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## Social Construction of Technical Aids - Personal Meaning and Interactional Effects of Disability and Assistive Devices in Everyday Life

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# **Social Construction of Technical Aids**

Personal Meaning and Interactional Effects of Disability  
and Assistive Devices in Everyday Life

**Oskar Krantz**



**LUND UNIVERSITY**  
Faculty of Medicine

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*“O, for a chair, to bear him easily hence!”*  
(Shakespeare: Othello)



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# Förord

Det finns egentligen alldeles för många människor som haft ett inflytande på hur en avhandling i slutskedet blir för att alla ska kunna tackas i ett förord. Några kanske kommer att sakna sig själva; det är dock inte min avsikt att förringa era respektive insatser. Till er riktar jag således ett stort tack.

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Lund, januari 2009

Oskar Krantz

# Abstract

This thesis concerns the role of disability and assistive devices in everyday life among persons with, for instance, impairments related to mobility (e.g. wheelchair users) and bodily shape and configuration (e.g. dysmelia). Assistive devices are seen as both includators (assisting participation and emancipation) and excludators (limiting participation, restraining empowerment, and stigmatizing). Perspectives include, for instance, stigmatisation, body-image, coping, empowerment, agency, motivation, needs, and everyday life. Use of assistive devices is discussed from the ValMO-model: Value and Meaning in Human Occupations. The discussion concerns the useworthiness, as opposed to usability, of assistive devices from a perspective of not only physics-based effectiveness (Newton), but also from a self-image and agency perspective based on habitus (Bourdieu). In study I, the experience of prescription of active rigid-frame ultra light-weight wheelchairs was reported, using data on 278 prescribers in Sweden. Prescribers emphasised self-image, design, appearance and aesthetics. Even though prescribers want to prescribe an optimal wheelchair, they may lack the possibility to do so due to: (1) lack of practice and specialized knowledge; and (2) narrow regulations, both pertaining to municipal political decisions. Study II describes the experience of active wheelchairs and societal provision thereof utilizing thematic qualitative content analysis of eleven interviews with experienced users in Sweden. Results showed users experiencing injustice and unfairness negotiating wheelchair needs in terms of physical and social functioning (agency); changes of attitudes/organization are suggested. Study III was grounded theory study that showed an adaptation of stigma-handling strategies to situations in everyday life by women aged 20 to 30 with dysmelia, i.e. upper limb reduction deficiency. Strategies were comprehensive patterns of action aimed at controlling information about one's status as deviating from a contextual normality. A proofing or being attitude constituted a contextual adaptation understood in terms of a concealing or revealing tactic, aiming at delaying or promoting exposure to contextual attitudes and possible prejudices. If exposure was delayed, a person with dysmelia blended in. Exposure could be voluntary or imposed. After exposure, the relative importance of TULRD in the specific context could decrease, thus a boost of an amplification or altering of the attitude, i.e. boost was the interactional outcome enforcing the choice of strategy in another context.

## Keywords

Active ultra lightweight rigid frame wheelchair, Assistive device, Body-image, Congenital Limb Deficiency, Disability, Dysmelia, Gender, Hand prosthesis, Legislation, Needs, Prescription, Regulation, Self-image, Upper Limb Reduction Deficiency, Useworthiness

# Original papers

- I Krantz, O.; Persson, D. & Bolin, K. (2008) Prescription of active wheelchairs in Sweden: Matching person and wheelchair. *(Re-submitted)*.
- II Krantz, O. et al (2008) The experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced users in Sweden. *(Submitted)*.
- III Krantz, O.; Bolin, K. & Persson, D. (2008) Stigma-handling strategies in everyday life among women aged 20 to 30 with transversal upper limb reduction deficiency. *Scandinavian Journal of Disability Research*, 10(4) 209-26.

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# Introduction

One early historic reference to disability is the Mutilated Greeks' Debate at Persepolis, 330 BC. In short, the debate emerged after Alexander reached Persepolis and encountered a larger group of Greeks, newly released from Persian enslavement. The debate concerned "whether to return to Greece with money in hand and disperse to their old families, who might be shocked by their appearance, or to stay as a mutually supportive group and receive benefits in Persia with their local partners".<sup>1</sup> In general, the ancient Greeks were uncomfortable with impairment and imperfection, and this led to the exclusion of persons with disabilities and the banishment of the anomalous.<sup>2</sup> Therefore, the debate at Persepolis was important for the par-takers, as well as an example of issues relevant even today, since disability still has the effect of being a social barrier. For instance, many persons may feel somewhat uncomfortable with impairment and imperfection, and many persons with disabilities are excluded from parts of society.<sup>3</sup>

This thesis concerns the role of disability and assistive devices in everyday life among persons with disabilities. However, the focus is neither on medical conditions which in turn lead to disabilities, nor on a 'nuts-and-bolts' level of assistive devices. Instead, assistive devices and disability are seen as parts of a larger context, not as isolated examples. Disability can be "an interaction between impaired bodies and excluding environments".<sup>4</sup> On a personal level, assistive devices can be one means of overcoming these environmental obstacles. However, an assistive device can accentuate the existence of disability, potentially leading to stigmatisation. Therefore, assistive devices can be seen as both physically assisting participation and as socially limiting participation.

