in a shared rented apartment, which she considers unsatisfactory and temporary, no spatial accessibility alterations has been tailored for her. In her previous apartment, she had an electrically adjustable kitchen and a bathtub, which she yearns for.

Tina describes herself as sporty and wants to give an impression of a lively, active, young woman. She does not want to use assistive products like a walker, which do not express her true identity, but create a false impression of old age and fragility. Her main motivators for modifying mainstream products into assistive purposes of use have been their lower price and lack of stigma.

3.2.5 Analysis of the Data

A case study focuses on the relationship between particular and common (Peltola 2007, 112) and it aims at a local explanation (Laine & Peltonen 2007, 104–105). Through the diverse data, which draws from both common and particular, this research aims at describing and interpreting how users experience the design of assistive products in use, what the stigma associated with assistive products is like, and how users manage the stigma. The personalisation of assistive products is studied as a case. The purpose is not to map the prevalence of personalisation, but rather to show that such a phenomenon exists and to describe and discuss it. A sample perspective, where the acquired data serves as a piece of reality, a sample of it, and where results are specific to the data and interpretations only tell about data (Koskinen et al. 2005, 64), has been applied here.

The analysis of the data can be considered theory-driven

in the sense that it has involved theoretical concepts and also the phenomenon under study has become formed according to something already known (Tuomi & Sarajärvi 2009, 97). The analytic frame for this research derives from the theoretical assumptions about stigma and its management. As the analysis progressed, the early findings also began to require theoretical views on the meaning of products in the construction and expression of identity. Although I applied assumptions from the theoretical framework, I did not "shut my eyes" to the data, in which sense the analysis also has characteristics typical of data-driven analysis. My aim has been to use the theoretical assumptions as a tool for structuring data. Instead of either strictly theory-driven or data-driven, the analysis can rather be characterised as theory-guided, which means that theoretical couplings and earlier knowledge have only guided the analysis (Tuomi & Sarajärvi 2009, 96–97).

The analysis began with the user interviews. The semi-structured interviews produced rich data. The interviews were recorded and the recordings transcribed both verbatim and selectively. I chose to transcribe verbatim those interview sections that were related to the research questions. That is, the discussion-like interviews also meandered to various unrelated topics. In addition to speech, the interviews transcribed verbatim included expressions like periods of silence, pondering and laughter. Particularly laughter and sense of humour were something that the interviewed users expressed often. The precision of the transcription ranged from contentual notes with quotes to literal transcripts with marked emphases on words (Koskinen et al. 2005, 319–325). Inferences were made both from the recordings and the transcripts. In addition, I made notes during the interviews and took photographs.

I structured the transcribed interviews around the interview themes, which naturally formed the first layer of the analysis. The data indicated interviewees' negative experiences of current ready-made assistive products and positive experiences of personalised assistive products. At this point, the analysis was also data-driven, but the perspective was, nevertheless, on stigma

and its management. I sought for common features or recurring patterns or themes that "jump out" or "make sense" (Miles & Huberman 1994, 246) within the original themes. When focusing on the experiences, I could recognise descriptions of different kinds of products and their qualities. They evolved further into a grouping that appeared to consist of negative, neutral and positive assistive products. In negative products, I could identify medical instrument-like products, products that seem to exaggerate and misrepresent disability, and products that appear to treat users as a homogeneous group. In neutral products, the management of stigma appeared to be central resulting in two kinds of products that enable passing as any user, of which some direct attention away from stigma and others resemble mainstream products. In positive products, I identified products that resemble accessories, products that seem to convey self-expression, and products that appear to create feelings of pride. In spite of the theoretical hold, the formation of the grouping also resembled the stages in data-driven content analysis (Tuomi & Sarajärvi 2009, 109) proceeding from reading the transcripts, finding meaningful expressions and reducing them to simplifications, searching for their similarities and differences, to combining them into different classes.

The analysis proceeded with the Internet database and the questionnaire. The chosen 483 products in the database were also examined from the viewpoint of stigma and its management. As described, the analysis also began to require conceptions of self-presentation. I could use the grouping, which I had formed based on the analysis of the user interviews and literature, as a broad frame. Consequently, the analysis of the database resembled theory-driven content analysis. Since the written descriptions of the products in the database varied, the emphasis was in photographs. I did not, however, entirely depend on photographs, since some products had written descriptions about stigma and, for example, a user's lifestyle or the style of her home.

Based on the analysis, I proceeded to group the products in the database into five categories: personalised products, customised products, tool-like first prototypes, simple everyday products and conventional products. My aim was to uncover additional information in order to develop the grouping that I had formed when analysing the user interviews. Since the database was not specifically about stigma or personalising assistive products, all groups were not in the scope of this research. The ones which dealt with stigma or personalising assistive products in order to either manage the stigma or express identity, appeared relevant from the viewpoint of the interview findings, even giving support to them, and were included and used in developing the grouping further.

Since the experienced stigma or its management were not always apparent in the products in the database, the analysis required my interpretation. Personalised products, however, were described by their users in a way which revealed that users had experienced stigma and aimed at managing it or expressing other qualities of identity. Also in some of the photographs of customised products, it was visible that the products had been designed in a way that also acknowledged aesthetic evaluation and appearance-related features, but users had not necessarily described them as such.

Tool-like first prototypes required most interpretation in relation to stigma and its management, since users had not described them negatively. They were described as functional, usable objects that enable their users to do something they might not be able to do at all. The focus seemed to be on their utility function. No descriptions of their aesthetic appreciation or cues for their identity-related qualities had been provided. Simple everyday products and conventional products had least personalised or customised features, but they did not resemble tool-like first prototypes either. Users had not described them from the viewpoint of stigma or its management, but the products seemed to resemble mainstream products. Conventional products were eventually excluded, because they did not include as-

sistive properties and, thus, they were not in the scope of the research.

In evaluating the products that required most interpretation, I tried to view the products as a designer would do. I tried to evaluate their success as products that are supposed to provide various functions. However, my focus was on product appearance, because based on literature, the analysis of the other data sets, and earlier research, it appeared to be essential in the formation of stigma. Moreover, product appearance could be linked to identity more than functionality, because functional requirements can be more similar between users (Mugge 2007, 116). I paid attention to the size, colours, materials and forms of the products, and how the properties complement each other or serve various product functions. In addition, I paid attention to products' resemblance or difference from mainstream products. I tried to consider the images the products might potentially evoke and for what the products and their qualities could stand. The benefit of a design researcher's standpoint is that it can produce different kinds of pieces of information, which can complement the information produced by health-care or medical professionals (see also Olander 2011, 35) that tend to predominate in research on assistive products.

Later, as the grouping, which was now called a typology, had been developed further, a research assistant, who had not participated in the analysis so far, was given a task to explore the database in order to review the typology and its validity with a larger data (see Chapter 3.2.2). He divided the qualified 634 products he had chosen from the database into categories, which portrayed products that were entirely created by their user, products that were personalised by their user, and mainstream products that were applied to assistive purposes by their user, and reviewed the typology. Most of the products were also included in my earlier analysis of the database, but they were now analysed differently and from a different viewpoint. The research assistant searched for findings that could support, disprove or complement the typology or parts of it. Based on his work, I fine-tuned the typology further.

I explored the questionnaire in parallel with the user interviews and the Internet database. The answers in the questionnaire revealed how users experience their assistive products and how satisfied they are with them. I identified descriptions of product properties that might influence stigma such as the large size of a product. What was also apparent in the answers was the importance of an assistive product fitting its user and her lifestyle also in other terms than ergonomically. The answers concerning products seemed more relevant from the viewpoint of the research questions than the answers relating to services. The latter, however, also echoed the need to acknowledge users' individuality. I also explored the questionnaire from the viewpoint of the tentative typology. My aim was to view the typology in a wider context, which might shed light on the circumstances where the personalisation of assistive products could occur.

When I analysed the interviews with professionals, I had already developed the typology based on literature and the analysis of the user interviews, the Internet database and the questionnaire. The interviews with professionals were recorded, but not transcribed. As already recounted, after each interview, I made a summary of the interview based on my notes and the recordings, and sent the summaries to the organisations for the interviewed professionals' approval in order to check that I had made accurate interpretations. The analysis of the interviews centred on the interview questions: the stigma of assistive products, the personalisation of assistive products and development ideas. The aim was to reflect the findings in the other data sets. The eleven interviewed professionals had quite similar conceptions.

Since the research topic concerns intimate issues, also particular ethical considerations have been required when handling and presenting the data. Each interviewed user has consented to publishing both transcripts of their interviews as well as pictures taken in the interviews, however, it was mutually agreed on paper that all material is handled anonymously. Therefore, the interviewees' personal details have been covered. All data in the questionnaire is in anonymous statistical form. In the da-

tabase, there is a statement that grants permission to use parts of it for non-commercial purposes of use when the source is acknowledged. In addition to that, a permission to use the database anonymously as data was requested and granted from a representative of the database. The professionals I interviewed signed an agreement where they granted me a permission to use and publish the interview material. In the agreement, they also approved the publication of their names and the organisation and their position in it.

In the following chapter, the results of the research are discussed with references to the original empirical data and literature. They all contributed to the results, but particularly the interviewed users are often quoted, and their inventive products presented, in order to illustrate the individual users' viewpoint. Through narratives and situational descriptions, a case study unfolds the experiences of persons, the experiences of studying them, and enhances a reader's experience of it (Stake 2005, 454).

Since the original interview data is in Finnish, the following quotations have been translated into English. Due to linguistic differences, modification has been required in order to guarantee legibility. What has made the translations difficult is that all users used colloquial language, some of them dialects, and some others repeatedly used expletives such as "like" or "sort of"[89]. All along with stuttering and pauses were transcribed in the Finnish quotations. However, most of them have been cleaned out from the English ones, if they have been considered meaningless from the viewpoint of the content. Meaningless removals have not been marked in the English quotations. I have, nevertheless, marked pauses that I have found meaningful, such as indicators of hesitation, with the mark (.) and the removal of meaningful words or continuation from another part with the mark … . I have underlined the words the interviewees have emphasised and provided additional, clarifying information inside square brackets [ ]. In spite of the linguistic modification required due to the English translation, the content meanings of the quotations have been carefully translated.

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89 "Niinku" (the original Finnish expression).

4 A Typology of Assistive Product Functions

"Well quite purely for appearance-related reasons, because I am rather vain. So they must be just a certain way. I have <u>not</u> aimed to <u>reduce</u> my own disability or <u>cover up</u> my own disability, because that is something that I don't quite accept that things are taken so far that you try to <u>cover</u> your limitation every way you can. Because it shines, the more you cover it the more it starts shining through. When you make it a normal thing for yourself, a normal part of your life, then it does not shine. But after all I'm so much into beautiful things that I want that both me and my home look stylish also through my wheelchair." (Laura about her reasons for personalising assistive products.)

This research asks how young adults with physical disability experience the design of assistive products in use, what is the assumed stigma associated with the products, and how young adults manage the stigma. In analysing the data, answers have also been sought for how young adults with physical disability have personalised their assistive products, why they have personalised the products, what kinds of qualities the personalised products are composed of, and how the qualities relate to young adults' identities.

The exploration of literature and the analysis of the empirical data have resulted in users' experiences of both ready-made assistive products and personalised assistive products. With the help of the diverse angles offered by the literature and the empirical data, the process has proceeded with an intermingling dialogue between the common and the particular. As explained in the previous chapter on the analysis of the data, the experiences have evolved into the form of a typology. The type and role of the diverse data in the formation of the typology are presented in Figure 2 below.

Figure 2. The type and role of the diverse data in the formation of the typology.

Literature	Questionnaire	Internet Database	Interviews with Professionals	Interviews with Users
Common				Particular
Earlier research on assistive products, theoretical assumptions about stigma, managing stigma, and expressing the self, categories and classifications: *the wider frame.*	Users' satisfaction with and experiences of current ready-made assistive products: *shedding light on the factors leading to personalisation and influencing it.*	Users' inventive solutions for assistive products: *the occurrence and variety of product modifications.*	How stigma and personalisation appear in the work of professionals, who work with users: *information on users' requirements, narrowing the focus.*	Users' experiences of assistive products, stigma, and how and why users personalise products: *information on individual first-hand experiences, focusing on individual users.*

A Typology of Assistive Product Functions

In literature on assistive products, taxonomies of assistive product outcomes can be found, but even if some of them (see e.g., Jutai et al. 2005) deal with issues like social significance and subjective wellbeing, their emphasis is on products' utility functions and not on what assistive products represent. Correia de Barros (2012, 169–188) has recently grouped stroke patients' spontaneous product inventions, but also her focus is on the inventions' utilitarian purposes of use and the patients' methods of innovation.

In the typology I have created, I can identify broadly three kinds of types, *negative types*, *neutral types* and *positive types*, which concern assistive products' representational qualities and functions which relate to users' identities. Although the interviewed users and professionals consider many of the current ready-made assistive products functional in the sense that they perform their utility functions and enable tasks that would otherwise be impossible, other shortcomings exist. The negative types derive from the stigma users experience when using ready-made products. The neutral types concern both ready-made and personalised products. It seems that the experienced stigma has motivated users to personalise products. The neutral types appear to deal with the management of the stigma. The positive types stem from users' experiences of using personalised products and they extend from managing stigma to expressing the self.

It is important to note that within the types, some of the subtypes are overlapping and some progressive in relation to their expressiveness. One assistive product can have qualities that are associated with several subtypes. Since I have approached products and their use in terms of user experience, also characteristics that extend beyond physical product properties have come up and show in the typology. It needs to be kept in mind that the typology concerns *functions*, which are presented by way of viewing assistive products *as* something.

4.1 The Stigma Associated with Ready-Made Assistive Products

I have divided the negative types into three subtypes depending on the characteristics of the stigma associated with assistive products. The subtypes are closely interrelated and some of them overlapping, but their stigma arises from slightly different factors. *Instruments* appear to bear the stigma of disability, and to be associated with medical equipment and characterised by contradictions in contexts of use. Assistive products as *Misrepresentations* seem to exaggerate and misrepresent disability. *Uniforms* do not seem to acknowledge the diversity and individuality of users, but instead can reduce users to a stereotype. The stigma caused by uniforms relates to anonymity and homogeneity. Even though the negative types focus on utility functions and other functions like aesthetic ones may not be taken into consideration, their use can create strong emotional experiences. Users can experience the negative types as unpleasant and as inducing feelings of shame, embarrassment, dependence and even disgust.

4.1.1 Assistive Products as Instruments

The design of instruments can be considered insufficient. Instruments may fulfil the objectives of utility function quite well, but they lack important social, aesthetic and identity functions. They may be usable and ergonomic, but they do not take into account other requirements or preferences. In that sense, the design of Instruments is not complete. Instead of being finished, their design can be characterised as mechanical, which means that they resemble compiled tools or even machines. As compilations, they may take account of their users' physical characteristics resulting in individually adjusted solutions, but neglect requirements set by the broader context of use. Some of the interviewed professionals estimated that, even though ready-made assistive products can be customised with different materials and colours, the available choices may not be sufficient for users. Instruments that emphasise accessibility, physical compatibility,

performance, durability and reliability seem to solely bear utility value and only involve what Desmet and Hekkert (2007, 58) call "instrumental interaction". Compared with other consumer products, which take into account various dimensions of user experience, they appear one-sided.

Descriptions of instrument-like assistive products could be found in all interviews with users. However, they vary according to the interviewees. For instance, Carla, who uses a mobility scooter, does not consider it as negatively as Laura, who does not use it. Carla is satisfied with her scooter, but shares negative experiences in relation to some other assistive products like a wheelchair. This finding echoes what also others have found. Resnik et al. (2009, 83) present the acceptance of mobility assistive products as hierarchical and depending on the type of disability and the assistive product used. According to Scherer (1996, 128), a person with congenital disability may have better accepted both her disability and the modifications it may require than a person who becomes disabled in later life. She suggests that assistive products may act as "reminders of the independent functioning they have lost" for a person who becomes disabled in adulthood. Also one of the interviewed professionals assumed that, if a user starts using assistive products later in her life, as an adult, there are more thresholds to use them.

Differences between the interviewed users' experiences of similar assistive products may well derive from their different experiences of disability. Carla unfolded in the interview how she does not "flinch" in the presence of some assistive products the way she used to do, because her partner is in a more severe condition and, because of that, also uses those products. The products have previously troubled Carla more, but now she has got accustomed to them. Depending on users' previous experiences, Instruments can, nevertheless, be effective in materialising the health-care context that is surrounding disability.

In the interviews with professionals, users' different attitudes towards using assistive products came up. Users can altogether refuse to use assistive products because of such factors as illness, the stage of illness or age. In this case, users may attach negative

associations to assistive products or experience that the products represent deterioration and giving up. A user may think that if she starts to use a walker, for instance, she will never get rid of it, or wonder if she is already so old she needs an assistive product in the first place. Some other users employ assistive products to be able to function and accomplish tasks, regardless of how the products look. They may endure and accept that they cannot do anything (Olander 2011, 89, Article 2). Then there are people who use assistive products because they help, but who, at the same time, are particular about how the products appear.

One of the interviewed professionals assumed that if a user has always used assistive products, the products may have become part of her persona and they are not experienced as stigmatising. This requires a lot from their appearance according the interviewed professional: the products need to "look like their user" and fit her style.

The interviewed professional who is specialised in prostheses and orthoses noted that some people who have used a particular prosthesis for a long time, perhaps decades, may have difficulties in changing it into a new one. According to the interviewee, they may have various reasons, some of which are not realistic. In such cases, a new prosthetic leg, for example, is stored for a year or two, until the old prosthesis is completely unusable in order to enable a user to adjust to the change. The interviewed professional thinks that people do not want to have something new and different, because the old one is comfortable. A person may also have become attached to a product, because time can enhance product attachment through such things as memories (Mugge 2007, 61–73).

The incompleteness of instrument-like assistive products was particularly apparent in the interview with Alex. He described wheelchairs that stick out as "box-like". He is glad that he does not have "the most embarrassing looking" products and refers to chin controls that he mostly considers tacky. Alex suspects that the reason for the embarrassment of some assistive products not only derives from bad design, but also from insufficient design. He refers to wheelchairs, which he had tried years ago.

"It was the lack of design. They were a bit like (.) someone had taken a cross-ruled paper and drawn a square-by-square box and decided that it will become a wheelchair. That's not designing then." (Alex describing the design of wheelchairs.)

The interviewed professional who works with young people told in the beginning of the interview that he has not noticed young people feeling embarrassed about using assistive products, or trying to hide them. This is, according to him, because using assistive products is self-evident for young people, it eases their everyday life and increases independence. He explained that the young people he meets in his work are usually familiar with their disability, which may influence their experiences. Instead, he brought up that some users may fear that other people consider them lazy, if they change one assistive product into another, because they are not able to use the first one anymore. In the course of the interview, the professional admitted that some young people have been embarrassed about their assistive products, if the products have not met their aesthetic preferences. He recalled that he has never heard a young person characterising her assistive product as "cool", but rather as "not nice-looking, but functioning". Another interviewed professional described how some families who have a small child with disability may hesitate to use assistive products, because they do not want the products to label their child. The families wish that the products could be "disguised" in order to make them appear something else.

In the Internet database, products that can be characterised as tool-like first prototypes appear bulky, coarse, and despite their technical features, somewhat childish when semantically evaluated. They look like first hand-made prototypes of products. The forms are often amorphous like freehand cut. They consist of different materials, which are connected with, for example, glue, tape or screws. The joints are visible and unfinished. The products are often attached to a user, they attach a user

to her surroundings, or they are carried along. Some of them include straps and hooks. In each case, they are body-related. Many of them are holders or universal rods. Some of them involve intimate activities and situations like going to the toilet, which may affect the way they appear and are perceived. It is visible in their design that they are not supposed to be in public view. If they were, their use could be experienced even as humiliating. The tool-like first prototypes are strongly driven by utility function and appear to be developed in order to enable a user to carry out a task that she would not be able to accomplish without the developed product. In that sense, the tool-like first prototypes are somewhat advanced regardless of their unfinished appearance, because without them, there might not be a way to carry out the task. The importance for some users to carry a task independently out in the first place, regardless of the product's appearance, was also mentioned by one of the interviewed professionals.

Instruments tend to attract negative attention. They can appear what Saguy and Ward (2011, 54) call "hypervisible" and be difficult to hide. They seem to stick out negatively, create feelings of embarrassment, and weaken users' social identity in relation to people who do not have disability or who do not use the products. They can foster negative differentiation. One of the interviewed professionals characterised some hoisters as "enormously sized"[90], which may make users hesitate using them, particularly in public. Similarly, one of the interviewees in Olander's (2011, Article 2) research considers a standing frame far too large and as if it had come out from the Frankenstein's laboratory. The interviewed professional also recounted how a user he had met had experienced the reversing alarm of a powered wheelchair awkward. The user had not considered him- or herself dangerous enough when using the product that an alarm would be necessary. The alarm had raised inconvenient attention.

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90 "Julmetun kokoinen" (the original Finnish expression).

Figure 3. Laura's standing chair in her living room.

Also the interviewed users are concerned about how they and their homes appear to other people. Carla talked about "quiet viewing"[91] referring to other people staring. All interviewed users have experienced other people looking at and paying attention to their disability or assistive products. They consider it to be "normal" behaviour, although some of them specify that they themselves do not stare at people, or that they stare in a different way and for different reasons. The different reasons are likely to derive from their own disability and their use of assistive products. Nevertheless, Laura thinks that other people staring can cause feelings of shame or embarrassment.

Sally described, remembering her primary school years, how her doctor had suggested a pillow, which she could put behind her back to improve her reach when sitting at her school desk. She had immediately rejected the idea as embarrassing. Instead, the caretaker of the school had shortened the seat in her chair. That way her chair appeared to be an ordinary chair and did not differ from other chairs in the classroom.

Tina believes that anything that is different attracts attention. She described how she prefers asking help to using a reacher when shopping. For her, asking help is less embarrassing and shameful, and it usually results in more positive reactions. Contrary to Tina's experience, Laura told that her reacher has roused positive curiosity among her friends. Nevertheless, she admitted that some assistive products are eye-catching and do not merge into their surroundings. Along with mobility scooters, she considers her standing wheelchair (Figure 3) particularly horrible, and too massive. For her, as a user of a sporty manual wheelchair, a powered wheelchair attracts negative attention most.

> *"I personally would experience it so that, even if I'm not using it myself, a powered wheelchair is perhaps something that attracts attention most. And it also attracts <u>negative</u> attention most."* (Laura about the attention a powered wheelchair attracts.)

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91 "Hiljainen katsominen" (the original Finnish expression).

Laura proposed that the reasons for powered wheelchairs' negative attention may relate to the products' motored power. She described them as "motored gadgets"[92] that are run fast by reckless users. For her, they appear, alongside her standing wheelchair, as "terrible wrecks"[93]. She thinks that powered wheelchairs are difficult to use and with them places are difficult to reach. In the interview, Laura wondered if she is the only one who thinks that, if someone uses a powered wheelchair, she must be severely disabled.

> *"Because they are such motored gadgets, that have, or well, they do work with an electric motor, so well, they are like that, go fast and [giving a laugh] users are reckless, and it is difficult to get anywhere and [they are] terrible wrecks and, difficult to use by the way. And in particular I feel that, of wheelchair users even otherwise, I don't know if it's just my thought or a more general thought that, if you are using a powered wheelchair, then you really are severly disabled."* (Laura about the attention powered wheelchairs attract.)

Laura continued to ponder reasons for the image of a powered wheelchair and concluded that it is such a visible part of its user and, perhaps, because of that, its deviation sticks out. She also thinks that other people's negative experiences of incautious wheelchair users affect perceptions.

> *"Mmm, I think it must be that, at least for a powered wheelchair it surely is that, it is <u>such a visible</u> part of that person. So, it probably is so that the deviation really sticks out from there. So that is, that is the reason."* (Laura about reasons for the negative attention powered wheelchairs attract.)

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92 "Moottorivehje" (the original Finnish expression).
93 "Hirveä rohjake" (the original Finnish expression).

For Alex, who uses a powered wheelchair, the product does not seem to represent severe disability. This may be because Alex is accustomed to powered wheelchairs, but perhaps also because his wheelchairs are customised in several ways. The chair he uses in floorball, for example, is customised with the colours of the floorball team. Due to the similar colours, it can enhance group identity among the players. What might also foster positive user experience is that it is and also looks like a piece of sports equipment, not only an assistive product.

When it comes to being different, Carla thinks that what distinguishes her from her friends is that she needs help and that nothing is straightforward for her. Like Laura, Sally associates the special and ugly appearance of assistive products with the negative attention they attract. She compared the treatment of people who do not appear ordinary to children's way of excluding different children from a group.

> *"Well one thing is likely to be that they look special. They don't sort of look ordinary. And then, if someone doesn't look ordinary, of course that person rouses other people's interest. And then, if they even look <u>negatively</u>, or they are so called <u>ugly</u>, or they are not pretty according to the current conceptions of beauty, so. It is kind of, a bit like (.) children's mentality that, she does not belong to the group, because she is different."* (Sally about reasons for the negative attention assistive products attract.)

Laura described how she did not want to attract attention or "stand out from the mass" when she was a teenager. She refused to employ a standing frame and a mobility scooter then, because other people did not use them either. A standing wheelchair was "an impossible thing". One of the interviewed professionals stressed the fluctuating and uncertain phase of life that young people, particularly teenagers, go through. She emphasised the sense of belonging and being able to identify with

other people as important in creating stability when everything is changing. As a child, Laura also experienced her special bicycle as stigmatising, because her friends did not ride similar ones. Laura and Carla both speculated afterwards that some of the feelings of stigma may derive from the fact that when people are younger and more insecure, they tend to imagine what other people think, even if other people might not necessarily think that way.

> *"I think it must have been that when you didn't <u>want</u> to stand out from the crowd, you wanted to be like everyone else. And then when you were <u>not</u>. So you didn't by any means want to emphasise further, <u>more</u> that you are different. You didn't know how to use it as a resource."* (Laura about reasons for feeling embarrassed when using assistive products.)

The interviewed professionals emphasised the importance of self-esteem in using assistive products. The professional working with young people, for instance, thinks that those who have recently become disabled, or who have difficulties in forming a new identity with disability, issues related to stigma may be emphasised. Another professional pointed out that, whereas a strong self-esteem and a starting point that supports it can help, uncertainty can complicate the use of assistive products.

Assistive products' health-care or medical associations are apparent in the data in several ways. In the questionnaire, for example, a 38-year-old woman describes how she looks much healthier on her mobility scooter than in a powered wheelchair. Also Carla described how using a walker makes her feel less ill than when using a wheelchair, because she is walking with her own legs (cf. Resnik et al. 2009, 82).