In this thesis, perspectives on disability and assistive devices include stigmatisation, body image, coping, motivation, empowerment and everyday life. Use of assistive devices is discussed from the perspective of the ValMO-model: Value and Meaning in Human Occupations.<sup>5</sup> Assistive devices are also discussed in relation to useworthiness, as opposed to usability, from not only an operational perspective of activity management, but also from a self image and agency perspective based on

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<sup>1</sup> Miles (2003)

<sup>2</sup> Hughes et al. (2005a)

<sup>3</sup> Reeve (2002)

<sup>4</sup> Shakespeare (2005)

<sup>5</sup> Persson et al. (2001)



habitus, i.e. a person's internalised social experiences, memories and patterns of behaviour.<sup>6</sup>

The two forms of assistive devices discussed are active wheelchairs and upper limb prostheses. Active wheelchairs are aimed at being operated actively by the user, mainly utilised by persons with mobility impairments due to, for instance, spinal cord injuries. Upper limb prostheses are typically used by persons with one (or two) arms/hands less than the typical configuration of the majority of human beings, i.e. what can be considered as a 'normal' bodily configuration and shape. This can be due to, for instance, congenital limb deficiency. However, 'normal' refers to a societal level of perceived normality; a person being born with this configuration has no reference to personal normality being two-handed.<sup>7</sup>

The reasons for focusing on active wheelchairs and upper limb prostheses include that they are both examples of devices used by "healthy disabled" persons, i.e. persons whose impairments are comparably predictable and stable and who consider themselves healthy (as opposed to sick) and do not "expect to die any sooner than any other healthy person their age".<sup>8</sup> In short, persons whose only obvious difference compared to others is having an impairment that in most cases can be perceived by the person her/himself as rather unimportant, yet has the interactional possibility of constituting a stigma.<sup>9</sup> For instance, among persons in the UK living with the effects of Thalidomide, only 37% considered themselves disabled. Furthermore, 70% reported their quality of life to be good, or better than good.<sup>10</sup> In a study of Israeli war veterans with disabilities, the severity of impairment had little effect on perceived quality of life compared to the subjective assessment of the implications that followed, e.g. stigmatisation.<sup>11</sup>

Another reason for focusing active wheelchairs and hand prostheses as examples of assistive devices are that they are answering demands in everyday life on different levels. A person using an active wheelchair as means of mobility is stranded without a functioning wheelchair, i.e. denied, on a very basic level, activities in everyday life. A person using, or not using, a hand prosthesis still has the physical possibility of everyday life participation. On the other hand, a hand prosthesis can have other effects on everyday life, for instance from a perspective of concealing/revealing a physical deviation from what may, or may not, be a situational normality. A wheelchair can be rather difficult to conceal, thus constituting a more direct presentation of self.

Assistive devices have been found to be of importance concerning perceived quality of life.<sup>12</sup> One factor when evaluating the function of an assistive device is

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<sup>6</sup> Bourdieu (1984, 1991, 1992)

<sup>7</sup> Lutz & Bowers (2005)

<sup>8</sup> Wendell (2001)

<sup>9</sup> Goffman (1990a)

<sup>10</sup> Bent et al. (2007)

<sup>11</sup> Ben-Sira (1986)

<sup>12</sup> Najmna & Levine (1981); Asada (2005); Gallagher & Desmond (2007)

“whether it satisfies the needs of the disabled consumer”.<sup>13</sup> ‘Needs’ have been discussed by, for instance, Hallström & Elander (2001), utilising a definition by Georg Henrik von Wright, i.e. as something “bad for the person to be without”.<sup>14</sup>

In Sweden, the overall goal of disability policy is that persons with disabilities should have the possibility to participate fully in all parts of the society and to live active and independent lives.<sup>15</sup> One necessary tool for achieving independence can be assistive devices with adequate properties.<sup>16</sup> The Swedish Handicap Institute<sup>17</sup> calculates that one in five, or 1 800 000 persons, of the Swedish population between 16 and 64 years has a functional limitation; the dominating categories are asthma/allergy and mobility impairments. Approximately 800 000 – 850 000 (9.5%) use assistive devices.<sup>18</sup> More specifically, 6.7% (5.2% men, 8.2% women) of the Swedish population between 16 and 84 years of age have mobility impairments, and of these, 3.8% (2.9% men, 4.8% women) have severe mobility impairments. Mobility impairment is defined as the inability to run a short distance, to get on a bus without problems or to take a short walk. Severe mobility impairments are defined as the inability to ambulate without the use of personal assistance or assistive devices.<sup>19</sup> The group of persons with disabilities is a highly diverse group due to differences in for instance impairments, sexuality, gender, stage of life, social class, ethnicity and living situation (whether in urban or rural areas).<sup>20</sup> As can be seen in table 1 below, the older age groups are over-represented due to normal aging.