> *"Well so yes, it always makes you look, particularly if you sit in a wheelchair, it makes you look <u>ill</u>. … But then again, if I go with a <u>walker</u>, I can go with my <u>own</u> legs. So, that doesn't feel <u>that</u> ill, because after all I'm walking by myself."* (Carla on whether assistive products can make a person look ill.)

Carla described further how her walker, which is an advanced model, does not appear "institutional", but instead, it has more "street-credibility", because "something has been done". In her walker, the advancement means particular paintwork and ergonomical handles. Based on her research Rauhala (2007, 93) suggests that the resemblance between an assistive product and medical equipment can lead to an unpleasant design that is not neutral, like a communication device that resembles a rectal syringe.

An assistive product that looks like medical equipment can underline its user's disability. It can one-sidedly contribute to the disabled role and everything that is associated with it. The appearance of medical equipment can associate an assistive product with illness and give an impression of a user as a patient. Instruments can construct, strengthen and maintain categories that relate to disability.

In addition to making users appear ill, Instruments can transform homes to look like institutions. Several of the interviewees portray current assistive products as "hospital-looking". In Alex's words, "a hospital bed looks like a hospital bed", even if it was in a private bedroom. The interviewed users are particularly unsatisfied with shower chairs. Alex parallels his shower chair to his T-shirt with a print "Patient" and, thus, with a hospital context, because the chair is "hospital-green" and not elegant (Figure 4). It stands out in his bathroom. Similarly, Laura described her shower chair, which is her old manual wheelchair, as "the horrible mint-green wreck"[94] that does "definitely not" fit her white bathroom (Figure 5). For Tina, a white shower chair is a "horror" assistive product that she would never like to use. In the Internet database, a person has replaced a traditional shower chair with a plastic garden chair, because it is attractive and does not remind the person of a hospital (Figure 6).

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94 "Kamala mintunvihreä rohjake" (the original Finnish expression).

Figures 4–6. Alex's hospital-green and Laura's mint-green shower chairs, and a garden chair applied as a shower chair.

Tina characterised white metal handrails as "hospital-like" that do not fit the overall style of private homes. For her, the colour white is boring and refers to hospital. In terms of design semantics, Vihma (1995, 112) associates the colour white with cleanness, tidiness and hygiene in kitchen utensils. She (ibid., 93–97, 146) considers colour an important sign, which can even be a limiting factor, but remarks that also form, material and the environment influence sign functioning.

The forms that follow utility functions and technological determinants, colours as green, white or grey, plastic and metal materials, can be considered product properties that mostly contribute to the "hospital-likeness" of Instruments. Hospitals often have white surfaces with green highlights. In addition, the working clothes of the hospital staff tend to be white and green. The forms of Instruments seem to refer to the straightforwardness of medical equipment, and the colours and materials to the hygiene and sterility of hospitals and to the robustness of technical tool equipment. Interestingly, many medical appliances, nev-

ertheless, are high-tech devices designed by industrial designers.

Similarly to the stereotype of a person with disability, also Instruments can be associated with dependence and lack of control. Carla described herself as a "control freak" and for her wheelchairs are "the worst", whereas a mobility scooter allows her to feel she has control.

> "Wheelchair (.) it's the worst. … The kind of total lack of control. I'm sort of a control freak. That's why that [mobility] *scooter* is for me like *unquestionable*, because *I decide*, how fast and *where* the scooter *goes*. But in a wheelchair I ca*nnot* decide, because I don't have the strength, myself. The worst panic attacks I have had particularly in a shop, in a wheelchair. (.) And the very thing that, because it's like (.) I'm one metre below everyone else. … It's not the assistive product as such, but how it relates to *me*." (Carla comparing a wheelchair and a mobility scooter.)

A product may assimilate into its surroundings or appear distinct. Instruments are peculiar in the sense that, depending on their context of use, they seem to either assimilate or dominate. In the health-care environment, they can merge into the surroundings. It seems as if the resembling products drew common qualities out of Instruments and created a consistent unity. In the domestic environment, Instruments may dominate the visual view and stick out. They can even be seen as "intruding" the domestic environment that does not share the same characteristics. An example of these kinds of "intruders" could be a ceiling lift that does not fit the style of a private home (Figure 7). In the Internet database, ceiling lifts are described as "ugly hospital-like hangers above the bed". They seem to have similar qualities with stigma symbols, which Goffman (1963, 59) characterises as "especially effective in drawing attention to a debasing identity discrepancy, breaking up what would otherwise be a coherent overall picture".

Figure 7. A ceiling lift in a private flat of an assisted living building.

Figure 8. An accessible bathroom in a private flat of an assisted living building.

Similar incongruence, as a result of products appearing to be in wrong contexts, can be seen in some accessible bathrooms. When evaluated from the viewpoint of their appearance, several accessible bathrooms appear to have more in common with hospitals than private homes where they, nevertheless, often locate (Figure 8). Even though most functions carried out in both are similar, accessible bathrooms seem to differ from regular bathrooms due to their assistive and accessible add-ons, and physical properties such as distinctive colours.

Based on their current design, it might be more sensible to evaluate Instruments in health-care contexts of use than in homes. However, Instruments appear and become viewed in unexpected contexts of use. Alex, for example, described how he uses his shower chair also for transporting in public places like airports. He is worried about his public image when using a product that feels inappropriate and appears as if it was in a wrong context. Instead, he thinks that the chair could have a more impressive appearance that he could portray.

> *"Well when I travel, so then it [a shower chair] completely shows (.) because it travels with me there at the airport and. Whoever can see you there [laughing]. And, I think it would be (.) you could show it then. If it was such black with red and yellow flames. I think that would be just nice and corny."* (Alex about using his shower chair for travelling.)

Alex believes that other people think that shower chairs are solely used in bathrooms, not in view and, therefore, they are not supposed to need better designing. Even if Alex used his shower chair only in the bathroom, and for a short time, he would appreciate if he could feel comfortable. Now the poorly designed shower chair makes a negative experience even in the bathroom.

Products may seem to be located in wrong places due to people's tendency to categorise things (Douglas 2002, 44–45). Perhaps Instruments appear wrong in private homes, because it is difficult to connect them with household objects. Bispo and Branco (2008, 3) point out that most assistive products, which users experience as stigmatising in social situations, are designed and adjusted for hospital contexts. Even though products in general tend to adapt to their environment (Vihma 1995, 59), some of them seem not. Actually, the other way around, the [domestic] environment seems to adapt to Instruments by starting to resemble a health-care context like a hospital.

Carla brought out how the use situations affect feelings negatively even more than single products. She described how using a ceiling lift involves so many situations that indicate the need of assistance and lack of control that she hopes she will not need the product at all.

> *"[T]hey are precisely the <u>situations</u>. So, one, for example, that I don't ever <u>want</u> is a <u>ceiling lift</u>. Because it means then <u>so</u> bad (.) a condition that, with the help of someone, I have to be lifted up with a ceiling lift and put down to the bed, taking a shower, going to toilet, all that. It's not the lift, because I know how to <u>use</u> it, I have used it [giving a laugh] (.) but it is precisely the lack of control associated with it."* (Carla about assistive products she would never like to use.)

4.1.2 Assistive Products as Misrepresentations

Misrepresentations can exaggerate disability and, in that sense, their functioning resembles Instruments. In addition to exaggeration, they may extend their stigmatising effects even further than Instruments by misrepresenting disability. Laura described mobility scooters and powered wheelchairs as "the archetypes of disability"[95] that are employed by people who have severe disability. For her, they appear large and fast and attract negative attention. She also considers them unnecessary for her current needs and as causing more disadvantage than advantage. Nonetheless, she has regularly been offered one.

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95 "Vammaisuuden perikuva" (the original Finnish expression).

"Well because, I have somehow considered that particular thing [a mobility scooter] the way that it also is a kind of a real archetype of disability, along with a powered wheelchair. I don't know what causes it. Eh, maybe it is that I have seen that assistive product also being used by really severely disabled people. So that may be what makes it a no, and somehow like. It is just so <u>unnecessary</u>! Because I can propel well without it and I also <u>want</u> to take care of my condition, for example. So, why would I take some assistive product to hang around in vain, mainly to keep it in some corner. Because I probably would never have time to use it, so. But it is some kind of an archetype of disability." (Laura about an assistive product she would never like to use.)

Sally calls assistive products "extras"[96], which nobody really wants. She thinks assistive products make her negatively unique. They yell out that they are odd. She thinks the plain word assistive device is hideous. In the interview, Sally referred to assistive products as "special equipment" or "special assistive equipment"[97].

"They look so like, they sort of look like assistive equipment, they look <u>extra</u> or something like <u>additional</u> that you don't really <u>want</u>." (Sally about what makes assistive products negatively special.)

Similarly as a cycling helmet makes its user's head look larger and out of proportion with the rest of her body (Vihma 1995, 138), a misrepresentative assistive product can appear excessive and distort a body shape. The distortion is not only physical. Sally brought out in the interview how her orthopaedic shoes have made her feel as if other people think that she has not only a physical disability, but also an intellectual one.

96 "Ekstra" (the original Finnish expression).
97 "Erikoisväline" or "Erikoisapuväline" (the original Finnish expressions).

"[S]o you feel yourself in some way so, just like negatively special or something like that. And, for instance, when I used those [orthopaedic] <u>shoes</u>, I felt as if everyone thought that she is a bit stupid as well, or." (Sally about the feelings of embarrassment using assistive products has created.)

Tina described how using assistive products can lead to situations where the user of assistive products is treated like a "second class citizen" because of the product and its image. She referred to a well-known situation, where people are talking to a personal assistant instead of a person using a wheelchair.

"Well, so (.) if you think the choice would be, for example (.) a wheelchair, because I have heard from wheelchair users that people regard, if you have some physical disability, you as if you had a disability in the head. So, for instance, if you sit in a wheelchair and you have some friend along and you go to a shop, then people talk to that friend, as if the person who sits in the wheelchair was not able to take care of things herself. And well (.) so in a way just the <u>image</u> that it gives." (Tina when asked about the stigma associated with assistive products.)

In earlier research (see e.g., Edwards & Imrie 2003, 248–250), experiences like the ones Sally and Tina describe above have been presented. Also Carla told about similar situations, which have happened to people she knows. However, her personal assistant added during the interview that this has not happened to Carla and her, because she withdraws from such situations in order to prevent other people overriding Carla. Sally pointed out that sometimes it can be beneficial, if an assistive product signals that its user has difficulties in moving. She described how she had once got a seat, because she had been using canes. But, another time, when she had not used canes, no-one had given her seat, although she was pregnant.

Also the accessibility requirements, which the use of assistive products often requires, can result in negative treatment. Edwards and Imrie (2003, 251) suggest that people who use a wheelchair can be considered to get "back-door treatment" or "back-door quality", when they use back doors, back alleys and everything but the front, when trying to find routes in the built environment.

Carla brought up in the interview how her fluctuating symptoms affect her need for assistive products. Sometimes she uses a cane, sometimes a walker and at other times a mobility scooter. She claims that the change of assistive products puzzles other people.

> *"But just what particularly puzzles [other people] is that when on one day I don't use any assistive products, one day I have a cane, the next day I come along with a wheelchair, then I come along again with a scooter and then I come along with a walker."* (Carla about her varying needs for assistive products and other people's reactions to it.)

Carla's experience resembles what Peters (1993, 26) calls "having a disability sometimes". It means that, in view, disability can lack consistency. Peters suggests that regarding appearance, some disabilities vary due to a change in the degree of disability, circumstances or the environment between the two extremes: visible and invisible or highly visible and less visible. An invisible disability can make a person appear able-bodied to others (Stone 1995, 418). Carla's example reveals that assistive products influence the visibility of disability and other people's impressions of it.

Also the interviewed professional who is specialised in prostheses brought out an interesting case of puzzling, or contradiction, in relation to visibility: Even if one of the trends in prostheses is to leave metal tubes visible, they can appear peculiar in particular situations. Tubes can look "cool" with shorts

when they are completely visible but, for example, with long trousers in a windy weather, they can appear odd. According to the professional, "you can see there is something weird [inside the trouser leg] and then you stare at it". When the originality of the tubes is not visible, they can appear something "undefinable", which can make them appear ambiguous in a way that complicates interpreting them (cf. Douglas 2002; see Chapter 2.2.1 above).

In addition to the stigma of disability, the stigma caused by Misrepresentations can refer to old age. Sally has felt that some assistive products have misrepresented her age and made her appear significantly older. She described how at twenty years of age she felt like sixty or seventy, when using particular assistive products. In her opinion, everything related to assistive products, their image and design, appears old-age and as if the products were meant to be used by elderly people. Many of their users are, however, young.

Dankl (2009, unnumbered) has suggested that walking canes, for example, can be seen as "agents of being old", whose "special power lies in expressing an image of old and impairment today". She claims that old refers to such negative connotations and stereotypes that people who are perhaps chronologically old, but young in mind and spirit, are not willing to endorse. According to Carla, who had earlier worked with elderly people, walkers are "grannies' gadgets"[98], whose design remains similar and lacks personality.

> *"[R]ight, so, I can just say, also through my own work, what kind of looking (.) assistive products elderly people had (.) and then they were for a long time, exactly similar, whether you were twelve or twenty or eighty years old. So because (.) there wasn't like any possibility to think that there could actually (.) add personality in them. But I don't know, it's the certain kind of articu-*

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98 "Mummojen vehje" (the original Finnish expression).

lation there (.) which is quite <u>commonly</u> heard, from several directions, how they give the kind of impression that they are like some <u>grannies'</u> gadgets, say for example a walker." (Carla about assistive products for elderly people.)

Carla talked about "the stigma of an elderly person"[99] that she associates with walkers. She told how she used to work as a practical nurse and saw "a good amount of" walkers. Due to those experiences, she refused to use a walker herself for a long time. She, however, was glad to receive a walker that she describes as "a newer developed model"[100]. In her opinion, it does not bear the stigma of old age. Also Tina thinks that some of the current assistive products, particularly a walker, can associate her with elderly people.

"Or then actually, if you compare [the personalised kick scooter], for instance, with a walker that is maybe also so often perceived as an old person's assistive product, so you don't (.) because you are not old, you don't want that you are like carica- [discontinues] or sort of like associated with that group." (Tina about associations with old age a walker creates.)

Both Sally and Tina, who are short in stature, have also experienced product qualities that they perceive as childish.[101] Tina has removed decorations which she considered childish, like hanging teddy bears, from her kick scooter that was originally designed for children, in order to make it more appropriate. In

addition, she has painted some of the striking bright red and yellow colours black. Sally has refused to use a bike that has a right size for her, but looks like a child's bike because of its childish decorations and accessories.

"[F]or example, the special bike I had, I was given that, so okay, it was made for me, it had suitable proportions and all that, but then there were that kind of <u>ball-like</u>, such children's <u>ball-like</u>, ends [of the handlebar], it's a wonder that there weren't any serpentines coming out, too. And then, there were some nice butterfly stickers [describing ironically]. And the way like, hello, I was then, what was I, a little over twenty years old. So kind of, that it looked, and still looks, we have it in the storehouse, as if it was a bike for a five-year-old, so no, and it like stands out a mile that this is an assistive product. This is not like a normal [bike]. … So that I would not, no more, use, because I feel like a five-year-old on it [laughing]. So well. It is probably the sort that, I would not easily ride it anymore." (Sally about her old bike that she would not like to use anymore.)

Assistive products can also misrepresent disability to users themselves and make them exaggerate their own disability and other people's reactions to it. Some of the interviewed users brought out how they may imagine other people's reactions. They described how they assume that someone thinks of them in a particular way, but then they realise that they may have imagined it. The imagined things appear to be mostly negative.

"So it is just pure transference, that is, you transfer your <u>own</u> feelings to other people, that is, if you feel some things about yourself, negative things, it is very easy to transfer them to someone else and think that also that another person has to think that way, because I think of myself that way." (Laura about transferring own feelings to other people.)

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99 "Vanhusleima" (the original Finnish expression).

100 "Uudempi kehitelty malli" (the original Finnish expression).

101 Not only old age, but also young age can be employed as a means of stigmatising. For instance, Hawkesworth (2001, 302) brings up how adults who have acne suffer from stereotyped images that present acne as a teenagers' inconvenience. She describes how adults with acne are perceived to be "too old for acne".

"And then surely one part is also that what you think and what your feeling is when you use it [an assistive product] so then you notice just <u>those</u> gazes that are sort of negative, so then you just look for that, if you yourself feel bad, of course you notice only those negative gazes." (Sally about how her own feelings towards an assistive product influence how she regards other people's reactions.)

"But these [feelings about how using different assistive products puzzles other people] also are, probably so strongly only between my own ears, making me wonder <u>what</u> people really think, like 'Go on, decide [laughing] what you have [laughing]!' But then again if I confront people about it, I notice I have been all alone with a thought like that, no-one else has thought that way." (Carla about the influence of her own thoughts on what other people might think.)

4.1.3 Assistive Products as Uniforms

Even though several assistive products can appear obtrusive and stick out negatively, others can be experienced as homogenising and lacking personality. The doors of hospital rooms, for instance, can be seen as an example of homogenising. In Finland, the rooms are often similar and marked with numbers. This is also typical of wards for people who have a long-term condition, even though they could be seen as dwelling in the hospital due to the duration of their stay. This can also concern nursing homes. Similarly to Instruments and Misrepresentations, Uniforms as a product group may differ from other consumer products, but within their group, Uniforms appear more homogeneous. They do not seem to acknowledge the diversity and individuality of users. Instead, they can reduce users into a stereotypical group with alleged similar characteristics and preferences.

In Finland, assistive products are provided for their users by the public sector. In the interview, Tina claimed that the available products, which are funded by the city and provided by health centres and hospitals, can be several years, even decades, old. And, their design can be old-fashioned. Laura thinks that, on the whole, ready-made assistive products have become more varied and the assortment and selection have widened. She believes that there are more manufacturers and, due to competition, they have to invest in the development of assistive products. However, similarly to the interviewed professionals, she pointed out that there is a big difference between what exists on the market and what is actually available for users (see also Olander 2011, Article 3). One of the interviewed professionals explained that there is a transition period at the moment in the public provision system: new products are gradually acquired, but users are also given old products, which are still usable. Not until those products have become unusable, the product stock can be renewed. According to the professional, the renewal of the stock can increase equality between users.

Sally described the current arrangement in the provision of assistive products as a "special system" through which users can choose only one kind of products. There are no real choices. She recounted how, at the most, there are different colours to choose from. In the questionnaire, a 15-year-old girl complains that her manual wheelchair is not a beautiful vehicle for a young woman. She wishes that the wheelchair, which is now black, had more colours. The number of currently available colours is not necessarily sufficient for all users. The interviewed professionals also acknowledge this, but pointed out that choosing colours outside the colour charts makes products more expensive. Large manufacturers do not necessarily set out to make individual colour changes either, and as noted by one of the interviewed professionals, changing colour can be expensive for small operators as well, even if they did individual modifications.

Laura, on the other hand, favours black, but still she thinks that the available colours in wheelchairs are insufficient. Colour

seems to be a product property that polarises opinions, perhaps depending on whether users want to positively highlight their assistive products or make them blend with other products or clothing. One interviewed professional proposed that users can be roughly divided into those who prefer their assistive products to be plain black and to those who want products with more and brighter colours. Another professional in the same interview had experience of middle-aged and elderly adults preferring to appear elegant and, therefore, choosing what she characterised as "neutral black" assistive products, but perhaps colourful clothing.

The main cause for the problematics concerning Uniforms can be found in lack of variety and choice. One of the main differences between assistive products and other consumer products is the possibility to choose (see also Bispo & Branco 2009, unnumbered). Consumer products are chosen, but assistive products are used by necessity. Little attention is paid to choice and the assortments of assistive products are poor. Similar findings have emerged in current patient clothing, which does not allow users to express what they would express in the case of personal or mainstream clothing, and which has a lower status than care workers' clothing (Topo & Iltanen-Tähkävuori 2010, 1686, 1688).

One of the interviewed professionals pointed out that in Finland, people have not become accustomed to the fact that users would choose their assistive products, but instead professionals are involved in the choosing process. Another professional suggested that, currently, users compromise over product qualities: they can live without some qualities, if a product fits otherwise. Several professionals remarked that users weigh the advantages and disadvantages of product qualities, whether the qualities are truly beneficial. According to one professional, the key issue is what a user wants to do in her life, whether she wants to return to the situation before becoming disabled or move in some other direction, and how assistive products and their qualities can contribute to that. Another professional stated

that once the advantages of an assistive product outweigh the assumed stigma of using it, the product is used.

Standardisation has been suggested as one cause for the stigma associated with assistive products and also for their lack of beauty (e.g., De Couvreur & Goossens 2010, 3; De Couvreur et al. 2009, 2). Standardising products may lead to standardising users and to ignoring individual nuances. Ravneberg (2009, 110) suspects that the public service provision, which Sally called above a special system, can, on its part, foster unisex, standardised products for all ages and lifestyles. Also "inclusive", "universal" and "for all" design approaches may bear the risk of producing homogenising products in their aspirations to fulfil as many needs as possible. But, in an ideal situation, inclusive products allow for individual variation. Many of the interviewed professionals see inclusive products potential due to their more mainstream qualities. Also Olander (2011, 1) emphasises that the aim of the approaches is not that one size would fit all.

Carla thinks that even in their details, assistive products are designed to meet the requirements of a too wide user group, even if details could be the very way to realise individual variation. Alex described ready-made assistive products as dull-looking, and designed for the masses and according to a particular liking that is supposed to make the products sell well.

Carla proposed that both "basic universal tools" that are similar to a large user group and individual products that derive from a more user-centred approach should be available. In the interview, Alex recalled wheelchair designers who themselves use a wheelchair. Also Sally's comment on the one-sidedness of current ready-made assistive products calls for designers who are familiar with the use of the products. In her opinion, the current products are not only ugly, but also functional shortcomings exist.

"Well, often they [ready-made assistive products] are quite ugly. Then they also are the way that you notice that those who have designed them do not really use them. In a way there is such a one-sided viewpoint. And well, usually they just are so that, they don't function." (Sally about negative traits of assistive products.)

People with disability are as heterogeneous as people in general, but Pullin (2009, 89–90; see also Ravneberg 2009, 110) has claimed that in the design of assistive products, more attention has been paid to "clinical" than cultural diversity. He remarks how people who share the same disability may not have the same age, culture, taste, education or priorities, but still they are offered similar assistive products. Similarly, Ravneberg (2009, 102) claims that little attention has been paid to the gendered nature of disability, ethnicity, class or lifestyle. Teikari and Björkman (2006, 5) suggest that considering people to be a special group based on disability can easily lead to considering the group homogeneous. The authors claim that the focus is, then, on some average group based requirements instead of individual variety. Also the interviewed users emphasise that shared disability does not mean shared style. Sally pondered why the segmentation of mainstream consumers is different from that of people with disability and suggested the small size of the target group, and lack of money, as potential reasons for it.

"[S]o the thing is that because everywhere else there are target groups and such, so among them [mainstream products] you can always get, so it [the target group of mainstream products] is just so wide, there are different types of people and people with different styles and there are solutions with different styles for them. But in a sense, if you have some physical disability, for example, then that's what you are. And then because the target group is not like, it's not at all about that there are also different <u>styles</u>. So someone with physical

disability can be totally different kind from someone else and I think that <u>it</u> is not overarching enough that they have some kind of physical disability. It is the same as if someone said that blonds buy this and brunettes buy that. So, eh, it's not like that. But perhaps it is, it could be that the target groups are so small that no-one is interested. Where there is no money, so (.) I don't know." (Sally comparing mainstream products and assistive products.)

Laura wondered in the interview, if people who are involved in the provision of assistive products might have an attitude problem regarding users' aspirations to individuality. She has an impression that they do not necessarily accept if someone wants to have something unique. She suspects that they have got accustomed to the prevailing needs and, if someone diverges from "the disabled mainstream", they may not understand it.

"Let's say that if they [people involved in the provision of assistive products] have got accustomed to the fact that <u>every</u> person is given a particular shower chair. And then when someone gets the idea of asking something completely different. So then it may be that, well, because the others don't get it, so you won't get either. That can happen sometimes." (Laura about meeting individual requirements and how attitudes can affect that.)

Laura wondered further, if all people engaged in the provision of assistive products are open to users' desires to keep up with the development and trends in design.

"And well then, everyone doesn't accept either that someone would keep or would like to keep up with the development in assistive products, that is, even if a user knew that, hey, now this kind of a <u>new product</u> has been

launched, could we try it, so there is <u>no</u> money, can't be done, not possible, but that may also have something to do with willingness. Of course also costs, I can't really have everything because everything costs so much. But there are particular like, maybe money, and a bit of attitude problems as well." (Laura about meeting individual requirements and how financial resources and attitudes can affect that.)

Also Carla has experiences of similar problems. She described how people who are in charge of the provision of assistive products have wondered why Carla's friend, whose identifying colour is yellow, would like to have yellow spokes in his wheelchair. They have not understood what he would do with yellow spokes. The interviewees' experiences suggest that the way policies like health strategies design, brand and release values (DePoy & Gilson 2010a, unnumbered) could perhaps be considered. Alex brought out that the attitude of public administration is that they cannot "do good", by which he refers to designing more mainstream or inclusive solutions in the environment, if it also provides an opportunity for misuse or even vandalism. He explained how, for instance, positioning everything low enough for a wheelchair user would also provide access to children, which could cause misuse or be dangerous.

Some of the interviewed professionals think that rather than attitude, the problem is the funding system that does not cover individual solutions. According to them, the professionals involved in the provision of assistive products are aware of users' individual preferences, but the process still emphasises products' usability and utility functions. If a more attractive solution is more expensive than a familiar customary one, it is not usually funded. The impression, according to which individual products are more expensive and require more work, is still prevailing. One of the professionals, however, pointed out that, if a product is not aesthetically pleasing, it may not be used.

An example of being aware of users' individual preferences is apparent in another interview with professionals. The interviewed professional had seen even small details becoming crucial to users. According to her, some users, for example, do not want any commercial texts in their products, or visible bar codes, because they do not want to be "numbered", even if the code is only for the product. Other users, particularly young ones, want that it shows if a product they use is the newest model. The interviewed professional recalled a user who had placed stickers on the backrest of a wheelchair, and when the backrest broke, each sticker had to be re-placed on the new backrest, because the user considered them part of his or her identity.

Sally believes that the older she gets, the easier it has become to claim for assistive products of the kind she is ready to use. She noted that the basic models and systems are offered automatically, if users do not express other requirements. Also one of the interviewed professionals supposed that young people may not dare to demand. Sally has fought for her right to have, for example, an electrically adjustable kitchen. Not until it was decided at court, could she get financial obligation for it from the city. Similarly, Ravneberg (2009, 105, 112) reports that her interviewees have had to struggle to get products they find appropriate. Sally thinks that young people may not dare to say what they want, because that requires a particular attitude. She emphasised in the interview that there is a point in requiring individual products, because assistive products are not used, if they do not meet users' individual requirements. Still, she wondered whether some of her individualistic requirements are vain, because they are not needed from the viewpoint of utility functions. Also the professionals pointed out that an assistive product should be of the kind that fits its user, because that means that the product will also be used. One of the professionals proposed that an assistive product should function well, but at the same time be less restricted by its main utility function.

Lack of choice is not only a matter of having more variety in products, but it can also have more profound consequenc-

es. Bispo and Branco (2009, unnumbered) suspect that lack of choice can associate users of assistive products with people who have no choice at all. Lack of variety in assistive products can position people with disability unfairly in comparison with the users of mainstream products. There are also inequalities among the users of assistive products who may not have equal access to the newest products. Carla portrayed assistive products as "the basics of basic"[102] that in their impersonality lower human dignity.

> *"But then, well, pretty much (.) in all, all (.) assistive products too easily the thing, that they are so basics of basic (.) and then impersonal, so if you think somehow the kind (.) that okay (.) even if the purpose is not to lower human dignity, but still with them [assistive products] that dignity is lowered, because, eh (.) they are all <u>similar</u> for everyone."* (Carla about the similarity of assistive products and how it affects human dignity.)

4.2 Managing Stigma with Personalised Assistive Products

If assistive products are experienced negatively as Instruments, Uniforms or Misrepresentations, users may aim to reduce unpleasant consequences, which their use can have. Personalisation, or customisation, could be explored as a means of managing stigmatising product characteristics and the attention they attract.

The following two subtypes, *Shields* and *Mainstream Products*, which I formed when exploring the empirical data and literature, are based on users' experiences of both ready-made and personalised assistive products. The reasons for creating Shields and Mainstream Products seem to derive from the experienced stigma of ready-made products and, in that sense, their creation is motivated by stigma. They are, however, concretised as per-

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102 "Perusperus" (the original Finnish expression).

sonalised products. They can be viewed as neutral in the sense that they aim at reducing stigma by "neutralising" the stigmatising qualities of assistive products in relation to mainstream products. They do not yet emphasise individuality, but rather act as a means for passing as any user of any products. Shields can be characterised by discretion and Mainstream Products by ordinariness. By representing similarity, they both aim at social integration and strengthening identification also with people who do not use assistive products or who do not have physical disability.

4.2.1 Assistive Products as Shields

None of the interviewed users wants to hide disability and such evidence could not be found in the questionnaire or Internet database either. Particularly Laura is strongly against hiding something that she considers an integral part of her self. Nevertheless, all interviewed users seem to appreciate discretion and appropriateness that does not make them stand out in a negative way or portray them in a one-sided or misrepresentative way solely as someone with disability. The prosthetist orthotist, however, told in the interview that some people she meets in her work want to hide their prosthesis. According to her experience, they are mostly women, older children or people who may have social problems.

A person may want to direct attention from her disability to some other qualities of her identity or to "equalise" the less dominating parts of identity, even if she considers disability part of her identity. Assistive products can, already due to their assistive functions, diminish disability (Scherer 1996, 153), but the interviewed users seem to use personalisation at least partly for that. Tina, Sally and Carla all described how their personalised assistive products attract positive attention and turn attention away from disability to other aspects of identity. The way Goffman (1963; see Chapter 2.3.3 above) has proposed, they also use their personalised assistive products for breaking the uncom-

fortable first encounter with people who do not know them well or who are strangers. Laura described how her customised wheelchair can be a good way to open discussions, because it appears positively distinguishable. Tina and Sally unfolded how employing a piece of sports equipment as an assistive product creates an impression of a sporty lively young person (see also Resnik et al. 2009, 82). They claimed that these products are not perceived as assistive products.

As previously described, Tina has transformed a children's kick scooter into an assistive product for mobility by removing childish decorations, by painting and by adding some structural parts (Figure 9), and she uses the scooter instead of a walker. Tina thinks that the fact that the scooter is used for assistive purposes is not paid attention to, because the product itself is so interesting.

> *"It is totally different, it attracts [attention], because in that sense it's not that kind of a basic assistive product, so well, there you see the difference, that even if it <u>totally</u> is a mobility assistive device for me, but when I say that without this I would not walk around here, so, well, the matter is sort of, somehow passed over, because it [the personalised scooter] just is so interesting."* (Tina about the attention her personalised scooter attracts.)

Figure 9. Tina's personalised kick scooter that she uses instead of a walker.

Sally has similar experiences of using a mainstream kick-bike instead of a traditional assistive product for mobility (Figure 10). She described how people do not pay attention to her short stature when she is using the kickbike, because the bike attracts their attention.

> *"Well, it's like, when I have, for instance, that kickbike, I think it is fun, because it is such, so yellow and very perky. So it is fun that when I ride with that kickbike around the city so, for example, some small kids who usually say something like 'Oh look what a woman' or 'Look how short' or something like that, so they don't notice it at all, they say 'Wow, look what a <u>bike</u>, how <u>cool</u>, how <u>fancy</u>'. So that is really fun, it [attention] doesn't bother at all. And then I also have another kickbike that looks like a skateboarding-bike, so I also notice by using it that people look at it as if they're thinking 'Wow'."* (Sally about the attention using a kickbike attracts.)

Figure 10. Sally's mainstream kickbike that she uses instead of a traditional assistive product for mobility.

Figure 11. A tap that is a combination of an assistive grip and a curvy mainstream spout in Sally's kitchen.
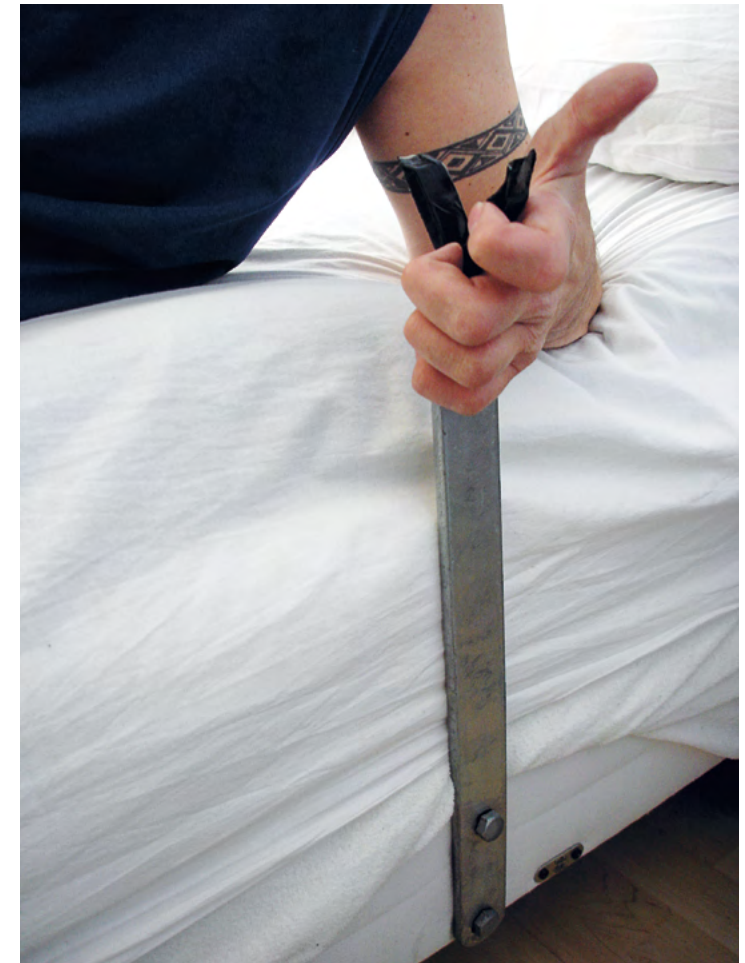
Figure 12. A transfer-handle to be used instead of a ceiling lift or an electrically adjustable bed.

Sally has also tailored assistive solutions in her home, particularly in her kitchen, in a way that fades out their assistive purposes. In the kitchen tap, for example, she has complemented and balanced assistive components with components that she considers well-designed (Figure 11). She explained that the grip of the tap is commonly used in hospitals in order to ease reaching and grasping, but due to the well-designed curvy mainstream spout, the tap as a whole does not resemble a hospital tap.

A similar example can also be found in the Internet database, where a user has ideated a transfer-handle to be used instead of a ceiling lift (Figure 12). The handle is made of metal and attached to a bed frame. The user considers it a good alternative to a hospital-like ceiling lift or to an expensive electrically adjustable bed.

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The professional who works with young people brought out in the interview that young people wish for assistive products, which would be a combination of both good usability and appearance.

Carla has personalised her ready-made assistive products, particularly her walker, cane and mobility scooter, with tribal stickers that are common among motorcyclists (Figures 13–15). She described how especially the personalised scooter attracts positive attention. She emphasised the importance of being able to turn assistive products into "her-looking".[103] For her, personalisation has become easy and natural. She told that she has become a "concept" in her surroundings due to extensive personalisation.

> "And the fact that when you can after all _make_ it exactly your own kind, your own looking, so it goes like (.) in a breeze. So I'm now already a _concept_, by and large, among my circle of friends, who wonder if things went _wild_ [with personalisation] [giving a laugh]. … Some people may stop and stare, because they don't get _at all_ why (.) but then again, for example, some little guys, they don't even think about _why_, but they just stare at the scooter as if they said 'How cool'." (Carla about the attention personalisation attracts.)

In the interview, Carla pondered how much people's positive reactions stem from the personalisation of assistive products and how much from her overall style that the products just follow. She thinks that her appearance alone can create a particular image.

Figures 13–15. Carla's tribal stickers, and a walker and a mobility scooter decorated with them.

103 Dittmar (1992, 41) considers clothes "the outer skin of personality and identity" and, consequently, looking or not looking like their wearer. Also products, in particular assistive products that are intimate and body-related, could be seen as such outer skin.

"Well, as a matter of fact, I don't quite know how much it is at first glance about paying attention to the <u>tuning</u>, instead I think that because already my own appearance is <u>tuned</u> as such, so it then gives a particular image and then they [personalised assistive products] do show when you [use them]." (Carla about the attention personalisation attracts.)

On several occasions, Carla emphasised the importance of her entire appearance that consists of separate items like clothing and footwear (Figure 16). All support the desired image and contribute to a "package".

"So well, there are many, many points, when you think about it, so eh (.) but I think that it is like the <u>scooter</u>, at first, but then when you look closer, when you see all those stickers on it. And then really, if I too, this hooded jacket and a leather-jacket on, so that attracts [attention], it is a sort of a <u>package</u>, at that point." (Carla about the attention personalisation attracts.)

Figure 16. Carla presenting her style.

Also Laura described how her customised assistive products are not perceived as mere assistive products. She mentioned that particularly her customised manual wheelchair does not stick out and override her, but instead, fades to the background and gives room for her as a person. Similarly, Ravneberg (2009, 107) brings out how one of her interviewees prefers neutral wheelchair colours, which match her clothes, because they make other people pay more attention to her, not to her wheelchair. One of the professionals told in the interview that some children want their prosthesis to appear "real-looking" in order to avoid becoming bullied, whereas others want that it is decorated so that it would not be "plain skin-coloured". Most professionals were of the opinion that the design of assistive products should be the way that neither an assistive product nor disability appears first, but the person.

Sometimes Laura even forgets that her customised products are assistive. Like Carla, she pointed out how, in addition to personalisation, her personality contributes to how she is perceived.

"It [what is best] must be that they [customised assistive products] are quite successful after all. Which means that <u>I</u> don't think of them as assistive products after all. So I always have to think that, assistive products, oh yes. Particularly these slopes were something that I didn't at first perceive as assistive products until I started to think of it more carefully. <u>But</u> it is also that I have noticed that my wheelchair, for example, is such a successful solution, of course it might stem from my own personality, but maybe also from a successful assistive solution and design and something else, because you don't notice <u>it</u> at first, it doesn't stick out. You don't pay <u>attention</u> to it at first. But to <u>me</u> as a person and not to my assistive product." (Laura about what is successful in her customised assistive products.)

It appears that a personalised product, if personalisation is eye-catching, can turn attention to the personalised product from its user's disability. But, if the product is personalised neutral, less assistive-looking, it can focus attention to its user without one-sidedly emphasising disability. With both, it could be possible to balance various aspects of identity and present a user as a person, not only as someone with disability.

Concerning the image personalised assistive products convey, the difference between positive and negative covering came up in the interview with Laura. She considers her sporty customised wheelchair, which conveys an image of a sporty person and turns other people's attention from disability, to be positive covering. Then, there is also negative covering that she associates with hiding disability, which she does not accept.

> *"Some assistive products are sports equipment. So, for instance my wheelchair, so this is sporty, kind of a bit sporty and also meant for going little faster with this, if you want. So that's not, it is not sort of, it is in no way the kind of <u>negative</u> covering. But you are right, there is that as well, there are like two types [of covering] then, so there is positive covering and altering and shaping, but then there is also that negative, which should be avoided."* (Laura about positive and negative covering.)

Tina thinks that through personalisation also the image of other assistive products, not just her own products, could be changed. Personalisation could be something that all assistive products could enable a user to do in order to remove stigma. She exemplified this with a wheelchair and how personalisation and updating could change its image. Alex proposed that through some kind of easily adjustable spare parts like Velcro® tapes also other assistive products, not only his, could be easily customised.

Different assistive products can be similar on the technical level, but connote different things. Hirsch et al. (2000, 77) suggest that some mobility scooters, for instance, can resemble

wheelchairs and walkers, but lack negative connotations, and be "styled to be fun and sporty rather than assistive and institutional". Similarly, Rønneberg Næss and Øritsland (2005, 4) associate canes with disability, but poles with sport. Also one of the interviewed professionals characterised poles as representing "a brisker going" than some other products, which, however, might be more appropriate in a situation when the level of disability has increased. Assistive products that resemble other consumer products can take advantage of visual metaphors and be more pleasing to users.

When describing her personalised mobility scooter, Carla brought out that assistive products for mobility and physical disability are a particularly effective combination of attracting negative attention, which could be managed with personalisation. It seems that for her, personalised assistive products can act as protection against undesirable associations.

> *"So well, with it [a personalised assistive product] you really can, so it [the personalised mobility scooter] is also a particular <u>protective aid</u>, because it is an <u>assistive product</u> and precisely a <u>mobility</u> assistive product, and a physically <u>disabled</u> person's assistive product, so it, when the image is like this, it is a protective aid."* (Carla about personalised assistive products as protection.)

Carla presented further how her personalised assistive products have restrained people from asking questions and, thus, shielded her from negative attention. At the same time, she brought up the different reactions children and adult people have.

> *"Adults and children react in such different ways. Adults look sort of (.) a bit confused (.) but then again, I have quite clearly managed to <u>quiet</u> those askers with these being <u>tuned</u>, so they don't even come over that fast, when the result looks that much (.) like a weird [laughing] <u>equation</u>, so these are then <u>protective aids</u>."* (Carla about personalised assistive products as protection.)

Some intimate assistive products may cause embarrassing social situations, which could be prevented with design that does not underline their purpose of use. Laura recalled that she would have appreciated, if incontinence protection had been nicely individually packed, so that the products would not have caused distressing attention when falling out from her school-bag in a classroom. She wondered if a nice packing could have "bluffed" people in that situation. She is, however, pleased that the packages, in which her incontinence protection arrives and is stored at home, are discreet. There are no striking descriptions of the contents on them. In the Internet database, various products that aim at discretion in intimate self-care can be found. Even if intimate assistive products are meant to be used privately, some of them are stored in places that also other people use, like in a bathroom, and the products can be in view. In Figures 17 and 18, a user has created a storage solution from an umbrella stand for catheters that is described as "a discreet hiding place".

Figures 17 & 18. A hiding place for catheters.

Another user has ideated a discreet bag, which is sewn by a tailor, for storing catheters under a wheelchair seat. It has a similar colour as the wheelchair and it is characterised as "barely visible". Also other items that are described as discreet can be found in the database. One user has ideated a discreet safety string, which can be used for maintaining balance in a powered wheelchair, because he does not want to use a large seatbelt. Another user has ideated a foot strap to be used in a wheelchair foot-bar. It is described as "reasonably discreet and blends in with the wheelchair and feet".

In addition to protection, Carla considers her personalised assistive products "licences" for her to be different or even to do peculiar things. She claimed that through her extraordinary style, people know how to treat her and do not startle. Carla's personalised assistive products and the entire appearance form cues for behaviour, which guide and ease interaction for Carla and for other people. If she does strange things, it is clear and justified by her special style. Carla seems to have managed to turn the misconceptions of physical disability into a strength through her unique style, of which personalised assistive products are part.

> "Eh, I'm very _sensitive_. I take things and people's judgements and (.) such _really_ easily personally. So, it [a personalised assistive product] is of course a certain shield then that no-one dares to come judge me outright, when I move with that kind of a walker, I have this kind of a shirt and a leather-jacket, so that signals _something_, but then _after all_ everybody, who knows me [giving a laugh] knows. … And this has been _always_. _Always_, I would've rather done that [something tomboyish like arm-wrestling on May Day], but I didn't dare. Now I have it _even_ clearer, like okay (.) _disability card_! [Yelling and waving an invisible card] I like wave, I have a license [laughing]. Whatever! I have like, eh, so much proof that I'm _not_ going strong, I don't care, so let's make everything out of it. So. And it is so that it's possible with these kind of [personalised assistive products]." (Carla about personalised assistive products as protection justifying difference.)

4.2.2 Assistive Products as Mainstream Products

Also Mainstream Products in the typology refer to passing and, in that respect, they resemble Shields. Mainstream Products can be seen as more ordinary than traditional assistive products. They can be considered products that users would have chosen anyway. They also convey the idea of inclusiveness and universality that is included in the inclusive design approaches. Parette and Scherer (2004, 219) have suggested that many people would choose also their assistive products according to similar criteria by which they choose other products, if they had similar choices. Some of the professionals emphasised in the interview that users with disability are as individual in relation to their assistive products as they are to their other products, or as other users are. Users, particularly young ones, follow trends and are aware of the latest brands and colours that are "in" also within assistive products. When asked Sally what makes her customised assistive products of her style, she stated that she would have chosen the same products, even if she had been taller.

> *"Mmm (.) well maybe that those I would have chosen even if I was tall. So, it is sort of just my style and my kind, it has nothing to do with what the requirements are or things like that, so that kind I would have chosen even then and why wouldn't I get it now, even if there's something extra but in a way that it does not show out."* (Sally about what makes her customised assistive products her-looking and of her style.)

Sally said that she appreciates "normal-looking" assistive products that would correspond to some current conceptions of beauty. Mainstream Products in the typology are natural, self-explanatory and neutral in attracting attention. Some assistive products, which are perceived as mere tools that provide a means of accomplishing tasks, can fade into the background of users' lives (Miller Polgar 2010, 19). But, in order to also fade

Figure 19. Sally's antique chest of drawers for childcare.

in social situations, they need to not look like tools. Assistive properties can be intentionally hidden or integrated into other product properties.[104] In Figure 19, Sally demonstrates how she, as short in stature, can use an antique chest of drawers for childcare. Due to suitable dimensions, the piece of furniture can also provide her assistive functions.

As discussed earlier, also assistive products' delivery and marketing contribute to the construction of stigma, not solely product design. Sally encouraged to market assistive products like any products through mainstream marketing channels, for instance, assistive products for women in women's magazines. Laura suggested that assistive products could be available in ordinary department stores or even in grocery stores instead of in specialised shops (see also Correia de Barros 2012, 283–284). She thinks that would change their image as special products, sensitise people to the products, and "normalise" the products.

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104 See also Jacobson 2009.

"I think it [having assistive products in ordinary shops] would be <u>good</u>. Because that way the gulf is lowered between the kind of people who have to use assistive products and the kind of people who haven't yet needed anything, because anyone of us can at some point need assistive products. So, whatever assistive products they might be, I think it would be <u>extremely</u> good to have them openly available, for instance, in a dairy store [giving a laugh] that by the way these kinds of products exist. So that it would become <u>normal</u>." (Laura about selling assistive products in ordinary shops.)

Currently, getting assistive products is not like typical shopping. Instead, a user and her requirements are studied and evaluated by various specialists before acquiring a product, and often someone else than the user of the product makes the decision about purchasing the product. (Brooks 1998, 7.) This was also brought out in one of the interviews with professionals as already discussed. The difference between typical shopping and shopping for special products is also apparent in communication and marketing. For example, the products for people with disability are specifically called assistive products, whereas similar products are just products for people without disability (see also DePoy & Gilson 2010b, 59).

Most of the interviewed users have used mainstream products as assistive products due to easiness, affordability and lack of stigma.[105] Laura, for example, has used long cleaning equipment for reaching. Carla takes advantage of all kinds of sticks that she can find from her garden and uses them as canes when gardening. In the Internet database, an aquarium net, a plastic bag, a

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105 Correia de Barros (2012, 179–180) discusses affordances in terms of using existing products unchanged for different utility functions than their original. I have earlier (Jacobson 2009) proposed that particular qualities of the physical environment could be seen as "affording" accessibility potential for people with physical disability like in the earlier example of Sally's antique chest of drawers for childcare.

towel, a string and a piece of cardboard are all used for picking up objects from the floor when using a wheelchair. Tina believes that assistive products that are simple, but inventive, are accepted better. She has received positive reactions from others when she has applied mainstream products to assistive purposes of use, like a dog leash to the tailgate of her car in order to improve her reach (Figure 20), or modified them. In the interview, she told about someone who has put a magnet to the tip of a telescopic antenna and used it as a handy carry-on reacher to pick up things. She herself used to have a telescopic pointer for reaching elevator buttons.

"So sort of the kind of simple, easily realised, but practical solutions maybe show some kind of cleverness, that <u>well</u>, you can also do it this way, so then it usually evokes positive reactions." (Tina about the reaction of a waitress, when she asked if she could have a beer crate upside down under her feet in order to improve her reach.)

In the interview, Sally demonstrated her solution for improving reach in her kitchen (Figure 21). The lowest drawer of the kitchen cabinets has been turned upside down and it works as an extra step. By stepping on it, Sally can reach up and when she does not need it, it can be pushed inside the cabinet.

Figure 20. Tina using a dog leash in the tailgate of her car to improve her reach.

Figure 21. A step in Sally's kitchen to improve her reach.

Figure 22. Sally's trick for adjusting a shower.

Another simple, but highly useful trick that Sally has created is a system with which she can pull a shower on her level (Figure 22). It is essential for her, because the shower is also used by her husband, who is not short in stature, and if he has left the shower up, Sally would not be able to lower it without the system.

In the Internet database, simple, everyday objects that are easily made, and some of which are potentially useful also for people without disability, can be identified. Figures 23, 24 and 25, for instance, show product applications and adjustments that ease everyday tasks. In Figure 23, a user with a wheelchair employs a tray for transporting objects on his lap. In Figure 24,

Figures 23–25. Transporting objects with a tray on a user's lap, coach tape on foot-bar to prevent feet from sliding, and a nail file attached to a hand lotion bottle.

another user has used coach tape on a wheelchair foot-bar to prevent feet from sliding down. In Figure 25, a third user has attached a nail file to a bottle of hand lotion to enable taking care of her hands. Simple everyday objects can be described as resourceful. The changes may appear small, but they can be crucial and benefit also other users.

The interviewed professionals, however, brought up some problems that applying mainstream products for assistive purposes of use, or using assistive products that are not approved, can have. First, such products may not be safe, because they are not meant to be used for assistive purposes. They are not tested according to regulations set for assistive products. Assistive purposes of use require a lot from products, because their users' abilities are not the same as those of the users of mainstream products. The qualities of approved assistive products can compensate in potentially dangerous situations when users' abilities cannot. Second, the products do not have similar guidance, maintenance or repair services as approved assistive products. Third, mainstream products may require regular adjustments like tightening screws, which some people with disability may not be able to do. The professionals emphasised that reliability is one of the key factors that contribute to using a particular product. Users with disability need to be able to rely on their products.

The opposite is possible as well. Products that are originally assistive can become mainstream products. Spectacles are a classic example as already discussed. Instead of being classified and perceived as assistive products, glasses have become fashion items, which can be bought from many places like opticians and service stations. Even people who do not need spectacles for vision are wearing frames due to image- and appearance-related reasons. Also various headsets that are common among mainstream technologies are changing the design of assistive products for hearing into more mainstream and high-tech hearwear (see also Ravneberg 2009, 108). One of the interviewed professionals brought up how mobile phones are changing the image of assistive products for communication. The products used to ap-

pear large and ugly and have obtrusive colours, which made them difficult to be accepted particularly by adults. Now the products are starting to resemble mobile phones.

Assistive products and their users can appear more ordinary also because environments may have developed tolerance for difference. Goffman (1963, 69–70) refers to *sheltering*, which means tolerance for certain stigmas around certain environments. Neighbourhoods of hospitals, for instance, can have a high tolerance for people with conditions that are treated in those hospitals. Similarly in my previous study, people who lived in the area originally built for war veterans were accustomed to disability.[106] One of the interviewed professionals emphasised the importance of the social environment, how other people react and to what they have become accustomed. According to her, where and among what kind of people a person lives influences experiences of using assistive products. She, however, remarked that the surroundings also affect the type and availability of products in the sense that practices vary according to a person's place of residence.

In the interview, Alex compared powered wheelchairs with cars and suggested that the design of assistive products could learn a lot from car design. The potential of car design has also been recognised in earlier research (see e.g., Resnik et al. 2009, 82; Stineman 1998, 57). Alex proposed also other design role models for assistive products like baby carriages and various hybrid vehicles. Tina drew an analogy between assistive products and computers that are assembled from individual parts. In both cases, the end result would be a complete product, but also individually customised. Popular established mainstream products could influence mainstream-like assistive products and act as sources of design inspiration. One professional brought out in the interview the potential of trends, but also celebrities and other famous public persons who use assistive products, in influencing the image of the products and the products becoming accepted and more mainstream.

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106 Jacobson & Pirinen 2007a, 164.

When asked whether it matters to use a mainstream product as an assistive product, or a ready-made assistive product, Alex stated that the question is hypothetical. He thinks that assistive products are never designed to be as elegant as mainstream products. In the interview, Alex started pondering: what if assistive products and mainstream products were similar. But he soon stopped his speculation stating that they never are.