One proposed definition of disability is “the difficulty or inability to independently perform basic activities of daily living or other tasks essential for independent living without assistance”<sup>21</sup>, thus focusing on the person as a basis of understanding. One definition of how disability can be experienced from a personal perspective is Morris’ (1992): “To experience disability is to experience the frailty of the human body”.<sup>22</sup> One of society’s dominant definitions of disability is the inability to do things. In contrast, disability can also be seen as a process of identity formation, an agentive embodiment of liminality. As such, disability is “a significant social phe-

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<sup>13</sup> Batavia & Hammer (1990)

<sup>14</sup> Hallström & Elander (2001)

<sup>15</sup> Proposition 1999/2000:79

<sup>16</sup> Arnell (1999)

<sup>17</sup> The Swedish Handicap Institute is run by the Ministry of Health and Social Affairs and the Swedish Association of Local Authorities and Regions.

<sup>18</sup> Hjälpmedelsinstitutet (2006); Hjälpmedelsinstitutet (n.y.) [www.hi.se](http://www.hi.se)

<sup>19</sup> Statistics Sweden: Living Conditions Survey. From:

[http://www.scb.se/templates/Product\\_\\_\\_12187.asp](http://www.scb.se/templates/Product___12187.asp) (in English) and

[http://www.scb.se/templates/Uppgiftslamnare\\_\\_\\_97599.asp](http://www.scb.se/templates/Uppgiftslamnare___97599.asp) (in Swedish) (Download: 2008-08-15).

The survey is performed bi-annually since 1975, and is performed by means of telephone interviews, approximately 12 000 and 13 000 persons every time. Since 1975, approximately 200 000 interviews have been performed. The figures utilised here are from the 2004/05 survey.

<sup>20</sup> Traustadóttir (2006)

<sup>21</sup> Annicchiarico et al. (2004)

<sup>22</sup> Morris (1992)

nomenon that can reveal and illuminate culture”.<sup>23</sup> According to Zygmunt Bauman, the carrying capacity of a bridge is not measured by the average strength of its components, but by the strength of the weakest of the components. The same is true for society at large, as the ‘carrying capacity’ of a society is “as much as the life conditions of its most humble and least potent members”.<sup>24</sup>

**Table 1: Persons with mobility impairments in Sweden (%)**

	Mobility impairment	Severe mobility impairment
All 16-84	6,7	3,8
Men 16-84	5,2	2,9
Women 16-84	8,2	4,8
All 16+	8,2	5,3
Men 16+	6,1	3,7
Women 16+	10,3	6,9
Age group		
16-24	0,4	0,2
25-34	0,9	0,5
35-44	2,0	0,6
45-54	4,2	1,8
55-64	6,5	2,6
65-74	14,3	7,1
75-84	33,9	25,9
85+	55,9	51,4

**Note:** The category “mobility impairment” includes “severe mobility impairment”. Furthermore, the overrepresentation of women is not explained by Statistics Sweden.

**Source:** Statistics Sweden (Statistiska CentralByrån, SCB); *Living Conditions Survey*.

People without personal experiences of disability may be convinced that having a disability is not only different or unpractical, but worse and tragic. Disability is thereby reduced to something absent, possible to describe only in terms of *what is not*. A person with a disability is in many situations identified as the disability, i.e. the function or part that *is not*; other factors are rendered irrelevant.<sup>25</sup>

A proposed framework for understanding disability is the WHO International Classification of Functioning, Disability and Health (ICF). Within this framework, disability may be understood as variations in human functioning due to one, or a combination, of the following factors: (1) body function and/or structure of the individual (loss or abnormality of a body part, impairment); (2) tasks and actions by an individual (difficulties in executing activities, i.e. activity limitations); and (3) individual involvement in life situations (restricted participation). Furthermore, environmental

factors are included as a part of the ICF concerning, for instance, the built environment as a hindrance regarding participation.<sup>26</sup> According to Scherer & Glueckauf (2005), assistive devices can be seen as key components concerning the environmental dimension of the ICF.<sup>27</sup>

Rehabilitation is closely associated with disability and assistive devices. Rehabilitation medicine can be defined as “the multi- and interdisciplinary management of a person's functioning and health”.<sup>28</sup> In Sweden, assistive devices are considered to be important both during rehabilitation and as a major factor concerning independence

<sup>23</sup> Titchkosky (2006, p. 3)

<sup>24</sup> Bauman (2007)

<sup>25</sup> Andersson (1993)

<sup>26</sup> WHO (2001); Imrie (2004)

<sup>27</sup> Scherer & Glueckauf (2005)

<sup>28</sup> Stucki et al. (2003)

in living, employment, education and recreation. However, in reality, users have been reported to be mainly satisfied with their devices, but unsatisfied with the societal system of service, maintenance and prescription of the device. For example, follow-ups need to be performed, as many users reported that none had been performed. Furthermore, the user has limited possibilities to choose an alternative device in Sweden.<sup>29</sup> From a legislation point of view, no such possibility exists; it is not possible to appeal any decision concerning assistive devices.<sup>30</sup> Furthermore, some municipalities and county councils<sup>31</sup> utilise specific time-limits concerning intervals of active wheelchair supply, i.e. a new wheelchair cannot be prescribed unless a certain time has passed, regardless of the condition of the current wheelchair.<sup>32</sup>

In this thesis, the terms assistive device, technical aid, assistive technology and device are used when referring to assistive devices, i.e. artefacts/gadgets of varying size and shape, commonly used, or meant to be used, with varying degrees of success, by persons with disabilities. Examples may include wheelchairs, prostheses, etc. An assistive device is defined as “a product or device utilised by persons with disabilities, especially constructed or commonly available, that compensates the functional impairment”.<sup>33</sup>

The thesis begins with a description of the background and previous research concerning disability and assistive devices in everyday life. Thereafter the aim of the thesis is defined, continuing with a discussion of methods used. The results of the three studies are presented. Finally, results are discussed and conclusions presented.

## Disability

All through the modern history of disability, persons with disabilities have been seen as ‘flawed’ and ‘in deficit’, thus having ‘tragic’ lives.<sup>34</sup> Rehabilitation services have developed in close association with war.<sup>35</sup> After World War I, a changed concept of disability emerged which included rehabilitation and replacing what was missing.<sup>36</sup>

According to Frank (1984), the state policies concerning disabilities began by supporting injured soldiers and later expanded to supporting workers unable to remain in the work force due to disabling conditions acquired at work. Only during later decades, this has been extended to persons not able to enter the work force at

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<sup>29</sup> Wressle & Samuelsson (2004)

<sup>30</sup> HsL: Hälso- och Sjukvårdslagen, SFS 1983:763

<sup>31</sup> In this thesis, the terms county councils and county are used synonymously.

<sup>32</sup> Peterson et al. (2006)

<sup>33</sup> International Standardization Organization, ISO 9999:2007 “Technical aids for disabled persons – Classification”.

<sup>34</sup> Hughes et al. (2005a)

<sup>35</sup> Eldari & Jelic (2003)

<sup>36</sup> Ville et al. (1994)

all.<sup>37</sup> Finkelstein (1993) describes that once disabled people are defined as unemployable, “it seems logical for the medical experts to concentrate attention on ways of making them 'normal', or as normal as possible”. The argument was that if disabled people became abled people, they would no longer be dependent upon charity and state handouts. But, as treatments (e.g. physiotherapy), services (e.g. provision of assistive devices) and benefits (e.g. allowances) multiplied due to the expansion of the ‘disability industry’, sharper boundaries between categories were needed in order to fit persons with disabilities into the system. Finkelstein (1993) underscores the 1970’s and 1980’s “rapid increase in disability scales and measures”, and for someone with a disability, the de-individualisation and categorisation has become something of a fact of life. For instance, it is impossible to gain access to services or benefits needed without accepting the disabling categories and being labelled ‘disabled’.<sup>38</sup>

### Body mobility and relocation

One cause of mobility impairments (leading to active wheelchair use) are injuries to the spinal cord. This type of injuries may have a variety of causes. Examples include, but are not limited to, three main groups: (1) spina bifida (SB); (2) traumatic spinal cord injuries (SCI); and (3) disease-related SCI. However, SCI and SB are separate conditions with different aetiologies. SCI is traumatic and/or occurs later in life. SB, on the other hand, is present from birth and has other complications associated with it, for instance hydrocephalus (HC) and cognitive affects among about 50% of persons with both SB and HC.<sup>39</sup> Other mobility impairments can include, but are not limited to, multiple sclerosis (MS), lower limb amputations and neuromuscular impairments. In this thesis, where active wheelchairs are studied, the share of active wheelchair users with MS or other neuromuscular impairments may be smaller than those with SCI and SB, for instance due to the continuing change in impairments following from MS compared to the relative physical stability of degree of impairment following from SCI. However, this is just an assumption. Nevertheless, SCI was chosen as an example of mobility impairments in study II.