Some assistive products could, however, easily resemble mainstream products, because they can have similar functions that are common to all people. Alex described how also some other residents in his apartment building, like a family with children, decided to have an electrically operated front-door when they heard about Alex's door. They also found it useful, even if they do not use assistive products. In Carla's opinion, kitchenware and cleaningware are products that facilitate the work of both people with and without disability. Whether it would be good that assistive products would not look like assistive products depends, according to her, on their purpose of use. Sally pointed out that some mainstream products can actually be more usable than assistive products. She demonstrated in the interview how a bottle opener designed by Alessi is not only good-looking but, in her opinion, also performs its function better than an assistive product for the same purpose of use (Figure 26).

Figure 26. Sally comparing two bottle openers, one designed by Alessi (left) and another that is an actual assistive product (right).

Even though applying mainstream technology to assistive purposes of use might be more cost-effective, and diffuse the image of an assistive product, it may also have image-related disadvantages. Rauhala (2007, 99–100) describes how a young girl using a cigarette holder as a mouthpiece of a communication device evokes ambiguous and even negative connotations, because the impression appears as inappropriate.

Another disadvantage in using mainstream products as assistive products relates to the special status of assistive products, which entitles their users to special arrangements and treatment. Tina brought up an example of how current laws and regulations restrict the possibilities of a person with disability to use other than approved standard assistive products. She wants to use modified mainstream products as assistive products for mobility, but is not allowed to use them in public transport, because the regulations set criteria for what is conceived of as an assistive product and permitted in vehicles. DePoy and Gilson (2010a, unnumbered) argue that through legislation, people are defined as disabled and their lives designed to maintain disability benefits. There are mainstream products that could be used for assistive purposes of use, but they are not included in the disability benefits and, therefore, not paid by the public sector or insurance.

4.3 Expressing the Self with Personalised Assistive Products

If a person has a different image of herself than other people do, she may, according to Leary (2000, 7246), engage in managing impression and "repairing" her "damaged image". The use of stigmatising assistive products such as Instruments, Uniforms and Misrepresentations can lead to wrong impressions that users may want to correct. In addition to managing stigma through Shields and Mainstream Products, which concentrate on passing, personalisation can also be extended to managing impression, that is, to presenting the self. One of the professionals brought

out in the interview how some users increase their products' "cosiness" with small "tricks", like decorations, in order to make them more their looking, because ready-made assistive products are often considered ugly. Another professional described how one user had drawn eyes and eyelashes on a mobility scooter, another decorated an assistive product with Marimekko® patterns, and a third one painted an entire product. One professional recalled a user, who had decorated a basket in a wheelchair in a way that makes the product stand out from other products.

In the typology, positive types, which derive from users' experiences of personalised assistive products, aim at expressing users' identities. They all focus on positive self-presentation and their use can create feelings of pride. Whereas the negative types emphasise instrumental interaction, the positive types offer users also other functions, some of which relate to identity. Because of personalised and customised features, the positive types can provide users with possibilities to manage and modify products, to experience joy, success and pride, and to explore identities when using them. Their use can enhance aesthetic experiences, positive emotions and meaningful associations, which support users' identification and attachment with products. Even though here the positive types that meet users' identity-related requirements and preferences are personalised products, their qualities can be seen as opportunities and future design guidelines of assistive products in general.

Based on the analysis of the empirical data and literature, I have divided the positive types into three subtypes: *Accessories*, which are adaptable, context-fit and enhance group identification, *Handicrafts*, which emphasise individuality, uniqueness and self-making, and *Prestige Items*, which involve pride, attitude and empowerment. While Shields and Mainstream Products help social integration, Accessories, Handicrafts and Prestige Items focus more on positive differentiation and emphasise users' individuality. They seem to reflect Green's (2009, 37–39) notion about positive identities not being exclusive to those who perform extraordinarily. She describes how many "ordinary

people" with disability or illness do not hide their condition anymore, but "celebrate difference" and proudly express and construct their individuality. She, however, remarks that other people still tend to define people with disability according to their condition. The positive types in the typology can be considered a users' attempt to influence, or even correct, people's misconceptions.

The positive types can be viewed as stimuli that help match a person's various roles, which also relate to other qualities than disability or the role behaviour associated with it. A sporty assistive product, for instance, can enable its user to experience herself, and to be perceived by other people, as a sporty person and not only as someone with disability. Bispo and Branco (2009, unnumbered) suggest controlling the signification process of assistive products by communicating information about a user's identity that equals her social expectations. The authors illustrate how "contradictory symbols" can extend assistive products beyond their utility functions and result in solutions that communicate lifestyle-related qualities and challenge a preconceived perception of disability. According to them, a small child's walker, for example, could resemble a toy instead of an assistive product for mobility (see also Poulson & Richardson 1998, 164).

All interviewed users of this research are concerned about the images their assistive products convey and how other people react to them. Laura thinks that the feedback she gets from her surroundings and society is extremely important. She considers herself lucky, because she has received positive feedback also concerning her other characteristics, not just her disability. Her disability has not been highlighted, but rather other aspects of her identity. She pointed out that she has been brought up as a person, not as someone disabled. The importance of a supporting starting point was also mentioned in one of the interviews with professionals as presented earlier. Interestingly, Laura thinks it is difficult, if not impossible, to control the image a person gives, but Laura herself has clearly managed how she appears in front of other people by customising her wheelchair.

In the Internet database, several personalised products that are tailored according to the individual style of users or their homes can be identified. They do not only fulfil users' usability requirements, but also other ones like aesthetic preferences. They are characterised through adjectives that refer to aesthetic values, design and the avoidance of stigma. They appear to be more expressive than the neutral types in the typology. In addition to products with personalised features, the database introduces customised products that are also tailored, but users have not specified them as personalised. Nevertheless, their appearance suggests that they have been designed in a way that takes into account also other qualities than usability. When compared with other products in the database, like the tool-like first prototypes, customised products appear to resemble more personalised products than the others and have, therefore, been connected to the positive types in the typology.

4.3.1 Assistive Products as Accessories

Since assistive products are closely related or even attached to the body, they resemble accessories or clothing. One of the interviewed professionals stated that particularly for people who "live" in a wheelchair, that is, use the chair their entire time awake, the chair parallels to clothing, like a jacket or a pair of shoes, and it needs to be of its user's style and accepted by its user. Ravneberg (2009, 107) brings up how one of her interviewees "wears" her wheelchair and "dresses" it every morning. Ravneberg (ibid., 110) envisions that as extensions of the body to be shown to other people instead of hiding, wheelchairs could become "rollwear" and assistive products for hearing "hearwear". Similarly as bicycle helmets can be positioned, depending on whether they are viewed as garments close to their users' bodies or as separate cycling equipment, on the traditional borderline of fashion and clothing design and industrial design (Vihma 1995, 135), assistive products could be viewed as part of their wearer's apparel and contributing to her appearance, instead of considering them solely assistive equipment.

In the typology, an Accessory can be characterised as a continuation of its user and as an integral part of her appearance. It contributes to the "overall experience", where product functions and multi-sensory qualities are congruent with the intended (Hekkert 2006, 168). Figures 27 and 28 show two examples of coloured wheelchairs selected from the Internet database. In the first example, a user describes how she has painted her wheelchair in order to make it match her clothing. In the second example, another user has chosen colourful wheelchair tires and spokes that are characterised as attractive. One user tells that, in her wheelchair, she uses lap and hand cushions that match her gray, white, beige and black clothes. Aesthetic and appearance-related values also come up in the questionnaire in relation to the comfort and pleasantness of assistive products. A 13-year-old boy, for instance, likes that his manual wheelchair has patterns in wheels.

Figures 27 & 28. A coloured wheelchair to match its user's clothing (left) and attractive tires and spokes (right).
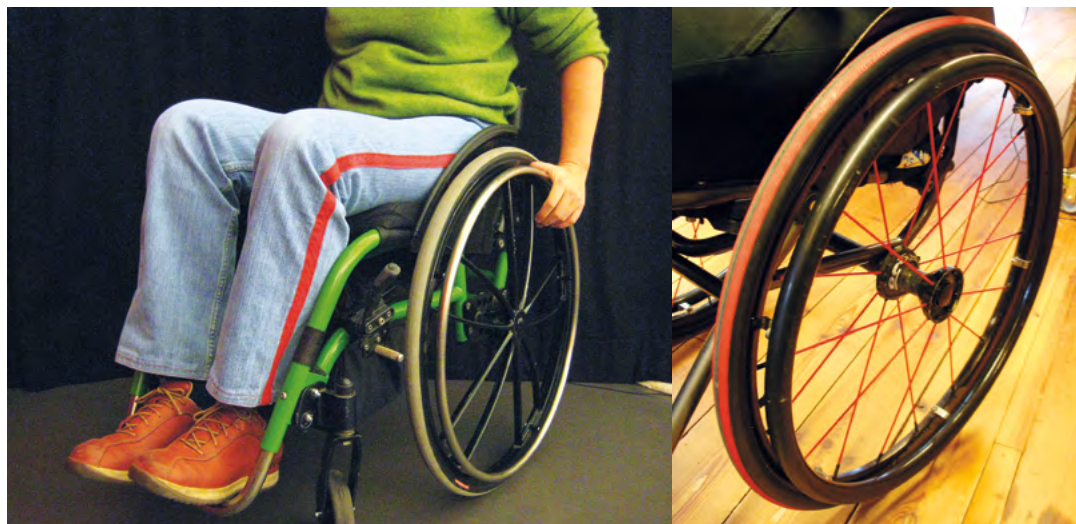
The characteristics of the user, the assistive product and the environment should all be acknowledged when prescribing assistive products (Scherer 2010, 2–3).[107] At the same time as Accessories acknowledge the individual requirements set by users and the contexts of use, they can also enhance group identity. Whereas Uniforms tend to categorise their users in negative, even stigmatising, ways, Accessories can enable positive fitting in and sharing a similarity in voluntary and controlled ways.

All interviewed users employ personalised assistive products in order to convey an image that is consistent with their identities, but also to identify with other people. Laura, Sally and Tina want to look like sporty young women. Laura has a customised manual wheelchair with special wheel rims and carbon fibre material, and it has a streamlined sporty looks. Sally and Tina apply mainstream sport equipment as assistive products for mobility (Figures 9 & 10). Carla has decorated several of her assistive products for mobility with tribal stickers typical of motorcyclists (Figures 13–15), because the personalised products express her identity better than the traditional ones would. Alex has customised accessible and assistive spatial properties to fit the overall style of his home and, for example, his powered wheelchair in a businesslike style to suit the image-related requirements set by his work. Instead of sticking out, Accessories can finish appearance. They contribute to a harmonious pattern (Douglas 2002; see Chapter 2.1.3 above) or a visual unity (Hekkert 2006, 166–167).

Carla literally considers some of her personalised assistive products like her walker and her cane (Figure 29) accessories. They accompany her style. She described how her handbag is attached to her walker with a chain and the chain remains in the

107 Scherer presents that the characteristics of the user include mood, background experiences, judgement and preferences, outlook, abilities, aptitudes and attitudes, the characteristics of the assistive product refer to appropriateness for the consumer, conspicuousness and benefit from use, and the characteristics of the environment are comprised of exposure and opportunity, support from others, resource availability and cultural expectations.

walker even when she does not carry the bag. Judging by the way Carla told about it in the interview, it seems as if the chain, and its close association with her handbag, supported the walker as an accessory. Carla's assistive products seem to have their own identities and she has even given them names. By all this, she has aimed to make the products more personal.

> "Yeah, so at least that walker is an accessory. It is a clear accessory. … So look, that <u>chain</u> is there for when I have a handbag, so I put the chain (.) so I put the handbag on the chain also for safety reasons. … But it [the chain] is quite like, it hangs there, even when I don't have a handbag [giving a laugh]. … This [cane] <u>is</u> like an accessory. As such. It is like (.) when you figure out your own [style] (.) so, I also have <u>names</u> for all these. … Well, more personal. So, it is that personalisation again, simply." (Carla on whether assistive products could be compared to accessories.)

Sally compared assistive products with clothing and pondered in the interview how different clothes match different styles and contribute to the whole, but current assistive products do not offer choice. For her, it is important that also assistive products would be more varied and fit their user's overall style and way of being instead of appearing assistive, one-sided and unconnected.

> "There is the kind of (.) I don't know, maybe you kind of want that those products that are assistive products would not look like assistive products, but what belong to that person's style and way of being. So, for instance, if you think about clothes, so okay, all people have a shirt and a pair of trousers, but people with different styles take shirts and trousers that are of different styles. But if you have a special system, so then you only have one kind of [an option] that you can take, you don't have <u>any</u> choice whatsoever." (Sally comparing assistive products with clothing.)

Figure 29. Carla and her personalised cane that she considers an accessory.

Sally emphasised that functionality, by which she refers to assistive purposes of use, is most important, but also aesthetic values could be paid attention to in order to increase appropriateness.

> "Well just the most important thing is that it [an assistive product] is functional, but then just the aesthetics that it would suit my style and anything else, if people go shopping for something so they do want that it suits them and it is sort of part of their mindset and system[.]" (Sally about important qualities of assistive products.)

Figure 30. An accessible wooden shelf positioned behind the sink in Alex's bathroom.

An Accessory is a perfect fit to its user ergonomically, functionally, semantically and aesthetically. Due to a variety of options, it resembles a Mainstream Product. An Accessory may appear so natural and appropriate that it is difficult to recognise. In that sense, Accessories also resemble Shields. When Carla was asked to tell about her personalised assistive products in the interview, she had to ponder a while, because she said it is sometimes hard for her to distinguish what is conscious personalisation and what is just her genuine spontaneous style. It appears that making assistive products her-looking has become quite self-evident to her, and that personalisation is such an integral part of her assistive products that it is hard to notice it anymore.

Alex described how it is difficult to distinguish his and his wife's, who does not have disability, style in their home. His customised assistive products have become an integral part of their home. Alex has ideated an oaken extension for a wheelchair user behind a bathroom washbasin, which works for his wife as a shelf for storing bathroom equipment (Figure 30).

Figure 31. An accessible threshold that fits the oaken style of Alex's home.

There is also a hardened glass wall in Alex's bathroom, which Alex considers not necessarily practical, but stylish. He explained that he and his wife "stole" the idea from an interior design magazine. Alex has also insisted on oaken thresholds, which fit the overall wooden style of the home (Figure 31). According to him, the particular thresholds were not easy to find, but he would not have accepted another kind.

Alex also wanted to have accessibility modifications like lowered light switches made already in the construction phase, because that way there would not be signs of renovation. Alex's

solutions show that personalised and customised assistive properties can merge into the surroundings and support the overall style. They also reveal that family members affect how ideas are realised. Alex explained in the interview how his wife sets the criteria, such as particular materials and colours, and he takes the criteria into account in customisation. Alex characterised his family as traditional in the sense that he goes to work and earns the income, while his wife, who is at home with children, has a better opportunity to devote attention to their home.

Since an Accessory merges into the domestic context of use, it appears as the opposite of an Instrument. An Accessory not only accessorises its user, but it can also accessorise her home. As Alex's examples implicate, accessory-like assistive products can adjust to the style of a home and appear an integral part of its furnishings despite their assistive and accessible properties. Similar context-fit is apparent in Laura's case. Laura lives in a house that was built at the turn of the 1960s and 1970s, and she wants accessibility modifications to take into account the period during which the house was built. In addition to that, she wants them to take account of her preferences, which she describes as down-to-earth. For her, some of the current accessible and assistive solutions appear too modernistic and not necessarily fitting the style of her home.

> *"It must be [the house looking] and because this, for example, is from seventy, sixty-nine, this house is I guess originally built so, I think it would have been totally gross to install some kind of an ultra modern fancy gadget system[108]. So, no, no, it would not suit this house at all, so that kind of, because I myself like this kind of down-to-earth and other that kind of colouring. So yes, it does matter like from the appearance viewpoint as well."* (Laura about appropriate accessibility modifications in her home.)

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108 "Ultramoderni hieno hökötyssysteemi" (the original Finnish expression).

Laura told that her husband has made slopes for her wheelchair in front of the front- and back-doors of their house, because that way they have got slopes of the kind they have wanted, which fit their house. In addition to that, she thought making slopes was an easy task and it was no reason to bother the landlord. Also the Internet database includes examples of assistive and accessible solutions that integrate into the style and construction of home. For instance, an elevator has been customised in a way that makes it fit the style of an old house.

Paying attention to aesthetic values can enable assistive products to blend into their users' environments (see also Miller Polgar 2010, 21). Laura described how her friend, who was visiting her, had not paid attention to her new wall-mounted shower chair, because it merges into one of the bathroom walls, against which it can be lifted (Figure 32). Her friend had just noticed that the bathroom is more spacious than before. Spaciousness had also been Laura's aim, along with style, in changing the chair. Laura told in the interview that she had heard of someone painting a shower chair in order to make it match the colour of a bathroom wall, even though some people in a health centre, who had given the chair, had opposed it. Laura admitted that she would have done exactly the same, had her bathroom wall and the shower chair not both been white. One of the interviewed professionals stated that, in his work, he tries to modify assistive products so that the modifications, which are often functional, do not "shine", but, instead, assimilate into the original products that are being modified.
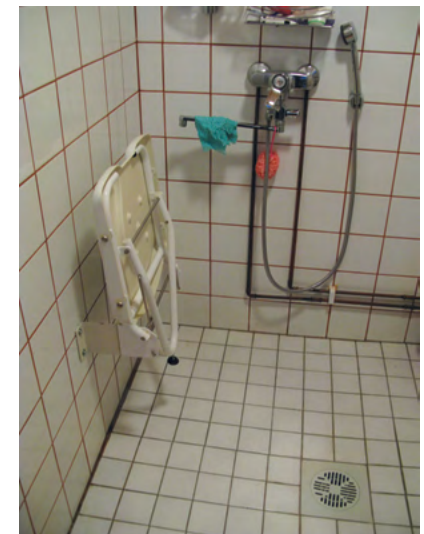
Figure 32. Laura's new folding shower chair in her bathroom.

Laura emphasised the importance of materials in creating context-fitting assistive products. In her opinion, most assistive products could be manufactured from a variety of materials, and even if they were manufactured from the same material, they could be designed in a way that takes into account the context. She illustrated this with an example of wooden handrails that would fit the style of her home better than the ones that she characterises as ugly, metal and white.

> *"[S]o for instance for these kind of old houses I think <u>wooden</u> handrails would suit <u>a lot</u> better than any ugly metal white painted ones. Attention should be paid to materials and other qualities."* (Laura's insights into context-fitting accessibility modifications.)

Also Sally brought up the poor suitability of handrails. In her opinion, handrails should fit the whole bathroom and make a satisfying unity. She encourages people who decide on the types of assistive products that are funded by the city to have a more holistic approach, which takes into account the entire home, not just single items. The importance of nice and context-fitting handrails was also mentioned by one of the interviewed professionals. She noted in the interview that the whole could become "uncoordinated"[109] because of handrails, which do not fit the context.

Alex suggested in the interview that assistive products, for example, powered wheelchairs could be "extremely elegant". By extreme elegance he means paying attention to materials, colours, the frame, tyres, wheel rims and controls. Alex, who uses an electrically adjustable bed, considers the Swedish Hästens beds a good example of elegant, yet functional products that could be employed for similar purposes of use as hospital beds, but that would appear totally different. For Alex, his bed parallels to a sofa. He pointed out how he sits on his powered wheelchair

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109 "Huolimaton" (the original Finnish expression).

the entire day and is not able to relax when sitting on a sofa like other people. Instead, he is able to relax when lying on a bed. Therefore, also the appearance of his bed is important to him. The bed needs to be suitable for sleeping, but also for relaxing when other people are present. In order to solve that, he has inserted an electrically adjustable hospital bed inside a wooden mainstream double bed frame, which is the right kind of material and colour, in order to make it appear ordinary and similar to his wife's bed (Figure 33).

Similarly in the Internet database, a user has chosen an electrically adjustable mainstream bed, because he has not wanted "a bed that looks like it comes from a hospital". The chosen bed is described as attractive and identical to the other bed next to it.

Alex unfolded in the interview further how he did not acquire an accessible table suitable for a wheelchair user, but instead, asked a manufacturer to modify a regular table with unnoticeable additional parts, because that particular table had the right wooden material and style (Figure 34), and also nice accompanying chairs.

Several accessible and assistive modifications which seem to merge into the home interior, like custom-made kitchens, can also be found in the Internet database. For one user, who has designed a kitchen, it has been important that the kitchen "should not look like it was designed for people with disabilities". Some other examples in the database are structural modifications like

"a well-planned wooden terrace", which a user has planned together with a landscape architect (Figure 35), and an outdoor ramp that blends in with the environment and has the same style as the house. In Figure 36, there is a wooden ramp, which is accessible for a wheelchair. It is located in a place in the archipelago and, according to the description, several seating areas with a beautiful view have also been built.

Figures 35 & 36. A wooden terrace a user has planned together with a landscape architect and an accessible ramp for a wheelchair in the archipelago.

Also single products that could be characterised as homely such as a tilting wooden holder for a bottle of oil in a kitchen (Figure 37) that appear to take into account the context of use and its surrounding objects can be found in the database.

In addition to varying abilities, Accessories adapt to different phases of life, lifestyles and trends. Sally, for example, proposed that childcare furniture could be more accessible to mothers who have disability. Also in the Internet database, there is modified childcare furniture. In addition, the database portrays working equipment and workrooms. Sally's proposal and the examples in the database reveal the need to consider different roles that people with disability can have. Alex unfolded in the interview how he used to have a hippy style with traditional Peruvian and Indian clothing, but after starting his work in a more conventional company, he changed into a business style, which also his assistive products follow.

Figure 37. A tilting wooden stand for an oil bottle next to a stove.

"So it also follows your own situation in life. … In the nineties I had (.) such different kinds of, eh, Peruvian patterns, I had a backpack that (.) such a bit hippie looking (.) and had quite a lot of those Indian style clothes and everything, I had red, green jeans and. Now that I am working at company X everything I have is very discreet, like a bit of a business look. So I have a black, black discreet this [points to a powered wheelchair] and that doesn't attract attention, respectively that backpack of mine is such a black Samsonite's backpack. And so forth so that it is all that kind of like very discreet. Because I visit customers and companies' managing directors and others so sort of they [assistive products] should not like attract attention. But it [style] always follows that phase of life." (Alex about how phases of life influence personalisation.)

Alex would like to have assistive products that can be updated according to styles and occasions. He envisioned in the interview products, of which some would be casual and some festive. He wishes that he could communicate various things with his powered wheelchair by customising interchangeable parts. At the same time, he pointed out that assistive products such as powered wheelchairs are consumables whose lifespan is only some years. New updated versions could be regularly provided as in the case of mainstream products. Claxton and Murray (1994, 423) remark that as meanings change, also the contexts, in which people define their selves, change and products should be adapted accordingly. The authors emphasise the importance of symbols that help define self. Currently, Alex has plenty of customised assistive products. He described how even the small details of his powered wheelchair, like neoprene coverings, are customised.

In the Internet database, there are plenty of product adaptations that relate to hobbies, such as raised flower beds for enabling a user of a wheelchair to gardening. There are several

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accessible camper vans, sailing boats, motorboats, stands for using binoculars, taking photographs, and filming video photography, easels for painting and drawing, and even an accessible hen-house, just to mention but a few. Numerous accessible saunas show a Scandinavian context of use. Figures 38, 39 and 40 show adaptations, which enable wheelchair users to maintain lifestyles. In the left figure, a motorcycle has been customised to enable its user to participate in motorcycle races and exhibitions. In the middle figure, a customised boat is both accessible and steerable. In the right figure, a user employs a customised snowmobile as a means of transport.

The professional specialised in prostheses disclosed in the interview how people used to have different kinds of prosthetic legs, one for everyday use and another for bathing, for example, but nowadays it is rare. She described how she had applied for funding for her clients to have a prosthetic leg to be used in bath or sauna, but usually the applications had been rejected. According to her, a prosthetic leg for bathing is not seen as necessary, because bathrooms can be made accessible enough with handrails and shower chairs, which leaves no need for a specific leg, taking a sauna is not essential, and going to swim is merely a hobby. She stated that in the Finnish culture, of which sauna is most often a characteristic feature, also people who use a prosthesis should have a right to go. She pointed out that from the viewpoint of rehabilitation, swimming would be important. She told in the interview that some people go to sauna with their every-day prosthesis, which can make the prosthesis mouldy and rusty, because it has not been made for such use.

The appropriateness of Accessories not only includes the material environment, but also the social context of use. Social contexts are also central in the emergence of stigma and in its prevention. Examples of customised products that fit particular social contexts of use can be found in the Internet database. In Figure 41, a user has ideated a wrist orthosis for an interchangeable fork and spoon. The modified cutlery is ordinary. The user describes how he can eat independently anywhere, even in a restaurant.

Figures 38–40. An adapted motorcycle, motorboat, and a snowmobile for a person who uses a wheelchair.

Figure 41. A modified fork attached to a wrist orthosis.

Figure 42. Assistive wine and shot glasses.

Figure 42 shows custom-made wine and shot glasses that a user who has quadriplegia has ideated. The glasses are described in the database as "beautiful on the table and functional for a quadriplegic to use". They appear to enable equal and formal participation in social situations that otherwise might result in unpleasant experiences, if using traditional assistive products like a spout mug. Nowadays, the glasses are also manufactured for other users.

The need for taking into account storing assistive products is mentioned in the user interviews and also in the questionnaire in relation to product dimensions. In addition to fitting aesthetically, assistive products should fit home physically. In practice, this means that users wish that assistive products were smaller and lighter. Alex characterised the size of current powered wheelchairs as "car-like" and suggests that the products should be as small as possible. On the other hand, some answers in the questionnaire reveal that size and weight can prevent a product from falling over. Laura pointed out that storing seems to be forgotten in the design of assistive products. Because of that, the products appear unfinished for her. Wheelchairs are not always used inside homes, but still they need a place there. Also Carla wishes she had more room in her home for storing assistive products. She described how the furnishing of her home now goes on assistive products' terms, because they are so large. For Tina, being able to carry assistive products is important and she pointed out how changing an assistive product may also require changing other things like a car. She wishes for fold-away assistive products.

One of the professionals brought out in the interview that some of the young users he had met hope for multipurpose assistive products. They have drawers and cabinets full of assistive products, often for the same particular purpose of use. Apparently, all those products are needed in order to be able to carry a particular task fully out, but they need a lot of space and some of them do not work well. These young users wish there was a single assistive product that would adapt.

The need to view the overall situation and various product functions is apparent in the interviewees' relation to their assistive products. Laura described how she is regularly offered a mobility scooter instead of a manual wheelchair, but she refuses to accept it. In addition to considering it unnecessary and not pretty and fast enough, she thinks she would gain extra weight in using a powered assistive product. Apparently, this reasoning is hard to understand by people who are involved in the assistive product provision, because her needs are regularly assessed solely from the viewpoint of her disability. Similarly, Tina described how she yearns for the bathtub that she used to have in her previous apartment, because even if it was considered dangerous for her, it eased her pain. It was something the people who were in charge of accessibility modifications could not understand, because she was persistently offered an accessible shower instead. What also influences use situations is that assistive products are not always solely used by their users, but also personal assistants or family members, who may have requirements that influence design.