Traumatic SCI happen to approximately 100-150 persons in Sweden each year. The mean age at the time of injury is 31 years, and 80% are men, 20% women. However, the proportion of women is increasing slightly over time.<sup>40</sup> Disease-related SCI affect approximately 100-150 persons each year and occur as a result of, for instance, a tumour or an infection of the spinal cord.<sup>41</sup>

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<sup>37</sup> Frank (1984)

<sup>38</sup> Finkelstein (1980, 1993)

<sup>39</sup> NICHY (2004); Mattsson & Glad (2005); National Institute of Neurological Disorders and Stroke (2007); RBU (2007)

<sup>40</sup> Hultling (n.y.)

<sup>41</sup> Hjälpmedelsinstitutet (n.y.). According to Hultling (n.y.), between 30 and 60 persons are affected by disease-related SCI annually.

On a more detailed level, a spinal cord injury is the result of the spinal cord being damaged, thus restricting the nervous impulses to parts of the body below the point of damage. The spine consists of 29 vertebrae and 30 spinal nerves. These are split into categories: cervical, thoracic, lumbar and sacral.<sup>42</sup> Rehabilitation after an SCI should begin as soon as possible after the most urgent phase in a specialised setting.<sup>43</sup> In a Swedish study, three factors were emphasised in the rehabilitation process: (1) straightforward information, (2) participation in the planning of the rehabilitation programme, and (3) emotional support.<sup>44</sup> The selection of an appropriate wheelchair and seating system is an important decision during rehabilitation and requires consideration of the person's environment, posture and mobility.<sup>45</sup>

For women with SCI, one problem identified during rehabilitation after an SCI is vulnerability, in turn amplified by the lack of privacy, negative staff interactions and the fact that women have a minority status in SCI rehabilitation compared with men.<sup>46</sup> Negative staff interactions may consist of a perceived lack of respect and control.<sup>47</sup> Among men with SCI, certain aspects of a more traditional masculine role have been emphasised during rehabilitation. For example, the ability to modulate strong emotions may be more adaptive, and a dominant interpersonal style may be a barrier.<sup>48</sup>

In one study, some persons with SCI stated that their quality of life had actually improved since the spinal cord injury.<sup>49</sup> Another study emphasised experiences of personal development among persons with SCI, for instance opportunities to participate in personally rewarding activities previously unknown and personal 'maturation' in the form of becoming more patient, assertive and considerate of others.<sup>50</sup> Also, negative emotional responses (depression and anxiety) and disengagement (disability denial and avoidance) have been found to affect the quality of life among persons with SCI.<sup>51</sup> In Sweden, pain has been associated with lower life satisfaction.<sup>52</sup> In another study, life satisfaction two years post SCI was found to correlate with mobility and perceived health. Furthermore, many younger persons with paraplegia report greater life satisfaction than older persons and persons with other types of SCI. Also, higher education has been found to be associated with higher life satisfac-

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<sup>42</sup> Munthe-Kaas (1989); Magnusson (1997); Larsson & Samuelsson (1999); Udd (1999). Other complications can include, but are not limited to: Urinary and faecal incontinence, pain, spasticity, pressure ulcers, decreased sexual functioning, fertility, osteoporosis and strain injuries in remaining functioning parts of the body. Pressure ulcers are a result of pressure plus time, thus emphasizing the importance of pressure relief.

<sup>43</sup> Scivoletto et al. (2005)

<sup>44</sup> Sand et al. (2006)

<sup>45</sup> May et al. (2004)

<sup>46</sup> About 80% men and 20% are women (Samuel et al., 2007)

<sup>47</sup> Samuel et al. (2007)

<sup>48</sup> Schopp et al. (2007)

<sup>49</sup> Manns & Chad (2001)

<sup>50</sup> Yoshida (1993)

<sup>51</sup> Martz et al. (2005)

<sup>52</sup> Norrbrink Budh & Österåker (2007)

tion.<sup>53</sup> A Swedish study found that quality of life was better in persons injured longer ago, compared to those with a shorter time since injury. Presence of secondary complications (e.g. pain and severe spasticity) had a more negative effect on quality of life than the SCI itself.<sup>54</sup> Environmental factors have been found to be more strongly related to life satisfaction than to societal participation.<sup>55</sup> One aspect of physical function and independence emphasised is energy expenditure in everyday activities, for instance season-related accessibility, i.e. cold temperatures and snow on the sidewalks has a negative influence on mobility.<sup>56</sup>

## Body configuration and design

In this part, congenital limb deficiency and acquired amputations are discussed. The separation of CLD (Congenital limb deficiency) and acquired amputations is made due to the different aetiologies of the two. For instance, there is a difference between being born with CLD and acquiring an amputation later in life. A person with CLD may consider herself or himself bodily complete, as no trauma is associated with the bodily shape. CLD is the congenital absence of a limb and *transversal upper limb reduction deficiency* (TULRD) is the transversal congenital absence of an upper limb.<sup>57</sup> In the Scandinavian countries and Germany, *dysmelia* is used synonymously with CLD and as a general description of TULRD. The term *dysmelia* comes from the Greek language, where *dys* means abnormal, and *meli* means limb.<sup>58</sup>