The significance of viewing the use situations holistically is also apparent in Alex's preference for automation that assistive products can provide. He values how the automation of routines can save time for more meaningful things.

> *"Because I do simple routines in such a difficult way, so it is just what is like in contradiction with me. I then want to use that eh (.) available free time just, for something like playing with children and (.) other things that don't require automation. And, but when I just do some basic activities, so then those, I wish they would work."* (Alex about automation when asked about his reasons for personalisation.)

Also some of the interviewed professionals encouraged paying more attention to viewing the use of assistive products holistically. This, however, requires, according to them, new kind of thinking and knowing. Traditional assistive products are easier to the current funding and allocation system in the sense that people involved are familiar with them and all that is involved in acquiring them. When it comes to funding, for example, mainstream products that can have assistive, but also other purposes of use, are in the grey area. The current system is not flexible in such a situation. Another issue brought up by the professionals concerns the variety of channels, through which assistive products are assigned. For instance, some are provided by medical rehabilitation, whereas others like school or work equipment are handed out by other organisations. This prevents from viewing an individual user's situation holistically. The professionals proposed concentrating everything within a single place and bringing different expertises together.

4.3.2 Assistive Products as Handicrafts

Whereas Accessories tend to merge into surroundings, Handicrafts are individual in a way that makes them positively distinctive. They are customised to users or their homes and acknowledge the diversity of users. In this sense, Handicrafts are similar to Accessories and reverse to Uniforms. However, instead of group similarity, they emphasise individual difference and, thus, differ from Accessories. Their difference is positive and non-stigmatising, which makes them contrary to Instruments.

Current ready-made assistive products rarely allow to positively express individuality, let alone self-making, but can often one-sidedly highlight qualities associated with "deviance" maintaining the stereotype of disability and the dualism of "normal/abnormal". Handicraft-like assistive products do not, however, suggest becoming "normal" or mainstream, but encourage expressing the unique identity of each individual and highlighting positive differentiation. Laura, for example, described how she is uncomfortable with the idea of covering her disability. Instead, she wants to show it and also the other aspects of her identity.

"I'm a bit uncomfortable with that <u>covering</u>, particular qualities or hiding or that way, because I'm standing root and branch for <u>not</u> covering that I'm disabled, let it show what is apparent and there are also other qualities in me." (Laura about presenting her self.)

Also one of the professionals envisaged in the interview that prostheses, for example, could be more personalised in the future. In her opinion, a prosthesis fits its user better when it has a particular look compared with a traditional "skin-looking", which does not resemble real skin anyway. She thinks that sometimes a product appears to fit its user better, when the product looks nice.

In the 1980s, Zola (1982, unnumbered) argued that users of assistive products, including himself, have a need to make products more special, more of one's own. He described how he had given his assistive product his own "unique stamp". At first, he thought users alter products because they want to correct faults, but then he realised that users personalise their products and are proud of them.

By modifying products, users can transmit characteristics from their identities to the product appearance (Csikszentmihalyi & Rochberg-Halton 1981, 62) and, in that sense, Handicrafts could be viewed as a means of extending the self. They can express not only more versatile, but also more truthful images of their users. They could be viewed as new kinds of identity markers, which contribute to the images that people with disability want to convey.

What is particularly characteristic of Handicrafts is that they may not only be ideated, but also created by their users.[110] Belk (1988, 150) refers to Sartre's ideas of three primary ways of learning to regard objects as parts of the self, of which one is

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110 In her research, Correia de Barros (2012, 169–175) calls spontaneous product inventions, which are created by users, "artisanal objects", but as pointed out earlier (see Chapter 4), her focus is not on products' representational qualities, but on utility functions and methods of innovation.

creating an object. He states that an identity is retained in the object for as long as there is a mark of its creator. If creating an object is considered one way of incorporating the self into the object, and also the object into the self, Handicrafts can be important in expressing, and even constructing, the self.

Alex recalled that in the beginning, customising assistive products was motivated by utility. Something was not functional or usable and he wanted to improve it. Some of the examples in the Internet database seem to be similarly motivated. Users have not been able to accomplish particular tasks and have ideated new products or made functional improvements to existing ones. Alex's customisation, however, started to include also other dimensions that deal with aesthetic preferences and lifestyles. In the work of one the interviewed professionals, usability-related modifications are often the starting point, but the professional also aims at making them as aesthetically pleasing as possible.

When asked about his current motivation for personalising assistive products, Alex explained how he and his friends joke about it as a pursuit of being something special. In the interview, Alex pondered what being special or different means. He explained that there are "different differences" and within them differences, but after all, no-one is completely different, and yet, everyone is.

> "Among friends we joke that it's _a pursuit of being special_. (.) But these days, it is quite ordinary to pretend to be _special_ (.) while no-one really is. Then after all everyone is _just completely_ different. So it is, it is perhaps a bit mostly sort of (.) also a philosophical play about who really is different and is she different, because everyone is different after all." (Alex about personalising assistive products and being different.)

Aspirations to positive difference were also apparent in the other user interviews. The interviewees experience negative difference as stigmatising, but none of them wants to be "invisible". Laura associates positive difference with other people's curiosity towards her customised assistive products.

> "Eh, well there are positive ways to emphasise an assistive product, for example, what I think is that if I managed to get those spoke covers and to have those pictures painted on those wheels, so that would be that kind of positive emphasising. Because that brings, through them people have to pay more attention and look more carefully like '_Hey what did you have there_'. So that is that positive emphasising, yes." (Laura about emphasising in a positive way.)

For Sally, positive difference includes humour, cuteness and fresh metaphors. Sally distinguishes positive and negative uniqueness and described in the interview how, for example, her kickbikes are special "in a good way" and not "in an ugly way"[111]. She characterised them as something special like the MINI among cars. She believes that people are attracted to those kinds of assistive products, which they would like to have, even if they did not need their assistive functions.

> "Well it must be that they [assistive products that attract positive attention] are the way that they are solved an unusual way, but they are like, they are just nicely, just like, for instance, a car is, like that MINI or Beetle, that they are that kind, like cute-looking and funny and, that is perhaps what people think also they might like to have. So there is sort of that even _if_ it is a piece of special equipment or it is used as a piece of special equipment, it is the kind also others could use." (Sally about what makes other people pay positive attention.)

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111 "Hyvällä tavalla erikoinen" and "Rumalla tavalla erikoinen" (the original Finnish expressions).

People who do not have disability may well find some assistive products interesting instead of stigmatising, because they consider the products also useful for themselves (see also Stineman 1998, 57). In that respect, Handicrafts resemble Mainstream Products in the typology, but instead of passing, they attract attention. Tina has experienced that even single product features, like technology, attract people and rouse positive curiosity, because people find them exciting.

> *"Because what usually attracts <u>positive</u> attention among people is the <u>technique</u>. That is, if there's something, like something <u>exciting</u>. So then the interest is roused like 'Well, how does this work then?', 'Oh, how do you use this?' and that is like quite positive."* (Tina about the positive attention personalised assistive products attract.)

Carla explained that she wants to make her assistive products her own by personalising them with tribal strickers, because the strickers are typical of her. When viewed as Accessories, the stickers can, however, also be used for identifying with motorcyclists. Carla joked about assistive products being a good excuse for acquiring and placing more stickers, even if her aim is to make the products more personal. There is also a more practical side to the stickers as they are easy and affordable. Carla described herself as "extremely aesthetic" and referred to her former profession as a hairdresser and the importance of colours and shapes.

> *"Eh (.) those [tribal stickers] are 'my thing'. Those are my thing anyway. So, I just got a good excuse to get more of those stickers, when I had to start tuning these [assistive products]. Because I would not have dared to put flame stickers or something on doors [laughing]. But well, that was like a good excuse to, get, them. (.) So, look, they are easiest to <u>realise</u>. Relatively afford-*

able and they are easy to change, if you want, and (.) … I'm extremely aesthetic (.) have been, always. My first profession is a <u>hairdresser</u> (.) … it is the kind of aesthetics (.) colours and shapes like belong to that my that (.) simply I had to get <u>something for these impersonal</u> (.) things." (Carla about personalising assistive products with stickers and about her aesthetic preferences.)

Laura would like to make her wheelchair even more of her style by painting and taping spoke covers.

> *"I'm satisfied with the colour, so the basic black is just fine, but of course it would be nice to have here some details, so I'm thinking about spoke covers to these wheels then, so, to put black spoke covers and then to have them painted with something or taped with something. Appropriate pictures. So that could be something, how I would get it even more <u>me-looking</u> then."* (Laura about making her wheelchair more her-looking.)

Through personalisation, products can become more self-congruent and users more attached to them. Product attachment can prevent product abandonment, which has been identified as a problem with some assistive products. Laura is very attached to her customised wheelchair and cannot think of giving either it, or possibilities to customise it, away. She described how the chair is an integral part of her body, her legs (see also Ravneberg 2009, 106).

> *"Well I don't ever, I don't ever consent to give this manual wheelchair away. It is such, this I will <u>not give away</u>. It's my legs. And no, I will also not give away the chance to kind of decide myself what goes into it, to dictate myself what my needs are. So. I will not give my legs away [giving a laugh], let's say [it] that way."* (Laura about the assistive product of her dreams that she would never like to give away.)

Belk (1988, 143) suggests that people engage in activities that aim at self-restoration, if they involuntarily lose possessions that they regard as parts of their self and, thus, losing them equals to losing self.[112] He discusses how, for example, the creation of art, craft or writing can be viewed as an attempt to restore the self after a loss.[113] Belk illustrates how customising an automobile can be seen as a form of creating and nurturing an extended self. Similarly, the personalisation of assistive products could be considered a means of restoring the self after losing health or a body part. This kind of motive for personalisation could not, however, be found in the empirical data. Yet, Carla brought out in the interview how, particularly after separating from her former partner, she developed a strong will to start doing things on her own like personalising her assistive products. Personalisation may have strengthened her sense of self and accomplishment (cf. Mugge 2007, 115).

Even if a person would not be able to create a product herself, being able to influence its creation can be important (see also Olander 2011, Article 3). For Laura, choosing the qualities of her customised manual wheelchair (Figure 43) is fundamental. She described how she has been able to influence its special material and the amount and location of brakes. In addition, she appreciates that she has been able to choose a wheelchair according to the phase in her life.

> "I did get, I don't even remember what it is, but it is some a bit more expensive material [telling proudly] so inside a plastic tube go like subtle thin fibres, really, which don't get broken at all, so no matter how I would bump myself, they won't get broken [giving a laugh] so I could choose by myself, the kind that will be. And

then on the whole I could choose that kind of a wheelchair according to that phase of life, that is, I had the chance to choose the kind of a wheelchair that I could move by myself, for instance into a car. ... So the fact that I could quite well influence that. And there were also several kinds of brakes to choose from. So, whether I would want one brake or two brakes and where those would be placed and so forth." (Laura about customising her wheelchair.)

Figure 43. Laura's customised manual wheelchair.

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112 Similarly, Dittmar (1992, 46; see also Csikszentmihalyi & Rochberg-Halton (1981) in Chapter 2.2.2 above) considers the unintentional loss of material possessions a lessening of self.

113 Belk bases his thoughts on the research by psychoanalyst William Niederland and psychiatrist Bahman Sholevar.

In terms of choosing or customising fitting products, Handicrafts resemble Accessories, but they emphasise individual difference more. The qualities the interviewees have chosen may not necessarily appear extraordinary, because many of them can be considered basic among mainstream consumer products, but the ability to influence and to have choice are important.

> *"The biggest thing that I now experience as the biggest thing, which has also succeeded, is that I have been able to choose the colour, that it has been that black. Luckily I am, I don't have any more difficult colour wishes than that [giving a laugh]."* (Laura about customising her wheelchair.)

An example of the importance of considering users individuals in the design of assistive products is apparent in Sally's experience of shoe making. In the interview Sally unfolded how she has had bad experiences with her previous shoemaker, but she is extremely satisfied with her current one. She drew a parallel between the individual shoe making process and the story about Cinderella. She appreciates how in addition to the orthopaedic requirements, also individual aesthetic requirements are paid attention to.

> *"[S]o, mmm, why it is so <u>good</u> is first of all, for example, that style that they make those shoes with. They make it so that they look, mmm, at the foot a bit like Cinderella's shoe, so they look at it like in such a transparent system where they are able to sort of make all those required changes <u>inside</u> that shoe, whereas usually they are made outside, when, if you have a bit special type of foot, so the shoe will be <u>senselessly ugly</u>[114]. And the kind of that looks already from a distance that that is, that is a special shoe or then it looks like some granny's shoe, so well. But then again if you have the kind of place where they make all changes inside it, so*

Figure 44. Self-made handles.

Figures 45 & 46. Awarded manual wheelchairs in the competition for the dream assistive product.

then you have after all such a petite pretty shoe and no-one would believe that it even is a special shoe. So that is the kind of change I now experienced here and I was totally happy." (Sally about her customised shoes after changing the shoemaker.)

Handicrafts are mostly based on the findings from the interviews with users and literature, because few products can be characterised as Handicrafts in the other empirical data. Figure 44, however, shows an example of Handicrafts in the Internet database. A user has ideated and made unique handles of Cernit clay, which can be attached to products to ease their handling. It is not mentioned in the database, but the individual self-made handles could present a user, who has difficulties in grasping objects. Even if the handles may attract attention, the attention can be positive due to personalisation.

Figures 45 and 46 exemplify personalised manual wheelchairs that participated and were awarded in the competition for the dream assistive product, which was arranged alongside the Technical Aid, Wellbeing & Home Fair and Congress in 2009 in Finland. Due to their uniqueness, they can be viewed as examples of Handicrafts. The wedding wheelchairs for a bride and a groom in the left figure, could also be considered Accessories, because they fit well the overall wedding context due to decorations that resemble decorations typical of weddings.

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114 "Aivan tajuttoman ruma" (the original Finnish expression).

In Finland, also other competitions for users' ideas of assistive products have been arranged recently. Unfortunately, the entries have been confidential and only the winners and runners-up, like the aforementioned wheelchairs, have been published. If the material had been public, the entries could have been interesting data also for this research.

4.3.3 Assistive Products as Prestige Items

Assistive products as Prestige Items cannot be seen as class symbols in the sense that they would refer to their owners' superiority or preferential treatment (cf. Goffman 1951, 297). They are not likely to be viewed as occupational items either. It is, however, interesting that as, for example, some Instruments resemble medical equipment when worn or employed by the personnel in the health-care context, they can be seen as occupational items. The domestic context of use seems to change their symbolic qualities into stigmatising ones. Instead of referring to class or occupation, Prestige Items can be viewed as "equalisers", which rectify a situation by enhancing confidence and capability in the eyes of a person herself as well as other people. In their ability to "influence in a desired direction" (ibid.) instead of representing a person's position they, however, also refer to class symbols.

Some personalised assistive products can have other qualities that make them refer to prestige symbols. Such products can be viewed as a positive source of pride for their users. They can also become the envy of others as representations of something eligible. They can empower, encourage and enhance self-confidence. They are employed for both assistive and social purposes of use.

A Prestige Item embodies attributes like high social status, which are not typically associated with people with disability. Even though class symbols and their social gains can be associated with a high price that brings market value (Goffman 1951, 298–299), Prestige Items do not seem to embody this quality, even though the products may be expensive. Some Prestige

Items can actually be affordable as for Tina and Sally, who both employ mainstream products for assistive purposes also because assistive products for similar purposes are often expensive. Rather than from high price, the status of Prestige Items, and their meaning for users, derives from their expressiveness, individuality, uniqueness and rarity, which are socially valued. However, in the case of assistive products, any uniqueness does not result in high social status as can be seen in the case of Instruments, whose negative difference can lead to stigma. One of the interviewed professionals pointed out, when she unfolded how some parents would like to have an IKEA high-chair for their disabled child instead of an assistive product, that some pieces of the IKEA furniture can look rather unusual. But, she thinks that because they are not defined as assistive products, and they are internationally renowned, they are better accepted.

Similarly to Handicrafts, Prestige Items are characterised by positive difference. The social consequences of this, the difference, however, extend even further. Both Carla and Tina described how using a personalised assistive product creates feelings of pride and makes passers-by admire and even envy. While the use of Instruments, Uniforms and Misrepresentations can result in feelings of embarrassment, Prestige Items create feelings of pride. As Carla put it, she "dares" to use her personalised assistive products and does not have to hide them. Through her personalised assistive products, she also wants to realise her motto that, even though she has an illness, she can look otherwise.

> *"Well the fact that it rouses, among people (.) like interest and that I really <u>dare to go</u> with them [personalised assistive products] so there won't be sort of, like nah, please hide these or something, but that, very fairly you can sort of (.) There will be like on and on these kind of, like okay, do after me. Mmm, so because, eh, you are with the physique and also with the psyche a bit like below the norm, whatever the norms may be, but anyhow. Eh, but then again showing that you can be ill, but*

you don't have to look like it. Mmm. That is the, that has been such a, a motto." (Carla about what is best in her personalised assistive products.)

Carla brought up people's misconceptions of how a person with disability should appear in public. She described how, at the time when she had become permanently ill, it was difficult for people to understand that she was happy-looking.

"So that, that was sort of something like, so should I, really, look like I'm bursting into tears all the time. And wear really ragged clothes and that, oh dear, oh dear, I'm poor and ill and disabled and retired [giving a laugh] and what else (.) So that was the first, that people were not about to think that I could still then be like (.) cheerful (.) in a good mood [laughing]." (Carla about being ill and looking ill.)

Carla thinks that, due to her illness, she has grown to be the kind of person she believes she would have been. As the personalisation of her assistive products strongly derives from her overall style, her personalised assistive products have probably strengthened her sense of her self. Carla described how, in addition to pride, her products affect her attitude. She mentioned again how personalised assistive products can act as licences to justify the way she is. The licence of Prestige Items has, however, a slightly different character than that of Shields. It involves pride, attitude, and even some defiance and challenging.

"They do affect! My nose does go up in the air and particularly if I really, mmm, with boots and a leather-jacket so [laughing] (.) I have taken a lot of that attitude then as well that (.) I have a licence. That is (.) I don't need to like make excuses (.) Okay, I am the chair of the X association, so I should remember a bit [better], you know the kind of particular, but I've

been elected, as the chair (.) knowing, what, who, I am. What is my, system. So, I (.) keep on going in the same [giving a laugh] way, so, well, I am taking, partly just without ceremony advantage of that, disability card, you know like that disability, stigma and that, that I have a licence, to do everything, silly, crazy (.) that I would not [otherwise do] (.) because I've been, very, mmm (.) reserved earlier just about what other people think. I am, I always am, I won't get rid all of it anyway, but so I've got a bit more that, oh [whispering] think whatever you think, but [whispering]. Do it, do it after me! [Laughing] " (Carla about how personalised assistive products affect.)

Also one of the professionals mentioned in the interview that adult wheelchair users, for example, can gain a particular "attitude" by having special wheel-rims in their chair.

In the interview, Carla demonstrated the way she can open and lock her fold-away cane with a single wrist move. She told proudly how other people try to do the same, as if it was something simple. But, they cannot. She believes that such gimmickry prevents the stigma of illness becoming emphasised. It seems that Carla has managed to turn the stigma associated with assistive products and illness into a strength, of which she can take advantage. Also Alex described how he once was in a park wearing a T-shirt with a print "WTF?" that made a group of youngsters put thumbs up like saying "A great shirt!", apparently, also referring to great attitude. He proposes obtrusiveness that would be realised with a style and at which people could laugh. Saguy and Ward (2011, 67–70) suggest that such flaunting and exaggerating difference can weaken stereotypes, turn the source of stigma into pleasure and pride, challenge social norms, and gain social inclusion. Similar aspiration to individuality and attitude was also apparent in the fashion show, which a couple of young women both of whom use a wheelchair, recently arranged in a shopping centre in southern Finland. Through their

Figure 47. Sally's accessible kitchen that includes bathroom cupboards and that has been spiced with high-end design items.

own unique styles, their aim was to shake rooted conceptions of the way people with disability are supposed to be dressed. (Lempinen 2012, A11.)

A Prestige Item can embody qualities that derive from a user's identity allowing the user for identifying with the product. Personalisation can increase individuality, but also ready-made products can gain status and provide users with functions other than utility. Status symbolic qualities are quite common among particular ready-made mainstream products. Sally appreciates quality and good design and some mainstream products, which could be characterised as high-end design items such as a Smeg refridgerator, have offered her a means of "spicing" her accessible kitchen (Figure 47).

Products which have gained high status can extend their status to the milieu when they are used and placed systematically and consciously. Such products, and personalised assistive products in general, could be viewed as "disidentifiers" (Goffman 1963, 60)[115], which break positively through the perhaps otherwise negatively coherent appearance created by ready-made assistive products. The items in Sally's accessible kitchen could transmit their status to her entire kitchen, even though it has several accessible and assistive properties.

In the questionnaire, a 38-year-old woman describes her mobility scooter as "chosen by her heart"[116], because the scooter adjusts to her individual requirements, even if it is ready-

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115 In addition to prestige symbols and stigma symbols, Goffman identifies a third symbol, disidentifier. It breaks up an otherwise coherent picture in a positive way intended by the person. It challenges the validity of the virtual identity, that is, how other people view a person.

116 "Sydämeni valittu" (the original Finnish expression).

made. When asked about the appropriateness of the product, she writes that the mobility scooter is perfect and specifies that it is "lovely, I go with it whenever I want". Also a 17-year-old girl writes how her mobility scooter supports functioning independently, increases independence and, thus, boosts the self-esteem of a young person. These examples show that also some ready-made assistive products seem as individually customised as personalised assistive products and provide other functions than utility. They create feelings of pride, if they meet their users' requirements.

Laura thinks that any personalised assistive product could create feelings of pride, if its user had influenced it and it becomes part of her identity (see also Olander 2011, 94). In the interview, she emphasised the importance of choice. She described how the fact that she can experience her assistive products as her own, typical of her, makes her proud.

> *"Well let's say so that actually all assistive products act like that [create feelings of pride] in the stage when they have been made specifically according to that user's needs. If that user has been allowed to choose herself those things, what will be in the assistive product. For instance, it can be as simple as choosing the material of tyres, because you can make much as many material choices nowadays. So you can choose that and then the fact that you can choose for example the colour of the wheelchair, so that strengthens own identity and that this is my own. This is my thing. And that is, I at least personally feel the way that when I can tell people like 'Look what I have achieved', 'This is partly my piece of work', that 'I have been allowed to influence this myself'. So that does strengthen identity and the kind of, like that they [assistive products] must truly be suitable for users, made for users' needs, the user involved in making that choice."* (Laura about making assistive products individual by customising.)

Individuality seems to be particularly central to status symbolic assistive products. Sportiness, outgoingness and youthfulness are important semantic product qualities for Tina, but she emphasised that not all users subscribe to her view. Tina described how her friend, who is more girlish, would probably not like her sporty kick scooter, but would prefer something totally different. Laura appreciates space and room, but also she pointed out that individual preferences, "who likes what", should be acknowledged. Some people might want to live more tightly. She specified in the interview that spaciousness does not mean a white sterile environment.

> "And that fact that who likes what. Some like to live more tightly, others more spaciously. I am one of those people who appreciate that there is space and there is room. It doesn't mean that there should be sterile white walls in every single room, but that there is space. And where to live and where to be and where to act." (Laura about individual needs.)

Even if some Prestige Items can be affordable, Sally has invested in more expensive products. She believes that there would have been, for example, other suitable and also cheaper refridgerators, but she wanted to have one that is both accessible and good-looking. That has not been possible without her and her husband paying the extra cost that has not been funded by the city. Nonetheless, she has not been willing to give up her requirements.

> "Oh yes [design does matter], because the city paid a part of that [accessible kitchen], but well the city paid like only a small part and then they pay for like that most, most ordinary [alternative]. So we took ourselves a loan from a bank, so that we could get, like for example the kind of cupboard doors that we want. And the kind of table levels and systems we wanted. … But yeah, it has been just like that you have wanted like

Figure 48. Sally demonstrating her electrically adjustable kitchen.

good-looking and stylish, because the fact that even if it is a piece of special equipment it does not mean that it should be ugly." (Sally about the importance of design in her accessible kitchen.)

Due to various modifications that take into account her individual preferences, Sally considers her electrically adjustable kitchen to be the assistive product of her dreams. In the interview, she disclosed her feelings when the kitchen was ready and she could say that at 27 years of age she finally has a kitchen, whose upper cupboards she is able to reach (Figure 48). Since childhood, she had dreamt of such a kitchen.

Assistive products can gain status also through their creators. Renowned designers can transmit their status to products. Status could also be transmitted, if assistive products resembled products that currently have an established desired status. According to Vihma (1995, 68), two forms in different realms are associated, when their features are perceived to be similar. A metaphorical reference can be viewed as a particular characteristic of a product for creating images, looking like something (ibid., 71). As discussed earlier, Sally proposed that cars like the MINI or the Beetle could be "role models" for assistive products. Tina believes that a personalised assistive product could also gain status by embodying mainstream features like electricity as a power source.

> "[I]n principle, it [the personalised kick scooter] is precisely similar-looking [as a mainstream scooter] and if there was also _electricity_, so well it even is this kind of a (.) like could you even say some status, symbol, like really in a positive sense, perceive as. And then, still perhaps the kind of particular (.) that is, I would associate it with this kind of a sporty and active side, because if you compare [the personalised scooter] with some mobility scooter, it [the mobility scooter] will maybe create such a more _passive_ impression." (Tina about why her personalised scooter, with added electricity, would be an assistive product of her dreams.)

Interviews with users reveal that also users can create products that gain status symbolic value through personalisation. As discussed, Carla for example, whose personalised products rouse admiration, describes herself as a "concept", a phenomenon, whom everyone in her surroundings recognises. Prestige Items not only make their users proud of their products, but also other people may envy the products. Carla unfolded how her personalised mobility scooter together with her appearance evokes envious reactions and gives her a chance to "show off" (Figure 49).

> "I was at the May Day market with the scooter [laughing with her personal assistant], so well, so first of all, I had [giving a laugh] a student's cap on my head, so that there's at least some kind of proof that I'm not totally senseless [laughing], but well so, I had a leather-jacket and boots (.) and well so then I got the idea of how I could get a really good HD [Harley Davidson] pose with that [the scooter] [laughing and posing] and then as it [the scooter] was taped, so gosh, how popular I was among the little guys, or even such pre-teenagers were [saying] 'Wow!' 'How cool!' … 'Gosh I want one, too!' So I got the chance to show off there to little guys. So well, that scooter really is the sort, which evokes <u>a lot</u> of envy [laughing]." (Carla about the admiration personalised assistive products have roused.)

Similarly to Sally in relation to her yellow kickbike, Carla pointed out that children, as in her story of May Day, are often more open in their admiration, whereas adults tend to be more modest in their reactions.

Figure 49. Carla on May Day in a Harley Davidson pose on her personalised mobility scooter.

"But for some reason these [personalised assistive products] <u>signal</u> maybe after all that <u>okay</u>, you <u>can</u> say and talk to her (.) … But then again (.) grown-ups don't so much perhaps say out loud whereas children are like 'Gosh!' 'How cool!' Even a cane or a walker. Because these are taped [giving a laugh]. … But so yes, in the case of a forearm crutch or a cane, children may sometimes ask 'Why do you have that?' and when I say that I have somewhat bad legs, that I need this, so 'Aha'. (.) Children don't need more. And particularly if those have some funny stickers, so [giving a laugh] they don't [pay attention to the assistive purpose]. But there's something with grown-ups, grown-ups usually try to quiet those children [by saying] 'You can't ask' 'Don't, come [back] here from there' and 'Blablabla'." (Carla about the attention personalised assistive products attract.)

Also one of the professionals told in the interview that he had heard from young wheelchair users that particularly children tend to ask about their assistive products. According to him, users had experienced this positively, but usually parents had forbidden their children from asking further questions. Carla supposes that the reactions of adult people stem from unawareness. According to her, adults marvel and even avoid people with disability, because they do not know how to react in a situation, when they meet a person with an assistive product. Carla suggested that people marvel less, if they have someone in their circle of acquaintances who uses assistive products, and with whom they can compare.

Laura described how particularly her male friends have been envious when she has told them that she has chosen her wheelchair and all its details as if it was a car.

> "Well it is as if you chose yourself a car, so I choose myself a wheelchair [giving a laugh]. It is just, it was nice to describe to all male friends in that phase, when I had acquired a new wheelchair, what all there was. They were green out of envy [laughing]." (Laura about customising her wheelchair and her friends' reactions to her description of it.)

Personalised assistive products not only evoke positive reactions among people without disability, but they can also establish an aspired social position among people with disability. Alex discussed how the customisation of assistive products can act as a means of managing "peer pressure", that is, being acknowledged by peers.

> "[I]n certain eh (.) circles that eh (.) getting respect. … So sort of that (.) there isn't a proper word in Finnish for 'peer', that kind of 'peer pressure' or such between people who are alike (.) So I, for example, do powered wheelchair floorball so in that, in there we namely

nowadays have <u>game chairs</u>. So people customise them. There is one guy who has chromed rims and a colour painted with metal shine. It is just the kind of like Italian type of Ferrari customisation. While I have a red and white chair that is painted so that it would match the team colours. And well, so forth. Those are like, with those you can get like (.) something (.) perhaps not so directly respect but the kind of. Some have then [wheelchairs] in accordance with own taste." (Alex about managing peer pressure with his powered racing wheelchair.)

Even if it was suggested in the beginning of the chapter that Prestige Items do not refer to their users' superiority, also that kind of conception and actual examples do exist. Ravneberg (2009, 107) describes how one of her interviewees "radiates strong powers" when he uses his wheelchair that has special wheel-rims, of which one is decorated with a miniature silver skull, which make the wheelchair much more of his style. Pullin (2007, 6) flirts with the idea of designing assistive products that not only restore but also surpass human abilities in the context of hearing aids.[117] Even though racing wheelchairs and futuristic prostheses might not be fashionable, they can brand their users as "superhuman, inspirational, and remarkable" (DePoy & Gilson 2010b, 57).

The American award-winning Paralympic athlete Aimee Mullins, who had both of her legs amputated below the knee as an infant, has set an astonishing example of fashionable prostheses.[118] She has numerous prosthetic legs of various designs and properties, even to adjust her height. Mullins (2009) proposes that a prosthetic limb is no longer a replacement of loss, but "a symbol that the wearer has the power to create whatever it is

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117 See also Jacobson 2010, 8; Vaes et al. 2012, unnumbered; Correia de Barros 2012, 64.
118 Jacobson 2010, 8 (see also Correia de Barros 2012, 65).

that they want to create in that space". She continues that people with disability can become "architects of their own identities". The interviewed professional who is specialised in prostheses and orthoses has not noticed users having aspirations to superabilities by using innovative prostheses. She, however, admitted in the interview that sometimes people can have unrealistic expectations of what prostheses can do.

Turning disability into superability is not unambiguously positive. Silva and Howe (2012) bring out the problematics of superabilities in their example of the Paralympics. The authors (ibid., 188) suggest that by opposing extreme negativity, like viewing an impaired athlete as weak and frail, with extreme positivity, for example, superability, disability might become reinforced as a deviance. Silvers (2010, 5–6), for one, suspects that assistive products that turn disadvantaged people with disability into advantaged could be a threat to people without disability, because same opportunities would leave them with "a smaller number to whom they can feel superior". Douglas (2002, 117) proposes that when something cannot be defined it easily becomes dangerous, and powerful, because it can be destructive to what is already existent. She (ibid., 203–204) specifies that something that has previously been defined and treated as wrong can even become "a source of tremendous power", because it is put into a special ritual frame that separates it from others and maintains unthreatened and unaffected.

However, not all people with disability can turn their disability into a strength, let alone superability. Neither are advanced products available to everyone. Personalisation can be seen as a way of creating products that empower and strenghthen identity in a positive way. Personalisation can be considered a means of lifting or upgrading assistive products from an undesirable product category, or a wrong context of use, to a more valued one, which could eventually influence also how their users are viewed.

4.4 Additional Characteristics

More findings seem to support and validate the typology, but they are not restricted to any particular types. Rather, many of them could be viewed as their underlying factors, perhaps even motivating or enabling them.

One of the issues that was brought up by all interviewed users is the need for involving users in the design of assistive products. The inteviewees insisted that assistive products should be designed together with their users. Engaging users appears to be related to interviewees' aspirations to more individual products that meet users' actual requirements. Laura also pondered, if engaging users in design could make assistive products "normal" in use. By normal she seems to refer to the ordinary, but also frequent presence of the products.

> *"I don't even myself know what that way is [to make assistive products appear more ordinary], is it that participation [of users] and such <u>increasing of normality</u>. Would participation make assistive products quite normal, that they are quite okay, they're fine."* (Laura about the role of user participation in making assistive products appear more ordinary.)

Some of the interviewed professionals suggested that those users with disability who have specialities in areas like metalwork, which can enable them to concretely participate in the development of assistive products, could network with manufacturers and share their expertise and user experience. The professionals emphasised that, nowadays, people who become disabled continue with their expertise or acquire a new one by re-educating themselves. Sometimes disability can even turn out to be the very source of expertise that directs towards particular work like designing better assistive products due to first-hand user experience.

Laura believes that the manufacturers of assistive products are open to users' proposals, if users just dare to bring their opinions up. She thinks that the process, through which users could participate, should be made easier. Users could inform about preferences and propose qualities that seem to be missing from the products. Alex encourages facilitating customisation and personalisation. He mentioned someone who paints wheelchairs for users for an affordable price. He thinks that it would be best, if users could customise products before they have been manufactured for the market. Sally encourages designers to observe users' everyday life, because she, for instance, does not always realise that she may do something in a difficult way, as she is so accustomed to the particular way of doing. She may not be able to inform about a problem she does not recognise. Carla considers the users of assistive products to be "real world testers"[119], who could provide the design process with information on the actual use of the products. These views are in the core of the user-centred design approach.

Both Carla and Laura pointed out that users should be better informed about available novel assistive products and provided with opportunities to acquire them. Referring to her background in nursing and care work, which has increased her awareness of available products, Carla reminded us that not all users are aware of the latest turns in design, or have access to the information as independently as the most active and enthusiastic users. In addition to users, also health-care and social service providers may not be familiar enough with available assistive products (Rauhala 2007, 22).

Various concrete development ideas that concern single design features or particular assistive products came up in the user interviews. Alex, for example, proposed that powered wheelchairs could be more decorative and have shadings and chrome. He sees a difference between European and American designs and considers the design of European wheelchairs more

advanced, streamlined and elegant. When it comes to shower chairs, which have created negative experiences among most interviewees, Alex suggested that instead of being rectangular, they could be designed round, for instance, by bending tubes.

Some of the interviewed users seem to have contradictory opinions about accessibility. Carla thinks that apartments should be accessible from the outset. She listed features like doors should be wider, thresholds lower and front-doors different. She considers her large hallway positive, because she can keep her assistive products there. Issues that she brought up have emerged in regulations that are supposed to guarantee the accessibility of new apartments, but her apartment is older and accessibility is not built-in. In Alex's opinion, an apartment that has been designed according to those regulations might still not provide enough space, for example, for storing assistive products. Laura brought out a completely different view. In her opinion, accessibility is sometimes carried too far and it could even be considered positive discrimination. She thinks that other people might overthink how a person with disability gets along. According to her, people with disability are inventive in finding ways to do things. Laura's opinion may also be a practical issue, because some accessible and assistive environments, for example, for elderly people who are fit, could be crititicised for "over-accessibility", if they do not provide enough physical challenge, but instead cause physical regression. Jokiniemi (2007, 37, 145) has discussed "curling architecture", by which he refers to building overly accessible environments, which lack landmarks that people with visual impairment use in navigation. It needs, however, to be remembered that accessibility requirements are individual. What is accessible to someone may be disadvantageous or even inaccessible to someone else.

Financial issues were brought up in most interviews with users in one way or another. Current ready-made assistive products are considered expensive, particularly if they are advanced. Tina thinks that the prices are excessive and as discussed earlier, their high price has been one motivator for her applying main-

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119 "Tosielämän testaajat" (the original Finnish expression).

stream products for assistive purposes. One of the interviewed professionals supposed that, if a product is classified as an official approved assistive product, its price is higher than that of a similar mainstream one. Alex stated that he has a possibility to invest every now and then, if he wants something. He emphasised that, even though he has, due to long-term work, financial resources to customise, they are not a motivator for it. They are just an enabler. Later in the interview he, however, noted that customising is not an issue of money. Everyone can afford some customisation and both Tina and Sally actually consider personalisation more affordable than some ready-made assistive products. Alex, however, pointed out that customising an owner-occupied flat is easier than a rented one. Also Sally admitted that when she was living in a rented apartment she did not invest in high-quality or stylish modifications. Also Tina, who is now living in a rented shared apartment, noted that modifications in her previous owner-occupied flat were better. Alex appears to be well aware of the cost structure of ready-made assistive products and believes that approaching the design of mainstream products could decrease costs. Also other interviewees supposed that the more mainstream assistive products could be, the less expensive they would be. Based on the interviews, the costs of personalisation vary depending on the product and the way of personalisation.

In the interviews with professionals, the shortcomings of the current funding system were clearly brought up. They admitted that funding can restrict available choices of products and users' access to them. There are almost 40,000 assistive products listed in the AbleData database (AbleData), but how many of them are actually available to people with disability?[120] It needs to be remembered that in Finland, and in many other countries, the allocation and provision of assistive products is regulated by various factors such as tendering, which influence the

amount and quality of products that are available for users (see also Ravneberg 2009). In Alex's opinion, the current regulated practices in public health care, like public procurement rules with obligatory calls for tenders, do not support individual solutions. The professionals agreed on the fact that various stylish alternatives exist, but they are not funded.

The professional who works with young users told that young people sometimes dream of nice-looking products, which they have seen someone using, but it is hard to get funding for such products. He suspected that only insurance companies cover those products. Also other interviewed professionals pointed out the inequality of users: The private sector offers different products than the public sector. Also municipalities have varying means and services. According to the professionals, users are aware of this and joke about not becoming disabled, if one is not insured or lives in a particular town that has limited resources.

One of the interviewed professionals explained that the people involved in situations where, for example, product modifications are planned, are in addition to him and a user, the representative of the funding organisation and an occupational therapist. According to the professional, a user may not always have the possibility to state her other than usability requirements. Users may nevertheless have very clear impressions of the type of products they would prefer and they may have, for instance, visited assistive product fairs and brought product brochures to meetings with occupational therapists. In this sense, their role has become closer to that of rehabilitation professionals as Brooks (1998; see Chapter 3.1 above) predicted.

The interviewed users appreciate that assistive products are provided by the public sector, but some of them are willing to pay a price difference between the approved standard version and the version that would fit them better. Sally emphasised, referring to law, that basic products that have utility functions need to be available to everyone. However, if someone wants something extra she should have the possibility to choose, for instance, by contributing to its financial costs. She considers that

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120 Even though the number of assistive products in the database appears large, several products are modifications of existing ones, which do not show improvements in other than assistive features.

reasonable and is ready to do that. One of the interviewed professionals specified that when it comes to funding, it is all about what kind of an assistive product qualifies the set criteria, is it appropriate for its purpose or is it about paying something that seems unnecessary. Nevertheless, the interviewed professionals admitted that in addition to being functional, an assistive product should enable its user to participate in society, provide functions that its user desires, and also fit aesthetically. Yet, it should also be durable and reusable, and reasonably priced.

Although the interviewed users would rather use assistive products that express their identities or fit the styles of their homes, they admitted that sometimes they have to use products that they do not like. Sally unfolded how she had to use her old orthopaedic shoes, because they were comfortable and she could not wear other kinds of shoes then. She says she employs some "disgusting"[121] assistive products out of necessity.

> *"But well, so, I don't know, even if there are some sort of disgusting assistive products, you do use them out of necessity, when you must use, so just for example some sock aid, I don't bear to use it, but when I'm every now and then home alone or so, I <u>must</u>. Even if it's annoying, you can't help it."* (Sally about assistive products she would not like to use.)

The professional who works with young people told that young people often express that they would like to have more nice-looking products, or that their accessible kitchen, for example, is terrible, but they cannot help it. According to him, there is not much users can do (see also Olander 2011, Article 2). He said that some people who are interested in interior design may, nevertheless, try to create something nicer around their assistive products, but still, they often need to build around the products. The findings of this research, however, reveal that

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121 "Ällöttävä" (the original Finnish expression).

users can do things like decorate or redesign their products (see also ibid.).

Even though users criticise current ready-made assistive products and seem to prefer personalised ones, they consider some ready-made products' utility functions quite good. Carla, for instance, described how they particularly ease moving outside her home. Also in the questionnaire, a 37-year-old woman writes how "it feels unbelievable" that after several years she can go out of her home due to a mobility scooter. Alex thinks that particularly some material choices are good. He finds, for example, cellular plastic soft and durable. In Sally's opinion, however, the functionality of ready-made assistive products depends on the context of use and whether a user is inventive enough and can figure it out best.

The shortcomings of current products' utility functions come up in the Internet database as already discussed. Several assistive products have been ideated because functional ready-made products have not been available. The self-ideated products seem to enable particular utility functions that would not be possible otherwise or would need to be carried out in an alternative way, which might attract unpleasant attention. The examples include assistive products for eating and drinking, sports equipment and equipment for various hobbies. In such products, being able to carry out a particular task seems to be the main driver in design, because ready-made assistive products are not available. As was discussed in relation to Instruments, many of the products could be viewed as first prototypes, whose main, even only, driver has been to enable particular utility functions. Some answers in the questionnaire reveal shortcomings that relate to current products' dimensions, weight, adjustment, safety and reliability, durability, and ease of use. Even if the focus of this research is not on utility functions, the findings reveal that shortcomings also exist within those functions. All interviewed users and professionals emphasised the importance of usability and utility as a starting point, but remarked that they should not be the only focus in design.

## 4.5 Personalisation as a Means of Managing Stigma and Expressing the Self

The findings of the research have been presented in the form of a typology, whose distinguishing characteristics are summarised below, in Table 1. In the typology, assistive products have been presented *as* something in order to emphasise the products' various functions and diverse roles for their users, and the many-sided, interrelated and wide-ranging consequences of their use. All types are closely related and some of them are overlapping. It is likely, and for the positive types also hoped-for, that in practice, one assistive product would embody characteristics from various types, and that users may prefer a product that is a mix of types. For instance, one assistive product could be simultaneously used for protecting from negative attention and for expressing its user's identity. Another could embody characteristics from both Accessories and Prestige Items as in the case of, for example, Tina's kick scooter and Carla's cane and mobility scooter.

Table 1. The distinguishing characteristics of the types in the typology on users' experiences of ready-made and personalised assistive products.

NEGATIVE TYPES: THE STIGMA ASSOCIATED WITH READY-MADE ASSISTIVE PRODUCTS	
Instrument	Emphasised utility function. Associations with medical equipment. Wrong contexts of use.
Misrepresentation	Exaggeration and misrepresentation of disability.
Uniform	Anonymity. Homogeneity. Reduction into a stereotype.
NEUTRAL TYPES: MANAGING STIGMA WITH PERSONALISED ASSISTIVE PRODUCTS	
Shield	Discretion. Protection against negative attention.
Mainstream Product	Ordinariness. Inclusiveness.
POSITIVE TYPES: EXPRESSING THE SELF WITH PERSONALISED ASSISTIVE PRODUCTS	
Accessory	Adaptability. Context-fit. Identification with a group.
Handicraft	Individuality. Uniqueness. Self-made.
Prestige Item	Pride. Attitude. Empowerment.

(Shield and Mainstream Product: Passing. Integration.)

In the typology, the negative types, called Instruments, Misrepresentations and Uniforms, confirm earlier research findings about users experiencing some of the current ready-made assistive products as stigmatising. The negative types map users' experiences and, through them, it is possible to explore the dimensions and attributes of the stigma associated with assistive products. The findings reveal that, on the one hand, the stigma emerges from qualities that focus on utility function, which draws attention to disability. The products seem to resemble medical equipment, which further creates associations with illness and the health-care context, and makes the products stick negatively out. In addition to the focus on disability, the products can exaggerate and even misrepresent disability. On the other hand, the findings suggest that, by being solely based on shared disability, the products reduce users to a homogeneous stereotypical group without acknowledging individuality. The products are experienced as anonymous, impersonal and not supporting the diverse aspects of identity.

The types in the typology can be seen as progressive when approached from the viewpoint of their expressiveness and level of personalisation. In Figure 50, the types are placed on two axes, where product expressiveness is on the vertical axis and the level of personalisation on the horizontal axis. The amount of product expressiveness increases upward and the level of personalisation onward. Product expressiveness consists of negative difference, no difference and positive difference. Negative difference means that a product seems stigmatising. No difference means that a product is homogenising, or when personalised helps group identification, and positive difference that a product is positively distinguishable. The level of personalisation runs from no personalisation, managing stigma and expressing the self. No personalisation means that a product does not contain personalised qualities. Managing stigma means tackling stigma through personalisation. Expressing the self means that personalisation is extended to expressing individuality.
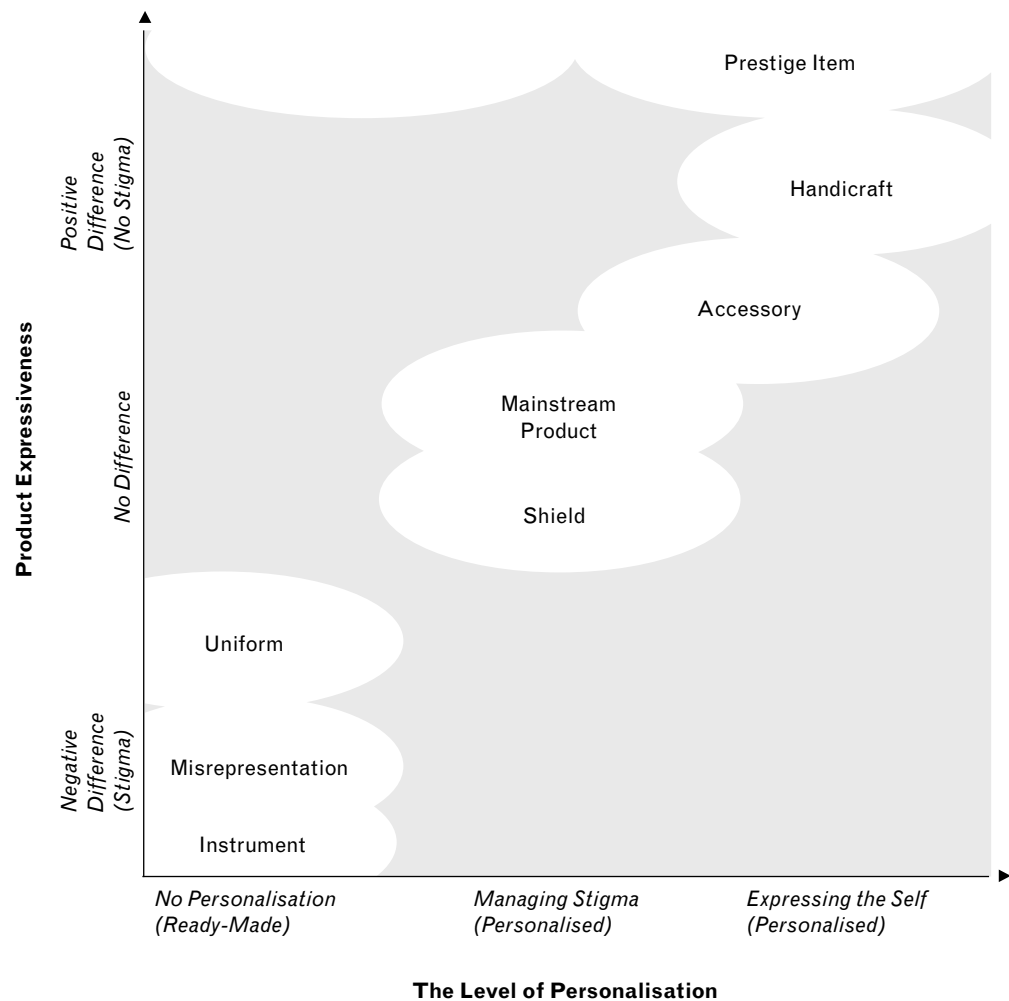
The Level of Personalisation

Consequently, Instruments and Misrepresentations can be positioned in the low left corner including no personalisation and creating a negative difference, being conceived of as stigmatising. Uniforms can be situated close to them. They contain no personalisation and due to their homogenising characteristics, they tend to stereotype and stigmatise users. Shields and Mainstream Products can be positioned in the middle of the axes being neutral in product expressiveness and containing some personalisation in order to help manage stigma and integrate socially. Accessories and Handicrafts seem to approach the upper righ corner, because they are more personalised. The expressiveness of Accessories is, however, lesser, because Accessories tend to emphasise group similarity and fitting in, whereas Handicrafts highlight positive their individual difference.

Figure 50. Product expressiveness and the level of personalisation among the types in the typology.

Prestige Items can be positioned both in the upper right and upper left corners, depending on whether they are ready-made or personalised. Some ready-made mainstream products, which are used for assistive purposes like Sally's kickbike, can be positively different due to their perhaps established high status, but may not have personalised features. Also Sally's single high-end design products, with which she has spiced her accessible kitchen, could be in the upper left corner if evaluated as single products. Her kitchen as a whole, however, could be positioned into the upper right corner, because it can be seen as a personalised whole, which Sally has put together from diverse products and qualities.

The positioning of the types in Figure 50 is based on the data. Individual assistive products can be located slightly differently on the axes. For instance, due to better design, ready-made assistive products could approach Accessories and become situated left in the figure. The white areas around the types in the figure show how also the types in the data are overlapping and interrelated.

The negative types could also be viewed as weaknesses of current assistive products and the positive types as current products' opportunities. The positive types are opportunities in the sense that personalised features can potentially be features of any assistive products. In a sense, they are latent features of all assistive products. A design approach, which derives from users' active involvement in the design process, can be considered a means of actualising the potential.

When considering an appropriate design approach that would allow for users' individuality, personalisation can take many forms. The interviewed users of this research, for example, personalise their products in various ways and through different techniques. For Carla, personalisation mostly means decorating assistive products so that they fit her overall style that derives strongly from her identity as a kind of a "toughie". Tina modifies mainstream products for assistive purposes and creates products that would express her identity, particularly her sporti-

ness, more truthfully. For Laura, personalisation seems to occur by selecting and assembling qualities, which result in individual products that fit her identity. Alex carries out personalisation with customisation that involves a strong aesthetic tone. He aims at creating a consistent style that takes account of changing situations, lifestyles and roles. The personalisation that Sally favours is characterised by high-quality mainstream products, most of which represent products that can be characterised as popular high-end design items. Some of the interviewees use different terms for personalisation. Alex, for instance, talks about customisation and Tina and Carla about tuning. Consequently, personalisation takes various forms from assembling individual parts and properties in order to create a pleasing composition to actual product modifications. It is initiated by users, focuses on product appearance and occurs in various stages. Some examples in the Internet database also present personalisation that serves utility-related goals. (Cf. Mugge 2007; see Chapter 3.1 above.)

Some of the interviewed professionals, however, bring out problems of personalisation, which they have encountered in their work. One of them is extra costs caused by the fact that some parts of the product may need to be replaced as a result of personalisation. One professional described in the interview how a user had tried to install a navigator to a powered wheelchair and drilled the most important part of the chair broken, after which the chair was unusable. Personalisation can also hinder reuse, because some personalised features made by one person may not please others. Personalisation can make products unsafe, even dangerous. Another interviewed professional recalled in the interview a user who had wanted a powered wheelchair to resemble a construction machine and modified it into nearly life-threatening due to extensive electrical adjustments. According to the professional, some users may not be aware of the construction of a particular assistive product or master such things as its electronics. However, mostly personalisation that users do tends to concern aesthetic values and does not involve extensive functional modifications. Furthermore, users are informed about modifications that they are allowed to do.

5

5 Discussion

The problematics of assistive products has hitherto been studied mainly within the fields of rehabilitation and occupational therapy. Previous research has indicated a need for unfolding more profoundly users' experiences of using assistive products and, particularly, social and psychological consequences of the product use. In this research, answers have been sought for how young adults with physical disability experience the design of assistive products in use, what the assumed stigma associated with the products is like, and how young adults manage the stigma.

This research contributes to earlier research by discussing the problematics of assistive products from the viewpoint of design. In addition to industrial design, examples from other fields of design, such as fashion and clothing design and architecture, have been presented here. The diverse angles have helped to comprehensively understand the multifaceted consequences of using assistive products.

The results of this research have been presented in the previous chapter in the form of a typology, whose distinguishing characteristics have been summarised in Table 1. The typology describes users' experiences of assistive products in terms of design. The negative types, Instruments, Misrepresentations and Uniforms, contribute to present knowledge by introducing various dimensions and qualities of the stigma associated with assistive products. Also previous research has presented stigma as a social construct, to which assistive products contribute, but its characteristics, connections to design, or the potential of design in preventing or diminishing the stigma, have not been sufficiently explored in detail.