The incidence of CLD is 2-7/10 000.<sup>59</sup> In Sweden, an incidence of 6.3/10 000 has been reported, with a slight male dominance.<sup>60</sup> In comparison, approximately 2 500 persons undergo an amputation every year in Sweden. Out of them, about 50 have an arm amputated.<sup>61</sup> The most frequent levels of CLD are transtibial (upper limb below the elbow) and transradial (lower limb below the knee). Furthermore, 84% of all limb deficiencies are unilateral. The right side of the body is more common (54%) than the left side (46%), and 72% had lower limbs affected, whereas 28% had upper limbs affected.<sup>62</sup> However, another study found upper limb deficiencies more common (58.5%) than lower limb deficiencies.<sup>63</sup> Another study found that approximately two-thirds of persons with limb deficiency has an upper limb affected,<sup>64</sup> and yet another study found that 74.4% has an upper limb affected.<sup>65</sup>

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<sup>53</sup> Putzke et al. (2002)

<sup>54</sup> Westgren & Levi (1998)

<sup>55</sup> Whiteneck et al. (2004)

<sup>56</sup> Manns & Chad (2001)

<sup>57</sup> Hermansson (2004a)

<sup>58</sup> Svensk Dysmeliförening (2006)

<sup>59</sup> Ephraim et al. (2003)

<sup>60</sup> Källén et al. (1984)

<sup>61</sup> Bohman & Sténhoff (1997); RTP & KFA (2001)

<sup>62</sup> Yigiter et al. (2005)

<sup>63</sup> Dillingham et al. (2002)

<sup>64</sup> Hermansson (2004)

Two studies emphasise unilateral upper limb deficiency, especially transverse left forearm, as the most common type,<sup>66</sup> slightly more common among females than among men.<sup>67</sup> However, comparisons across studies are difficult, as diagnosis definitions, nomenclature and data sources vary between countries.<sup>68</sup> Comparing men and women, more boys (60%) are affected than girls (40%).<sup>69</sup>

CLD occurs around day 28 of pregnancy.<sup>70</sup> Hereditary factors (<20%), viral infections (10%) and chromosomal abnormalities (10%) explains for a total of less than 40%, and more than 60% are yet unexplained.<sup>71</sup> Pruitt et al. (1999) find 20% to be based on single-gene-mutations and ca 10% to be due to environmental agents, although the remaining 70% remain unknown.<sup>72</sup> Hypotheses have been tested, but, for example, neither hormones in low-dose oral contraceptives<sup>73</sup> nor calcium channel blockers<sup>74</sup> have been found to increase rates of CLD. One example of a drug found to increase the risk of limb deficiencies is Thalidomide. Marketed in the late 1950s and early 1960s as a mild sedative drug in more than 20 countries, the drug resulted in 10-12 000 babies born worldwide with limb deficiencies.<sup>75</sup>

Persons with CLD do not experience phantom limb pain<sup>76</sup> but may experience greater sensitivity of the stump compared with the non-affected limb, explained as a function of differential input to the somatosensory cortex.<sup>77</sup> Scoliosis due to uneven weight distribution has been reported among children with TULRD.<sup>78</sup>

Children with CLD may be at higher risk for problems related to psychological and social adjustment due to stigmatisation. To avoid this, the child with CLD may conceal the deficiency.<sup>79</sup> Prejudices toward cosmetic differences have been found to emerge early during childhood.<sup>80</sup> Perceived social support is proposed to be the only significant predictor variable regarding depressive symptomology, trait anxiety and general self-esteem.<sup>81</sup> However: "Most limb-deficient children are normal in all respects except for their limb deficiencies, and few require anything other than routine

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<sup>65</sup> Stoll et al. (2001)

<sup>66</sup> Wilson (1998); Pruitt et al. (1999)

<sup>67</sup> Wilson (1998)

<sup>68</sup> Luijsterburg et al. (2000); Hermansson et al. (2001); Teoh et al. (2001); Dillingham et al. (2002); Ephraim et al. (2003); Luijsterburg et al. (2003)

<sup>69</sup> Yigiter et al. (2005)

<sup>70</sup> Shurr & Michael (2002)

<sup>71</sup> McCredle & Loewenthal (1978); Sifakis et al. (2001)

<sup>72</sup> Pruitt et al. (1999)

<sup>73</sup> Klitsch (1995)

<sup>74</sup> Sørensen et al. (2001)

<sup>75</sup> Bent et al. (2007)

<sup>76</sup> Simmel (1967); Skoyles (1990); Wilkins et al. (1998); Montoya et al. (1998); Flor et al. (1998); Gallagher (1998); Price (2006)

<sup>77</sup> Wilson et al. (1962)

<sup>78</sup> McNamee (1995); Hermansson (2004a)

<sup>79</sup> Hermansson (2004a)