What is new in this research is the significance of the neutral and positive types in the typology. The personalisation of assistive products has not been earlier studied as a means of managing stigma. The neutral types, called Shields and Mainstream Products, support this preliminary hypothesis. Through personalisation, the stigma associated with assistive products can be reduced. The neutral types show how personalised assistive

products are employed in passing as any user of any products, directing attention away from stigma, and protecting against negative attention. Personalisation is used for diminishing the obtrusiveness of stigma in social contexts. It can ease social interaction.

The positive types extend the preliminary hypothesis even further by also introducing personalised assistive products as a means of expressing the self. Accessories, Handicrafts and Prestige Items present how users express various qualities of their identities through personalisation and show their individuality. These qualities seem to differ from those, which are stereotypically associated with users of assistive products. Personalised products show that, contrary to some stereotypical assumptions, users are concerned about their appearance, and they are actively and inventively modifying products in ways which reassert their identities positively and more truthfully. Personalised products can act as stimuli for counterbalancing different roles that users can have. They can be used for correcting wrong impressions and conveying more truthful ones. They can bridge the gap between how other people view a person and how she views herself.

Personalised products can be experienced as a continuation of a user's identity or that of her home. Personalisation can be used not only for expressing, but also exploring, defining and constructing identity. Because of their self-ideated nature, personalised assistive products can support creativity, enhance self-confidence and strengthen reliance on one's own skills. They can give support in achieving personal goals. As empowering items that create feelings of pride, they can even help users gain respect and prestige. Using personalised products can create social significance.

Some of the current ready-made assistive products can categorise their users in a narrow way, but personalised assistive products can help users blend in with the surroundings, or identify with a group of people that shares a common interest. Consequently, personalised products contribute not solely

to the expression and construction of personal identity, but also of social identity. This is important, because the use of assistive products not only has consequences for personal identity, but also to social identity by either increasing or restricting possibilities of social identification and integration. Personalisation can enhance both.

Even though personalised products have both intra-personal and inter-personal qualities, they cannot be seen as a means of exercising control or power over other people (cf. Dittmar 1992; see Chapter 2.2.2 above). Rather, they can provide users with opportunities to influence and take control over their own identities (see also Olander 2011, 119). Personalised assistive products can act as "anchors", which both strengthen personal and group identity, and create stability particularly in a young person's unstable phase of life. On the whole, the neutral and positive types in the typology show that, due to personalisation, assistive products can be used as any products.

Considering the diversity of the types in the typology, it seems that designers and other experts have had a narrow understanding of users' expectations about the potential and consequences of using assistive products. By describing personalised assistive products, this research provides insights that could be adopted as design guidelines. They pinpoint functions and qualities, which current assistive products lack, but which could be taken into account in developing, and evaluating, the products. Adopting them as design guidelines could facilitate the application of the findings of this research. So far, personalisation has not been adopted as a design guideline in the development of assistive products. The typology could be used for both descriptive and predictive purposes in various design phases.

In order to study a complex phenomenon, and to gain an understanding of various factors influencing it, a theoretical approach has been needed. Theoretical assumptions about many different subject matters such as the construction and expression of identity and the role of products in them, the emergence and nature of stigma, managing stigma, and classification and catego-

risation have thus been explored. Since the topic of this research does not stem from a research tradition with established theoretical constructs, it has been necessary to also apply concepts from other fields than design research. Literature has consisted of texts from disciplines like social psychology, cognitive psychology and social anthropology in addition to design research. Also some texts in consumer research have been referred to. The research contributes to the field of design research by introducing the aforementioned set of theoretical assumptions for increasing understanding of the spectrum and the study of product use.

The research has been based on assumptions about identity as a continuously reconstructing process, in which personal and social are intertwined with the material, and in which a person herself can take an active role. Considering personal and social identifications to be intertwined processes, in which similarity and difference between people are integral, has turned out useful in studying the stigma caused by using assistive products. It has helped explore the ways in which an assistive product, as part of its user's appearance, can communicate aspects of identity and emphasise both similarity and difference. Some assistive products can act as dividers between people who have disability and people who do not. At the same time and through the same assistive properties, products can highlight similarity within one group and difference from another group.

In studying personalised assistive products, views of stigma as a socially constructed label to which also products contribute, and users as active in managing stigma, have proven particularly useful. Assumptions about stigma and its management have clarified personalisation as a way of reducing the obtrusiveness of stigmatising qualities and becoming regarded as a user of any product. However, the findings of this research reveal that stigma management techniques, like hiding or covering, are not enough. Users also want to show their individuality through the use of assistive products. Together with views on constructing and expressing the self, the assumptions about stigma and its management have enabled to consider personalisation a us-

ers' attempt for transforming the symbolic value of stigmatising products into neutral or positive. They have enabled to consider personalisation not only a means of managing stigma, but also a way of expressing the self. Moreover, they have helped understand how personalised products could connect people with and without disability by having qualities that refer to characteristics like a shared lifestyle. The theoretical exploration of the role of products in identity construction and expression has helped widen the context even further: the personalisation of assistive products echoes what is known about the use of products in general.

Assistive products enable users to accomplish tasks, which might not be possible otherwise. Some products can also substitute body parts. The significance of the physical body in the use of assistive products has repeatedly been brought out in literature and it was also apparent in the empirical data, particularly in Laura's interview as she described her wheelchair as her legs. The topic of this research could also have been approached from the viewpoint of how using assistive products influences a person's experience of her body. For example phenomenologist approaches that emphasise individual experience and the body could have been a promising context to explore the topic. In that context, also prostheses, which can be even more profoundly attached to the body than assistive products, could turn out a fruitful topic of study. But here, the particular focus has been more broadly on stigma and, hence, the social context of using assistive products and the social construction of meanings attached to the products have been scrutinised. The embodied nature of identity has, however, been acknowledged by the chosen conceptions of identity. The findings of this research show that some assistive products seem not only to extend their users bodily functions, but also their identities. If body parts are viewed as extensions of the self, and losing a body part is contrasted with losing identity (Belk 1988, 157), assistive products could even be viewed as extensions of a lost identity. Consequently, significant requirements, which concern users' identities, may fall upon as-

sistive products. Assistive product may have a far greater role in the construction and expression of identity than what current products allow for.

Through views on similarity and difference between people and the emergence of types and stereotypes, the research has touched upon the "otherness" of people who use assistive products. Such fields as gender studies and queer studies could provide an illuminating context to explore further the social construction of otherness caused by the use of assistive products.

In addition to exploring literature, also empiricial data has been collected in order to understand the phenomenon of personalising assistive products. Truthfulness and accuracy in interpretations have been striven for by approaching the research problem with methods that have provided diverse data. Through the triangulation of methods and data, the research has aimed at credibility, that is, congruence between research findings and reality.[122] This has been pursued by exploring questionnaire answers and an Internet database, by carrying out two kinds of interviews, and by applying various theoretical assumptions in structuring and interpreting the data. The research process has been explicitly described in order to ensure confirmability. Following the user-centred perspective, voice has been given to individuals and their unique experiences rather than presenting a survey. Instead of generalising, the research has aimed at deepening understanding the case (Stake 2005, 443).

The methodological choices have proven useful. In gathering information on the presumed stigma associated with current ready-made assistive products and experiences of using personalised assistive products, particularly interviews turned out productive. Focused interviews with professionals who work with users provided information on users' requirements from another viewpoint and support, but also complement the findings of the

other data sets. The key findings of the interviews concern the current image of assistive products as disability aids that represent deterioration and users' aspirations to more individual assistive products, and the need to acknowledge that better also in the current provision and funding system, giving support to the typology. Two of the interviews with professionals were group interviews, which made the interviews especially productive. The participants in both group interviews were similar enough in the sense that the group dynamics were not hindered by dominating participants (see Koskinen et al. 2005, 124–125). The summarised interpretations of the interviews were sent to the interviewed professionals in order to check their accuracy, prevent factual errors and increase credibility.

Interviews with users offered an access to individual firsthand experiences. As semi-structured inteviews, they provided guidance in the form of themes and preliminary questions, but without restricting the interviewees' freedom of expression too much. Due to the conversation-like course of the interviews, it was not difficult to discuss with the interviewees, although the questions concerned intimate experiences. As the interviews were carried out in interviewees' homes, the atmosphere was open, even relaxed. The themes centred on products, which proved to be a fluent means of handling intimate issues due to the concreteness of the products. All of these can be considered having influenced the credibility of the research positively. In order to make sure that the themes and preliminary questions reach the intended topics of interest, the themes and questions were evaluated before carrying out the interviews. The interviews were recorded and transcribed, and iteratively backtracked in the course of the analysis in order to increase the dependability of the research.

As described in the chapter on empiricial data, I had become acquainted with two interviewees, Alex and Tina, during an earlier user study. Since I had also interviewed both of them then, even if on a slightly different topic, I was more familiar with them than the other participants. Even though Tina's

122 In this chapter, the quality of the research is discussed in relation to Miles and Huberman's (1994, 277–280) standards concerning confirmability, dependability, credibility, transferability and application of conclusions.

housing arrangements had changed as she had separated from her partner and moved away from their apartment (Alex's housing arrangements were unchanged, but his family had grown), I considered myself better aware of their personalised products, and better able to focus questions than in the other interviews. This enabled me to deepen the conversation. A better understanding of the interviewees could also have lead to preconceptions and to positioning them differently in comparison with other interviewees, if not kept in mind when analysing the data.

All interviewed users were either working or involved in organisational activities. They can be characterised as active participants in society. The interviewees proved to be very conscious of the advantages and disadvantages of both designing and providing current ready-made assistive products, and they had actively been involved in acquiring and adjusting their own products. Importantly, the interviewees had ideated and some of them even designed various product modifications. Due to their inventiveness, the interviewees can be considered exceptional, perhaps even forerunners. It was possible to approach the interviewees as experts who share their insights for the development of assistive products. This may have prevented the emergence of power inequalities, which may position the interviewees as passive or otherwise subordinate to the interviewer in a research situation (see Rauhala 2007, 119).

Many of the interviewed professionals operate in key organisations in the Finnish assistive product field. Even though they do not encompass all operators in the field, they can be considered representative due to their vantage points. The interviewed users were not selected according to statistical grounds. Instead, those volunteers who qualified the pre-selected criteria became included in the data as described in the chapter on data. The data collection has not been based on the saturation of data, even if the interviews provided similar findings early on, that is, particular issues that were brought out in each of them. Rather, the objective has been to collect data from diverse angles and to exhaustively study the selected data. The findings do not tell

about the prevalence of personalised assistive products. Instead, they show that a phenomenon of personalisation occurs among young people with physical disability who experience ready-made assistive products as stigmatising, and describe and discuss it.

The open answers in the questionnaire provided information on users' satisfaction and experiences of assistive products. The questionnaire gave a larger frame of reference for both the interview and the database findings. Even though the questionnaire did not directly address the personalisation of assistive products, it could shed light on the wider context, in which personalisation could occur. By reporting users' satisfaction with their assistive products, the questionnaire provided information on how users experience the use of assistive products. In addition, it gave background information on factors that could lead to personalising products and factors that could influence it. Answers concerning services were not directly related to the scope of this research, but they echoed a similar need for individuality than answers concerning products. It needs to be noted that the questionnaire answers were collected and compiled by someone else than me. Also some of the answers had been written down by, for example, respondents' personal assistants. Some information could have been lost or changed in the process. But, triangulating methods and data has enabled to "cross-check" findings.

By presenting a myriad of users' inventive product modifications, the Internet database has not only showed the occurrence of modifications, but also their variety. Thus, the database has been important to the formation of the typology. Those products in the database that touch upon managing stigma or expressing the self support the typology by having qualities and motivations similar to the neutral and positive types. However, also potentially stigmatising products could be found in the database when the products were evaluated from the viewpoint of appearance. In some cases, it seemed that users' modifications, which solely involved utility functions, could emphasise stigmatising qualities. In interpreting such products, the problem

was that users had not described the products as stigmatising as brought out in the chapter on the analysis of the data. The analysis required more interpretation than in the case of the interviews, and reliance on experience, education and intuition as a designer.

The fact that users had not described the products in the database as stigmatising does not mean that they would not have identified or experienced them as actually stigmatising. They may not have described stigma, because many product modifications involved improvements that mostly concern utility functions. Moreover, the database did not directly address stigma, but examples of self-ideated assistive and accessible solutions. The identification of products that had solely utility functions seems, however, to give support to the negative types in the typology and their stigma, because of the lacking functions and qualities that concern product appearance and users' identities.

The questionnaire and the database, which offer a more general viewpoint on the topic, were employed to increase understanding on the research problem, but also to position and validate the interview findings, which focus on the particular. In addition, together with the theoretical assumptions that have guided data analysis, they connect the findings to a wider context, which can be considered improving the transferability of conclusions. They explain of which case a case is an example (see Laine & Peltonen 2007, 101). They represent people with physical disability, some of whom have described their satisfaction with and experiences of current ready-made assistive products (the questionnaire) and others, who have shared their inventive product modifications and ideas (the database). The interviewed users, who have personalised their assistive products, can be viewed as a special case in this context. The interviews with professionals, the questionnaire and the database have enabled to explore whether evidence of stigma and personalisation, the kind of present in the user interviews, or requirements for more personalised assistive products in general, could be found.

Even if the data sets support the findings of each other, the

studied user group sets some limitations to the transferability of the conclusions, but offers prospects for further research. Only the experiences of inventive young adults with physical disability have been explored here. The experiences of users who have other disabilities or who have not personalised their products have not yet been addressed. Nor has the research explored the experiences of users who are less active and participative and, therefore, might not volunteer, even if they could make an input. Additional interviewees and viewpoints could perhaps have increased the diversity of data by providing examples of other kind. Furthermore, users' experiences in this research have concerned solely assistive products for physical disability. Even though references have been made to audio and visual equipment, the focus has been on mobility products. Also other assistive products can be objects of personalisation and benefit from personalisation. Therefore, further research is needed. By providing familiarity, personalisation could turn out beneficial in the development of items like memory aids.

Gender- or age-related differences were not emphasised by the data apart from the interviewees' references to some products' associations with old age. This could have been due to the fact that four of five interviewed users were women and the focus has been on young adults in Finland. If more men and persons of other ages or cultures had participated, there could have been more differences. Even though wheelchairs, for example, have been claimed to express gendered, particularly masculine, identities (Ravneberg 2009, 111), the interviewed users of this research did not characterise their products as feminine or masculine. Tina, however, pointed out that her more girlish friend might not prefer her sporty kick scooter and, in the questionnaire, a teenager wished for a wheelchair that would be more beautiful for a young woman (see Chapters 4.1.3 & 4.3.3). Some of the intervieweed professionals, however, did have an impression that women, particularly young women, tend to personalise their assistive products more often than men. The professionals generally brought up the need to acknowledge

gender- and culture-related requirements in the future. Even though the database included examples from persons living in Sweden, cultural differences could not be found. This was, however, intended by knowingly selecting product examples from a culture that would be similar to the Finnish one (see Chapter 3.2.2).

Research on the significance of age, gender or culture in using assistive products could enrich the findings of this research, and provide further information for developing individual assistive products that might not cause stigma. Gender-, age- and culture-related product qualities could bring the assistive product design closer to the segmentation of mainstream products, in which users' various characteristics are taken better into account. Also designers of assistive products need to understand the societal and cultural framework that affects how products are interpreted (Hussain & Keitsch 2010, 154–155).

As the research and its methods did not attract teenagers for participation, another kind of approach would be needed in order to also reach their experiences and insights into the design of assistive products. Even if teenagers did not volunteer for this research, they might still personalise assistive products as the interviews with professionals indicate.

The illustrations have required some considerations. Even though the user interview material, including photographs, has been treated anonymously, the interviewees can possibly be recognised. The interviewees are likely to recognise themselves from the description of the data and the results of its analysis. People who are familiar with the interviewees and their personalised products, or are aware of the interviewees' participation in this research, may also recognise them. One of the interviewed users described herself as a public figure in her surroundings who could be recognised even under a false name, but she stated that she would not mind, if people recognised her. All interviewed professionals gave their written consent to publish their name, title and organisation.

In the questionnaire, all information is in an anonymous

form. In the database, people are likely to recognise themselves through the photographs of their products. Furthermore, some of the photographs openly portray people with their products. The use of the photographs has, therefore, also given reason for ethical consideration, which may have affected the clarity of the reported findings. As described on the chapter on the data analysis, the database also consists of product modifications that have addressed issues, which mostly concern products' utility functions and have resulted in product appearances that do not take into account aesthetic experience. Product modifications, which might present users in an unfavourable way, and potentially expose them to embarrassing experiences when aesthetically evaluated, have not been used here as illustrations, even though they could have visualised some shortcomings of current assistive product design. Instead, the shortcomings have been described in written text in the chapter on results.

5.1 Assistiveness

In this research, personalisation has also been explored from the viewpoint of changing or mixing product categories, and influencing how products are perceived and interpreted. Conceptions of classification and categorisation have provided ways to both comprehend and structure how the stigma of assistive products emerges and is perceived. Semantic product categories (e.g., Rosch & Mervis 1975; see Chapter 2.2.1 above) have enabled to explore the potential for removing stigma by reclassifying the products.

From the viewpoint of utility functions, assistive products such as a spout mug, a walker, a shower chair and a hearing aid can be seen as representing various superordinate product categories like kitchen utensils, vehicles, furniture and audio equipment and basic level product categories like drinking vessels

sels, low-tech overground vehicles, chairs and earpieces.[123] Consequently, based on their utility function, all products in each category can be seen as representatives of that category.[124]

It is interesting that even though assistive products belong to particular product categories, they also seem to be connected to each other when considered from the viewpoint of their appearance, expressiveness and associations they create. Some of them may resemble more each other than the most prototypical members of the product categories they represent based on their utility functions. A walker, for instance, can appear more similar to a shower chair than to other vehicles. Assistive products could even be viewed as "deviant" or "anomalous" in comparison with other consumer products, because they do not seem to fit their product categories. Instead, they may stick out as inappropriate, as if they belonged to a different context of use, or shared a quality that the other products lack. The quality seems to simultaneously unite them with each other and distinguish from other products in the categories. I call this dominating overarching quality *assistiveness* (Figures 51 & 52). It is important to note that assistiveness is not solely a perceived physical property of a product, but like stigma, it emerges in a social context of product use. Various factors influence its emergence, for example, the surrounding environment as discussed above.

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123 Audio equipment is not in the scope of this research, but has been included as an illustrative example in the exploration of the common quality. Visual equipment has not been included, because it has been discussed earlier (see Chapters 1.1 & 4.2.2) from another viewpoint, that is, the "mainstreaming" of spectacles. In addition, due to the special mainstream nature of glasses, visual equipment would not have been an illustrative example in this context. This, however, does not mean that there would not be other visual aids that might embody the quality under exploration.

124 The product examples are random in the sense that they have been chosen from several equally appropriate examples. The chosen examples, however, contain features that can be considered "most representative" (Rosch 1978, 30) among products inside the categories.

Figures 51 & 52. Assistiveness as a semantic quality among assistive product categories.

Kitchen Utensils	Vehicles		Audio Equipment	
	Bicycle		Digital audio player	
Fork	Canoe	Furniture	Stereo system	
Spout mug	Walker	Shower chair	Hearing aid	ASSISTIVENESS
Plate	Motorcycle	Bed	Radio	
	...		...	
Glass		Dining table		
...		Bookshelf		
		...		

Drinking Vessels	Low-tech, Overground Vehicles		Earpieces	
	Bicycle		Mp3 earphones	
Coffee cup	Kicksled	Chairs	Phone headset	
Spout mug	Walker	Shower chair	Hearing aid	ASSISTIVENESS
Glass	Pair of skis	Armchair	Radio	
	...		...	
Bowl		Dining chair		
...		Office chair		
		...		

From where does this assistiveness of products originate? Since assistive products are used for similar activities as mainstream products, that is, for eating, drinking, working or moving to mention but a few, their purpose of use seems not deviant or a source of stigma.

The findings of this research suggest that assistive products are often characterised as "hospital-like". They seem to blend well in the health-care context, because they resemble products that are used in health centres. An oxygen apparatus is likely to assimilate better into a hospital than into a private home. In a private home, the apparatus may stick out, because from the viewpoint of style, it does not seem to resemble any of its surrounding objects. Similarly, a ceiling lift was earlier (see Chapter 4.1.1) characterised as "intruding" into a home. Things in wrong contexts can appear as "pollution" as Douglas (2002) has characterised them. It needs, however, to be noted that even if a product could better fit the hospital context, it does not mean that a user would experience its use more positively, for instance, as a patient in hospital care. Based on the findings of this research, it seems that it is difficult for users to maintain a particular style when using ready-made assistive products. The products appear to be difficult to combine with an existing style, because of the dominance of assistiveness.

Also medical equipment can carry a high level of assistiveness. Could they be viewed as models of assistive products, because they seem to have prototypical features common to all assistive products and assistive products are often associated with them? Similarly like professional sports helmets can be viewed as "master products" that lend their colours and graphics to everyday cycling helmets and "form a style" (Vihma 1995, 144)[125], medical equipment could be considered master products that lend their characteristics to assistive products. For instance, ma-

terials, colours, forms and components are common to both medical equipment and assistive products. In a larger frame, a hospital could be viewed as a "master environment" that contributes to the composition of various care environments.

Due to their role as professional, often high-tech equipment, the assistiveness of medical equipment is, however, characterised by a different status. They are not employed outside health-care context and, thus, placed in "wrong" contexts of use. In the health-care context, their design may appear appropriate, because they embody qualities that are often associated with effective reliable care, which is exactly what hospitals and health centres are supposed to deliver. Problems arise when assistive products that resemble medical equipment are brought somewhere else. Assistiveness can be merged into the surroundings in the health-care context, but in a domestic context it can act as a distinguishing quality. Depending on the context of use, a product with a high level of assistiveness can appear a professional status symbol or a stigma symbol. Through the product use, the degree of assistiveness can also alter the status of its user.

What is assistiveness composed of? Does it refer to the construction and composition of parts, which follow products' assistive functions? The emphasis on utility function can lead to insufficient and inconsistent design, because other functions and properties are not paid attention to. The design of an assistive product, which has a high level of assistiveness, may be a mixture of materials, colours and forms that do not necessarily complement each other, but separately contribute to the product's assistive function. They could be seen as originating from the design of medical equipment, because their design seems to be dominated by requirements that are set in health-care contexts. In those, aesthetic, social and identity functions may not be considered as utility functions are. Or, the qualities of such functions might differ from the ones users prefer. Because of their resemblance to medical equipment, assistive products could be seen as tools for medical aid, not as consumer goods, in which case their statuses differ according to their users and contexts of use.

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125 Vihma (1995, 58) characterises master products as big, technically new and complex products, which function as "formal and aesthetic models", and whose style is transferred to the design of smaller and more common products.

In Figure 53, the types in the typology are positioned on a horizontal axis where assistiveness increases from left to right. Instruments can be viewed as highly assistive, approaching medical equipment, and they are proposed to have most assistiveness. The higher the level of assistiveness, the more a product can be seen as resembling medical equipment.
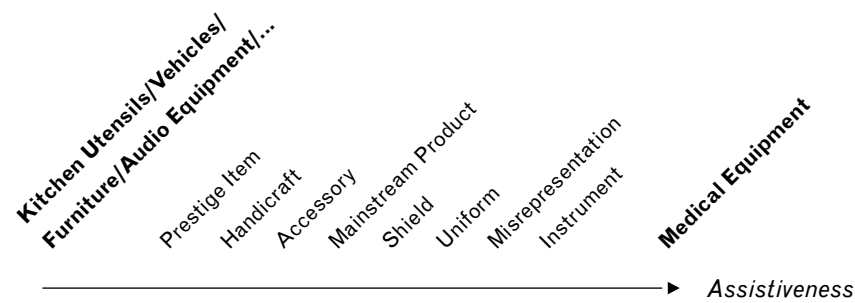
Figure 53. Assistiveness in the typology.

Due to the variety of their purposes of use, assistive products can also resemble other products like sports equipment or furniture. What makes spectacles a poor example of assistiveness, but an excellent example of a well-accepted assistive product, is their resemblance to clothing and accessories. They have been designed to lend their qualities rather from fashion design than the design of medical equipment, and they have succeeded in shaking off much of the stigma associated with assistive prod-

ucts. The users of glasses are many, which may also have influenced how ordinary the products have become to appear. In the future, also the need for other assistive products is likely to increase due to the ageing of the population, which may eventually affect how stigmatising they appear for others. In Figure 53 above, Prestige Items are portrayed as expressing assistiveness only little and approaching mainstream products, for instance, kitchen utensils and vehicles.

By identifying and describing the quality of assistiveness, the findings of this research provide knowledge of the representations of assistive products as part of the health-care context. Assistiveness is an exception that does not seem to follow the traditional categorisation of consumer products. It pinpoints product properties, which can be paid attention to in order to break down associations with the health-care context and to create more mainstream assistive products that acknowledge various dimensions of the use context.

Although products can have many contexts of use, the findings of this research suggest that an assistive product, which resembles a piece of medical equipment, appears to have only one plausible context and purpose. Even though the product is not employed in that context, it will nevertheless convey information about it. As homes are equipped with assistive products, they may start to resemble hospitals or care environments. Also users of assistive products can become identified with a specific context of use that the products represent. For instance, products that are designed according to the parameters of the health-care context can make their users appear as patients who are perceived, defined and dominated by their health condition also in other contexts, as if their other identities ceased to exist. When evaluated from the viewpoint of appearance, the problem with assistive products can be that their product category and context of use do not match.

No matter how they appear, assistive products can create confusion among people who view them. Assistive products, which resemble medical equipment, can be viewed as anoma-

lies in private homes, but personalised products, if they are still recognised as assistive products, could create different kind of, more positive, confusion. Because the design of assistive products has remained similar for long, and it has become recognisable, personalised assistive products can appear ambiguous due to their characteristics that associate them with several product categories. Accessories, Handicrafts and Prestige Items may not fit in the group of current assistive products, but they may not be seen like other consumer products either. In order to become perceived as fitting, new kinds of experiences should be more consistent with older ones (Douglas 2002, 46). Shields and Mainstream Products can potentially create the least kind of confusion, negative or positive, because they may conform to mainstream products on the market.

Based on the findings of this research, one hoped-for consequence would be that mixing product categories leads to more mainstream design of assistive products. Assistive products, which would look mainstream, could not anymore be one-sidedly associated with each other by an overt quality called assistiveness. That could also affect the way their users are viewed. Then, they would not be distinguishable from the users of other kinds of products. Instead, they would be connected with other persons, which could lead to new kinds of groupings not based on disability.

Even though ambiguities in the categorisation of assistive products and their users could reduce stigma, all consequences might not be desirable. One of the reasons for categorising products as assistive in the first place is that many assistive products are provided by the public sector. An assistive product is supposed to fulfil particular criteria in order to be funded. It is supposed to differ from other products. If a product does not meet the criteria, its user may not be entitled to it. Currently, this can prevent users from personalising products, or using mainstream products for assistive purposes. One way to solve the dilemma could be to reassess and revise the provision process of assistive products in tandem with their design. This calls for a

more comprehensive design approach that would take into account also assistive product services.

In general, it is difficult to design a product that would properly belong to more than one category, and it might not even be cognitively desirable, but a product form can, nevertheless, refer to something outside its primary category (Athavankar 1990, d18, d20–d24). It can have both primary visual clues that refer to its category and secondary ones referring to its symbolic values (ibid., d29). An assistive product could, therefore, express not only assistiveness, but also qualities like chairness, cupness or sportiness depending on the product. Based on the findings of this research, personalisation can be used for adjusting, even diminishing, the level of assistiveness.

5.2 Aspects of Design

Assistive products aim to connect users to their environment by providing access. Due to high-tech innovations, like new smart materials, products' assistive properties and, consequently, potential to connect users to the environment, have improved. Nevertheless, the findings of this research reveal that assistive products have enabled integration only up to a certain point. Being able to "come out" as disabled with the help of assistive products may have been the main issue at some point, but especially young people have began to experience product-related shortcomings. It appears that rather than experiencing disability as stigmatising, young people associate stigma with using assistive products. Assistive products have traditionally been viewed mainly as equipment for compensating disability and this perspective seems to persist also in their design. In line with earlier findings, the findings of this research show that some assistive products can be experienced as representations of disability and associated with stereotypical qualities that are assumed to belong to a person with disability. They contribute to what is understood by being disabled.

What assistive products currently express seems to solely

relate to their use as disability aids. They do not appear to provide users with other than assistive functions and utility value. They may not give users enough possibilities to identify with the products, nor to express, through their use, other aspects of identity than disability. Compared with other consumer products, the design of assistive products appears insufficient and selections and assortments poor, which directs which products to use. The diversity, and individuality, of users are not fully acknowledged in design. Professional designers, or users, are rarely systematically involved in the design process.

One-sided design, which brings out only one quality, and categorises users based on that quality, can reduce users into a stereotype. Through such design, physical disability can become a master status that overemphasises characteristics that are associated with it, and overrides other statuses. The socialising function of assistive products can turn out contradictory: while the products may connect their users physically to the environment, they may socially isolate them due to representations that emphasise, exaggerate and even misrepresent disability. Stereotypical information on users' alleged characteristics or skills can also control social interaction. It needs, however, to be remembered that information can ease interaction between people, but in its oversimplified and underlining form, the information assistive products currently convey can be labelling.

The findings of this research indicate that people with physical disability can associate two kinds of difference with their assistive products. On the one hand, some of the current ready-made assistive products stick out and attract negative attention. On the other hand, people long for possibilities to show their individuality by personalising their assistive products. In addition to highlighting individuality, people may want their products to indicate various group identities, not solely the one shared by people with disability. Negative and positive difference can also concern single product features like technology. Within Instruments, technology can be perceived as negative, if it is the primary product feature and seen in a domestic context.

In the case of Prestige Items, [high] technology can be positive and present users as forerunners. Even though high technology could provide the design of assistive products with a boost, it should not be the starting point, but users' goals, needs and preferences (Scherer 2002, 3).

Based on the findings, positive difference, which users have experienced when using personalised assistive products, appears to derive from qualities that seem to be missing from current ready-made assistive products. Positive difference concerns users' possibilities to express, even construct, different identities in various ways: choosing, customising, ideating or designing the most appropriate product. Such a product can also meet users' identity-related requirements and preferences, and provide many functions. Positive difference consists of physical product properties like colour, material, form and size, but also what products represent and are associated with.

The potential of mainstream products has also emerged in the findings of this research. The findings encourage to explore what the design of mainstream products can offer in each design phase, what kinds of assistive properties mainstream products potentially have, the relation between universal and individual product qualities, and the overlap of special and mainstream user requirements. I have earlier proposed that "the accessibility potential"[126] of the environment could be explored. By that, I have referred to the potentially accessible properties of the environment, which might "afford" accessible and assistive purposes of use selectively for people with physical disability. People without disability might not perceive the potential, because they would not need it. If accessible and assistive properties were not perceived by all, they might not become stigmatising either.

Assistiveness as a quality suggests that design could pay more attention to features which affirm the mainstream categories, to which assistive products seem to belong based on their utility functions. Strengthening the features could weaken assis-

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126 Jacobson 2009 (see also Correia de Barros 2012, 180).

tiveness. A thorough semantic analysis of assistive products could be made in order to explore further what stigmatising features are like and what is assistiveness specifically composed of. More attention could be paid to where and how assistive products are used. The actual contexts and purposes of use could be explored from a wider perspective: that of mainstream products. It would, however, be interesting to know if also some of the more mainstream products categorise users in negative ways, or even stigmatise them. All these offer prospects for further research.

The design of mainstream products and the available mainstream technology can provide assistive products with appearance, which could be perceived as less stigmatising due to their ordinariness. Even if some utility functions still needed to be realised in a different way in order to guarantee safety and usability, aesthetic, social and identity functions could be more similar. This could influence the conceptions of assistive products.

The problem is that recent technological innovations within mainstream products might not necessarily reach the design of assistive products, or, if they do, they may reach only some of them, for example, sports equipment. This may be due to financial issues, because assistive product design is mostly small business compared with other consumer products, and the buyers of assistive products are often non-profit organisations. Furthermore, the users of assistive products may not have financial resources to purchase the products themselves. Or, if they do, they may not be aware of them or have access to them due to delivery and marketing shortcomings. The issue is complex. Applying the practices in the design of mainstream products could reduce costs due to some shared resources and eventually also improve the affordability of the products.

Steps from the early phases of product development towards segmentation and individualisation, which would allow mass-customisation, co-creation and users' influence (Eger & Drukker 2010, 51), could also be taken in the design of assistive products. Instead of trying to find universal characteristics that designers could endow products with, products could be

designed in a way that allows users to make them more personal. This also concerns the inclusive design approaches, because inclusiveness may not be enough. Also inclusive design needs to provide possibilities for individuality, and positive difference from other people.

While Mugge (2007, 117) suggests that it might be less valuable to personalise utilitarian products, this research shows that assistive products, which are highly utilitarian, can significantly benefit from personalisation. Personalisation is introduced as one way of increasing individuality and positive difference, adjusting the level of assistiveness, and weakening stigma. Personalisation could influence all kinds of assistive products. Choices could become numerous, if a user was able to finalise a product herself by personalising it. Some assistive products could have a basic structure, which would be complemented individually with features.[127] For already existing products or for products that are lent to users, additional interchangeable parts, which do not prevent further use by other users, could be provided. What appears to be obvious in the design of many mainstream products could also be applied to the design of assistive products. This would also be in line with the aims of the inclusive design approaches.

In practice, personalisation would require a certain amount of incompleteness of design. I have earlier proposed that designers could leave the design of assistive products "open" or "incomplete" in a way that leaves space for users to complete the design.[128] Similarly, Zola (1982, unnumbered) envisaged that assistive products would not need to do everything from the start, but possibilities to make products "more own" could be provided. Users could be encouraged to make their own kinds of products. What Fischer et al. (2004, 35–36) call "underdesign",

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127 In mass-customisation, an accessible platform could be complemented with various "modules", from which a user chooses an individual composition that meets, in addition to accessibility, her requirements related to, for example, lifestyle (Jacobson & Pirinen 2007a, 166).

128 Jacobson 2009 (see also Correia de Barros 2012, 186–187).

provides users with social and technical instruments to create solutions themselves. It accommodates to unexpected issues in use. According to Keinonen (2009, 68), a too complete design can prevent users from adjusting and is "in open conflict with the view that ideal design is permanently unfinished, stimulates new interpretations, provides opportunities for adjustments, and trusts users being able to make them". Ladner (2010, 29) presents that empowering design that enables users "to solve their own accessibility problems whenever possible" could combine user-centred design and universal design. This, however, requires that designers are ready to give some of their current tasks to users and to take new responsibilities in terms of enabling users' endeavours (see Mugge 2007, 95).

Since the design of assistive products is influenced by various standards and regulations in order to guarantee safety, the incompleteness of design could probably include mainly appearance-related qualities because of safety reasons. The interviews with professionals revealed that sometimes personalisation attemps lead to potential hazards. The professionals pointed out that personalisation should be realised in a way that does not compromise products' guarantee or users' safety. In order to enable this, further research would be required on the forms and consequences of personalisation. Since the way assistive products appear has been identified as a key contributor to the emergence and persistence of stigma, being able to design the product appearance would be a significant improvement from the user viewpoint. Individual products, which would present the diversity of people with disability, could break stereotypical images down.

Personalisation might not only influence how assistive products appear, but it could empower users. The focus of this research has not been on the actual design process, but implications for it have arisen. One of them is engaging users more profoundly in the process, and based on the findings of this research, some users would like to take part in designing. The need to involve users has been widely recognised also in earlier research,

but the focus has mainly been on phases that follow design like rehabilitation. More research would be required to find out why the user-centred approach has not been established in the design of assistive products even though the need for it has been acknowledged also earlier and approaches like inclusive design have been developed.

The findings of this research echo user-centred procedures, which can be characterised as standard in the current design of many mainstream products. For instance, users can adopt different roles in various phases of design. Inventive people, as the interviewed users in this research, can participate already from the beginning and contribute to ideation. Most inventive users can even provide their own designs. Some other users can take part in later phases and contribute to the development by, for instance, evaluating prototypes and giving feedback. But, more attention can be paid to new kinds of product functions that have been presented in the introduced typology. It might make sense to also engage users who do not have disability in the development of assistive products, because they can be able to disengage themselves from the assistive purposes of use and provide insights into other important functions.

In addition to providing companies and designers with valuable experiences and insights, engaging users with disability in the design process can shift them from "passive objects" to skilled participants. Engaging users early can benefit companies in preventing design failures and the need to restart the process (Rauhala 2007, 123). In addition to the design of mainstream products, the assistive product design can learn from existing user-centred approaches applied in, for example, health technology development (see e.g., Hyysalo 2010). Since the design of health-care products may have similar constraints, it could turn out useful. It could also move assistive products closer to wellbeing products (see also Larsson et al. 2005), which would be a step towards mainstream products.

For the abandonment of assistive products, which previous research has identified as a problem, personalisation can be a

preventive measure. Some of the current assistive products may have negative self-incongruity, which means that even if users perceived their self-images positively, the products may be perceived negatively (Sirgy 1982, 289). The suitability of assistive products increases their likelihood of use, which often adds to the overall quality of life and wellbeing of users. As this research shows, personalised assistive products can be highly successful. Complementing assistive products with personalised features can strengthen product attachment and, consequently, prevent abandonment when it results from users' limited possibilities to identify with the products or to express identity through their use. For enhancing product attachment, also products with predetermined "personalities" that match their users' personalities can be designed (Govers & Mugge 2004, unnumbered), but personalisation that is designed and implemented by users would probably allow more individuality, be more empowering, and also more affordable. Personalisation could maximise the usefulness of assistive products.

In addition to providing assistive products with new functions, which relate to users' aesthetic, social and identity-related requirements and preferences, some of the existing utility functions need re-examination. Some examples in the database reveal that users have made inventions in order to enable particular utility functions, because ready-made assistive products have not been available for those functions. As for the interviews, they show that users employ assistive products for utility functions, and in contexts which differ from the ones their designers may have had in mind. The fact that there still are also shortcomings concerning utility functions is a rather unanticipated finding in terms of the preliminary hypothesis and considering that the design of assistive products has specifically focused on utility functions. Also utility functions seem to need further research, which could be carried out in tandem with research on other functions.

The findings of this research may not be restricted to the design of assistive products, but they can benefit also other areas of design and architecture in increasing accessibility. The findings contribute to the definition of assistive capabilities, mentioned as part of the definition of user experience in the standard for human-centred design for interactive systems (see Chapter 1.1) by outlining a more comprehensive view on assistive products and what being assistive means. Similarly, the findings contribute to the definitions of current inclusive design approaches and to their design principles. By presenting various product functions, which extend beyond assistive ones, the findings also complement the current definitions of assistive products.

This research is connected to current demographic change faced in many countries. Due to the ageing of the population, the need for assistive products, particularly accessible space, is increasing. Many regulations, for example in Finland, have been set to guarantee that new buildings are accessible and that existing buildings are renovated in order to be more accessible.[129] Despite their various benefits, so far the regulations seem to have been accepted with reservations among professionals involved in the planning and construction of new apartments, but also among residents. In public debates, some people without disability have considered the extra space resulting from accessibility an expensive waste of square metres. As presented earlier (see Chapter 4.4), also the interviewees of this research have contradictory opinions on accessibility. The new functions of assistive products introduced in this research can also benefit the development of versatile and adaptable space, which needs to merge together various requirements set by people who are in different phases of life, by identifying shared interests and aims.

In addition to implications for product design, implications for rehabilitation have emerged in this research. The findings uncover factors that influence choosing assistive products, are important for product attachment and product abandonment,

129 At the time of writing this the Finnish government has, however, agreed on a terminable trial until 2015 concerning annulment of accessibility regulations in floors higher than first and second in new apartment buildings (Government Communications Department Press Release 135/2013).

and contribute to a rewarding user-product relationship. The findings show contributors to overall accessibility and integration into the environment. Also findings that implicate a need to adjust the current funding of assistive products have emerged. Personalisation could offer a means of realising affordable individual assistive products.

Due to design approaches like service design, various areas such as allocation, prescription, provision, adjustment, maintenance, sales, marketing and advertising of assistive products could all be included in design. Also personalisation could extend to these areas. The interviewees, for example, call for an approach that would acknowledge users' individuality more comprehensively. Their experiences suggest that the current situation may work well for "average users" of assistive products, but there are also more subtle individual variation and preferences currently not acknowledged. Designing and customising the entire process could provide users with more individual experiences that would strengthen user-product relationship.

Assistive products as something else requires that they are viewed and accepted in a new way. In her research, Olander (2011, 119) has concluded that the difficulty is to change the views on assistive products in a way that corresponds to users, not to the perceptions of users hold by people who have prescribed and selected the products. A similar remark was made by one of the interviewed professionals in this research.

Assistive products' various functions, contexts of use, and integration into users' everyday lives could be shown. Presenting the user perspective could change the image of assistive products and their users. It could also affect users who do not have disability and who do not use assistive products. They might find connecting threads. Due to new images, users of assistive products could become role models for those persons who do not use assistive products because of stigma (see also Resnik et al. 2009, 84). The way some of the interviewed users of this research, for instance, use their personalised assistive products as accessories or status symbols seems far from the images cur-

rently presented in catalogues of assistive products. What assistive products signal needs to be considered on every level. A more comprehensive design approach, which includes all the aforementioned areas from allocation to advertising, could change the image of assistive products and the negative experiences of using them.

Nevertheless, Vehmas (2009, 117) has pointed out that societal structures and practices that concern disability are slow and difficult to change. According to him, if it is the only way to improve a person's wellbeing, it might sometimes be sensible to try to influence those characteristics that cause discrimination. Personalisation of assistive products could offer a way to both positively change how a person with disability appears and is viewed by other people. The findings of this research indicate that design can change the way people who use assistive products view themselves and potentially also how other people view them (see also Olander 2011, 105, 117). For example, the interviews revealed that personalised assistive products have already changed some persons' conceptions of how a person with illness appears. Perhaps personalised assistive products could positively influence conceptions of people with disability in general and, at least, the image or the category of assistive products. Personalised assistive products could be viewed as what Athavankar (1990, d13) characterises as "bold and distinctive alternatives", which enrich a current product category by adding new shades of meaning and change how a category is perceived. Personalisation can positively change individuals' experiences, but perhaps personalised assistive products could even be considered a way of "patterning reality" (Douglas 2002, 48) in a new way, of which products that do not appear assistive are part.

The findings of this research reveal that more expertise is needed in managing what is involved in the use of assistive products (see also Correia de Barros 2012, 280–281). The research presents benefits that engaging designers and users in the process can make. Health-care and rehabilitation professionals are able to evaluate users' medical and physical requirements,

and engineers are experts in technical requirements. Designers could provide products with functions and properties that extend beyond assistive ones. Such functions and properties could meet users' identity-related requirements and preferences, take into account the [social] context of use, and through that, perhaps also diminish stigma. By applying a more comprehensive design approach designers might even be able to identify some fragmented parts in the overall process and integrate them. For designers, the design of assistive products can offer inspiring, albeit demanding multidisciplinary design assignments.

Considering that much disability has been viewed as a medical condition, the direction the design of assistive products has taken is not surprising. However, along with the changing conceptions of disability, also those of assistive products could be reconsidered. By introducing a typology of assistive product functions, this research proposes new kinds of purposes of use for assistive products, and presents that assistive products need to and can be viewed as any products.

List of Illustrations

Figure 44: Self-made handles. Retrieved 19 October 2010 from http://www.spinalistips.se/tip-homemade-handle-202.html

Figure 45: Awarded manual wheelchairs. The photo taken by the author.

Figure 46: Awarded manual wheelchairs. The photo taken by the author.

Figure 47: Sally's accessible kitchen. The photo taken during the interview by the author.

Figure 48: Sally's electrically adjustable kitchen. The photo taken during the interview by the author.

Figure 49: Carla on May Day. The photo received from the interviewee.

Figure 50: Product expressiveness and the level of personalisation among the types in the typology.

Figure 51: Assistiveness as a semantic quality among assistive product categories.

Figure 52: Assistiveness as a semantic quality among assistive product categories.

Figure 53: Assistiveness in the typology.

Table 1: The distinguishing characteristics of the typology.

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Questionnaire

Quest 2.0. An electronic workbook of questionnaire answers from 757 respondents compiled by the Finnish National Institute for Health and Welfare (THL) during 2006–2009 in Finland. The questionnaire includes eight factors of satisfaction with assistive products (excl. accessible space) and four factors related to services. The workbook was received in June 2010 and is in the author's possession until it is exterminated according to the agreement.

Internet Database

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Abstract

In the design of assistive products, the focus is on the products' assistive utility functions. Less attention is paid to functions which could allow users to identify with the products, or to express their identities. Associations that assistive products create are seldom addressed. More research has been carried out on the stigma of disability than on the possible stigma caused by assistive products. Yet, it appears that rather than experiencing disability as stigmatising, particularly young people associate stigma with using assistive products and attempt to influence that. Personalisation of assistive products is a phenomenon that has not yet been studied, at least not from the viewpoint of managing stigma.

In this doctoral research, the stigma of using assistive products is explored from the viewpoint of design. Answers are sought for how young adults with physical disability experience the design of assistive products (including accessible space) in use, what the assumed stigma associated with the products is like, and how young adults manage the stigma. A perspective is adopted, which considers people with disability as active and inventive in relation to their assistive products. The personalisation of assistive products is explored as a means of managing the assumed stigma.

The phenomenon of personalising assistive products is approached as a case. Understanding the phenomenon is gained by exploring literature on products' role in identification, a questionnaire on assistive device satisfaction, an Internet database about users' inventive product modifications, interviews with professionals who work with users, and interviews with users who have personalised their assistive products.

A theoretical framework, which has also guided the analysis of the data, considers the role of products in identification. The social and material construction of the self, similarity and difference between people, and the emergence of roles, types and stereotypes are unfolded. The meaning of products in constructing and expressing the self is explored. Perceiving and interpreting products, various product functions and managing impression with products are discussed. Particularly products that stigmatise and stereotype are in the focus and light is shed on the nature and emergence of stigma, the assumed stigma of using assistive products, and people's techniques in managing stigma. Diverse angles help understand the multifaceted consequences of using assistive products.

The findings are organised into a typology where users' experiences of both ready-made and personalised assistive products are categorised into types and subtypes, which describe the various functions assistive products can have. The negative types, *Instruments*, *Misrepresentations* and *Uniforms*, reveal the complexity of the stigma associated with current ready-made assistive products. The neutral types, *Shields* and *Mainstream Products*, show how users managed the stigma by personalising the products. The positive types, *Accessories*, *Handicrafts* and *Prestige Items*, introduce how personalisation can be extended to expressing the self. The research reveals how personalisation adds aesthetic, social and identity functions to products that have previously been considered as having primarily assistive ones. *Assistiveness* is proposed as a shared semantic quality of assistive products, which could be adjusted through personalisation.

The research is positioned in the field of design research in industrial and strategic design. In studying assistive products' role in expressing and constructing their users' identities, the research interconnects conceptions of user experience, inclusive design and design semantics. The research contributes to earlier research by discussing the problematics of assistive products also from the viewpoint of design. It shows that design can have a significant role in diminishing the stigma of assistive products, and how users view themselves and are viewed by other people. The research proposes that more expertise is needed in managing what is involved in the use of assistive products and presents benefits that engaging users and designers in the process can have. By introducing personalised assistive products and their functions that extend beyond assistive ones, the research proposes that assistive products need to, and also can be, viewed as any products.

Keywords: Assistive product, Identity, Industrial design, Personalisation, Stigma.

Tiivistelmä

Apuvälineiden muotoilussa keskitytään tuotteiden avustaviin toimintoihin. Vähemmän huomiota kiinnitetään sellaisiin käyttötarkoituksiin, joiden avulla käyttäjät voisivat samaistua tuotteisiin tai ilmaista identiteettiään. Apuvälineiden herättämiin mielikuviin kohdistetaan huomiota vain harvoin. Apuvälineiden käyttöön mahdollisesti liittyvää leimaa on tutkittu vähemmän kuin vammaisuuden leimaavuutta. Silti vaikuttaisi, että erityisesti nuoret kokevat apuvälineen käytön, ennemmin kuin vammaisuuden, leimaavaksi ja yrittävät vaikuttaa siihen. Apuvälineiden personalisointia ei vielä ole tutkittu ainakaan leiman hallinnan näkökulmasta.

Tässä väitöskirjatutkimuksessa on selvitetty, miten nuoret aikuiset, joilla on liikuntavamma, kokevat apuvälineiden (mukaan lukien esteettömän tilan) muotoilun käytössä, millainen apuvälineisiin liittyvä leima on ja miten nuoret aikuiset ovat hallinneet leimaa. Käyttäjät, joilla on liikuntavamma, nähdään aktiivisina ja keksleliäinä suhteessa apuvälineisiinsä. Apuvälineiden personalisointia tarkastellaan keinona hallita apuvälineiden käytön oletettua leimaa.

Apuvälineiden personalisointia lähestytään tapauksena. Ilmiötä pyritään ymmärtämään tarkastelemalla kirjallisuutta, joka käsittelee tuotteiden merkitystä käyttäjän identiteetille, ja empiiristä aineistoa, joka koostuu apuvälinetyyttyväisyyttä mittaavasta kyselystä, käyttäjien apuvälineideoita sisältävästä internet-tietokannasta sekä käyttäjärajapinnassa työskentelevien asiantuntijoiden ja apuvälineitä personalisoivien käyttäjien haastatteluista.

Tutkimuksen teoreettinen viitekehys, joka on myös ohjannut aineiston analyysiä, keskittyy tuotteiden merkitykseen identiteetin ilmaisussa ja rakentumisessa. Siinä perehdytään identiteetin sosiaaliseen ja materiaaliseen rakentumiseen, yksilöiden väliseen samankaltaisuuteen ja erilaisuuteen, roolien, tyyppien ja stereotyyppien ilmaantumiseen, tuotteiden havaitsemiseen ja tulkitsemiseen sekä tuotteiden erilaisiin käyttötarkoituksiin ja tehtäviin vaikutelman hallinnassa. Erityisesti tarkastellaan tuotteita, jotka leimaavat ja stereotyyppittävät. Lisäksi selvitetään leiman olemusta ja ilmaantumista, apuvälineiden käytön oletettua leimaa ja yksilöiden keinoja hallita leimaa. Erilaiset näkökulmat tuottavat kattavan ymmärryksen apuvälineiden käytön monitahoisista seurauksista.

Tutkimuksen tuloksena käyttäjien kokemukset valmisapuvälineistä ja personalisoiduista apuvälineistä on jaettu tyyppeihin, jotka kuvaavat apuvälineiden erilaisia mahdollisia käyttötarkoituksia. Negatiiviset tyypit, *Instrumentit*, *Vääristelmät* ja *Univormut*, paljastavat nykyisten valmisapuvälineiden käyttöön liitetyn leiman monitahoisuuden. Neutraalit tyypit, *Kilvet* ja *Valtavirtatuotteet*, osoittavat miten käyttäjät ovat pyrkineet hallitsemaan leimaa apuvälineitä personalisoimalla. Positiiviset tyypit, *Asusteet*, *Käsityöt* ja *Statusesineet*, esittävät miten personalisointi voidaan ulottaa myös osaksi identiteetin ilmaisua. Tutkimus paljastaa, miten personalisointi lisää esteettisiä, sosiaalisia ja identiteettiin liittyviä käyttötarkoituksia tuotteille, jotka on perinteisesti nähty vain avustavina. *Avustavuutta* ehdotetaan apuvälineitä yhdistäväksi semanttiseksi ominaisuudeksi, jota voidaan säädellä personalisoinnilla.

Tutkimus sijoittuu muotoilun tutkimukseen ja edustaa teollisen muotoilun alaa. Se yhdistää käyttökokemuksen, inklusiivisen suunnittelun ja muotoilun semantiikan käsityksiä pohtiessaan apuvälineiden tehtävää käyttäjän identiteetin ilmaisussa ja rakentumisessa. Tutkimus tuo muotoilun näkökulman apuvälineiden ongelmallisuutta käsittelevään aiempaan tutkimukseen. Se osoittaa, että muotoilulla voi olla merkittävä rooli apuvälineisiin liitetyn leiman vähentämisessä ja siinä, miten käyttäjät näkevät itsensä ja tulevat nähdyiksi. Tutkimuksessa esitetään, että apuvälineiden käyttöön liittyvän kokonaisuuden hallinnassa tarvitaan lisää asiantuntijuuksia. Siinä ehdotetaan, mitä hyötyä on siitä, että myös käyttäjät ja muotoilijat otetaan osaksi apuvälineisiin liittyvää prosessia. Esittelemällä personalisoituja apuvälineitä ja niiden muitakin kuin avustavia käyttötarkoituksia tutkimus ehdottaa, että apuvälineet pitää ja ne myös voidaan nähdä kuten mitkä tahansa tuotteet.

Avainsanat: Apuväline, Identiteetti, Leima, Personalisointi, Teollinen muotoilu.