<sup>80</sup> Richardson (1971); Varni & Setoguchi (1991), Park et al. (2003)

<sup>81</sup> Varni et al. (1992)



pediatric care”.<sup>82</sup> Furthermore, parents of children with CLD are uniquely qualified to help and assist each other in the context of peer-to-peer support groups.<sup>83</sup>

For a person with dysmelia, three solutions are possible: (1) surgery; (2) prosthetics and other technical aids; (3) do nothing. The latter is often the choice if the dysmelia is minor.<sup>84</sup> A prosthesis can mask dysmelia, although camouflaging can prove harder for females than males, due to societal images of perfection.<sup>85</sup> Any given prosthesis may for one user embody disabling attitudes and prohibition of functions and roles, and for another user embody ability, i.e. enable functions and roles.<sup>86</sup> As a general rule, a lower level (and longer residual limb) makes prosthetic fitting easier.<sup>87</sup> When a short upper extremity stump is too short to fit with an appropriate-level prosthesis, a solution can be to surgically lengthen the stump. However, additional procedures and complications are common.<sup>88</sup> Nevertheless, most children with TULRD learn alternative techniques by themselves. According to Hermansson (2004a), certain alternative ways of performing tasks involve rather high strains and efforts, thus “use of technical aids or adaptive equipment is strongly recommended”.<sup>89</sup> In an article from 1963, it is concluded that a four year old may be more disabled by being forced to use a prosthesis than by not using it, since the prosthesis actually hinders the use of the “very useful stump”. Thus, use of prosthetics may be more disabling than non-use.<sup>90</sup>

## Intersectional experiences

Since the early 1980s, interest and attention has increased concerning gender aspects within the field of disability research.<sup>91</sup> Traditionally, research on matters associated with disability has neglected the impact of gender roles. Instead, research has implicitly focused on everyday lives of men.<sup>92</sup> Morris (1992) emphasises that the absence of disability is treated as the universal positive experience, whereas the experience of disability is the purely negative, and as such, defined by limitations.<sup>93</sup> The multiple forms of oppression of women with disabilities comprise an intertwined, intersec-

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<sup>82</sup> Setoguchi (1982)

<sup>83</sup> Kerr & McIntosh (2000)

<sup>84</sup> Bond et al. (1999); Chang & Jones (2002); Dudkiewicz et al. (2004); Gardsäter (2004)

<sup>85</sup> Taub et al. (2004)

<sup>86</sup> Desmond et al. (2002)

<sup>87</sup> Wilson (1998); Shurr & Michael (2002)

<sup>88</sup> Bernstein et al. (2008)

<sup>89</sup> Hermansson (2004a, p. 12)

<sup>90</sup> Mansfield & Knight (1963)

<sup>91</sup> Helmius (2004)

<sup>92</sup> Barron (1997a); Ferri & Gregg (1998). According to Crawford & Ostrove (2003), disability is the result of interaction between social oppression and bodily impairment.

<sup>93</sup> Morris (1992)

tional experience, and can be seen as an intersection of oppression against both women and persons with disabilities.<sup>94</sup>

Women with disabilities have traditionally been viewed as childlike, helpless and victimised.<sup>95</sup> Women are typically judged more by their appearance than men.<sup>96</sup> Women with disabilities may experience barriers in contacts with the health care system (e.g. structural, attitudinal, informational and in terms of lacking attention to their needs).<sup>97</sup> Women with disabilities are more likely to be unemployed than men with disabilities<sup>98</sup> and are more isolated within the social system of everyday life. They also have lower self-esteem than women without disabilities.<sup>99</sup> Women with disabilities are more likely than men with disabilities to develop depression and stress.<sup>100</sup>

Concerning men with disabilities, fewer studies are found. For instance, the subject of sexual violence and/or abuse is almost completely absent. However, one study showed that men may experience abuse, especially in the field of choosing and directing personal assistance providers.<sup>101</sup> Outside observers tend to attribute men's disabilities to external situational factors, whereas females' disabilities tend to be attributed to personal factors.<sup>102</sup> Comparing gender differences in rehabilitation outcomes after amputation, women tend to have a poorer outcome than men.<sup>103</sup>

Gender issues are one of the most important and least acknowledged dimensions of the societal construction of service and support systems for persons with disabilities.<sup>104</sup> Increasing availability of assistive devices, for instance wheelchairs, has the positive effect of supporting societal participation among persons with disabilities. However, women have not gained as much as men from increased availability.<sup>105</sup> Furthermore, differences in activity patterns, as well as bodily constitution, may imply different demands on assistive devices among men and women.<sup>106</sup>

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<sup>94</sup> Reinikainen (2004)

<sup>95</sup> Fine & Asch (1988)

<sup>96</sup> Rubin (1988); Hanna & Rogovsky (1991); Crawford & Ostrove (2003); Harjunen (2004); Reinikainen (2004)

<sup>97</sup> Coyle et al. (2000); Prilleltensky (2003); Kaplan (2006); Nosek et al. (2006)

<sup>98</sup> Smith Randolph & Andresen (2006)

<sup>99</sup> Hanna & Rogovsky (1991); Nosek et al. (2003); Isaksson et al. (2005)

<sup>100</sup> Hughes et al. (2005c, 2005d); Niemeier (2008)

<sup>101</sup> Benson et al. (2006)

<sup>102</sup> Hanna & Rogovsky (1991)

<sup>103</sup> Singh et al. (2008)

<sup>104</sup> Traustadóttir & Kristiansen (2004)

<sup>105</sup> Oliver (1990); Scherer (2006)

<sup>106</sup> Magnus (2004)

## Assistive devices

### Tools

A tool can be defined as “an extension of the hand in both physical and perceptual senses”.<sup>107</sup> To use a tool can be defined as “the external employment of an unattached environmental object to alter more efficiently the form, position or condition of another object, another organism, or the user itself when the user holds or carries the tool during or just prior to use and is responsible for the proper and effective orientation of the tool”.<sup>108</sup>

A tool is generally developed as a response to a perceived want or need and fulfils the function of an anticipatory addition. The function of a tool can be described as changing the world through its use, and from this point of view, a tool is disruptive since it alters what would have remained unchanged without it. Prostheses, on the other hand, can be described as “retroactive in regard to the body and anticipatory in regard to the world: they either aim at restoring the damaged body to its previous condition of wholeness or impose a normalising effect on bodies congenitally deficient”.<sup>109</sup> A prosthesis in itself can be regarded as an object, and only when integrated as a part of a user, the object becomes a prosthesis.<sup>110</sup>

However, any given device aiming at influencing an object functions under the same physical principles. The basic construction and function of any given tool can be understood as based on the principles presented by Sir Isaac Newton in *Principia Mathematica Philosophiae Naturalis* from 1686. In brief, an object stays in its present state until affected by an external force (Newton’s first law). The external force may be balanced by a counterforce. Newton defines ‘work’ as the amount of energy transformed when an object (with mass) is moved under the influence of a force. As a consequence, force can be discussed in terms of gears, e.g. a rotating axle altering the speed of rotation, torque and/or direction on another rotating axle. This can be achieved by means of, for instance, cog wheels and chain in bicycle gears. Another example is the use of a lever. The longer the lever, the longer way the lever has to be pressed in the appropriate direction, but the lesser is the force needed to press the lever. To use an assistive device or a tool is to make a lever longer. In this sense, tools and assistive devices are not separated.

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<sup>107</sup> Tsukamoto (2000)

<sup>108</sup> Beck, B. (1980) *Animal Tool Behavior: The Use and Manufacture of Tools by Animals*. New York: Garland STPM Press. Quoted in: Lestel & Grundman (1999)

<sup>109</sup> Rodenbeck (n.y.)

<sup>110</sup> Sjödal Hammarlund (2004)

## Assistive devices

For any assistive device, aesthetics and optimal design are important features, even though assistive devices have a “history of crudely fashioned devices”.<sup>111</sup> Assistive devices can be seen as both “tools assisting bodily function” and as a contributor to the “body/self as it is experienced and presented to others”.<sup>112</sup> This dual reality is due to being both an enabler – enabling participation in various contexts and occupations, and a disabler – as it is visible it may be perceived as a stigmatiser. As a result, these parallel experiences contradict each other.<sup>113</sup> Occupational therapists “play an important role in supporting the clients’ task of remoulding their occupational self image when prescribing assistive devices”.<sup>114</sup>

Sheldon (2004a) has argued that assistive technology is everything but neutral, as it “is created by the same oppressive society that turns those with impairments into disabled people”.<sup>115</sup> Furthermore, the common picture, as mediated through mass media, of the wheelchair as a symbol for the disability experience, may be criticised because it is not only inaccurate, but also “perpetuates widespread ignorance about the realities of impairment”.<sup>116</sup> This symbolism of the wheelchair is often used in many circumstances where ‘disability’ needs to be signalled, despite the fact, for instance, that only 4% of persons with disabilities in the UK use wheelchairs.<sup>117</sup> Previous research has highlighted the importance of informed users, for instance concerning the selection (and maintenance) of assistive devices as a way of reducing costs.<sup>118</sup> Furthermore, assistive devices have been shown to be of great use to a low cost, and contribute to increased quality of life and general health.<sup>119</sup> Cost-effectiveness studies concerning assistive devices are scarce, partly due to lack of definitions of assistive devices.<sup>120</sup> However, assistive devices can be defined as a product or device utilised by persons with disabilities, especially constructed or commonly available, that compensates the functional impairment.<sup>121</sup> Assistive devices are used in order to improve functioning performance, social interaction and autonomy.<sup>122</sup> In Sweden, the purpose of assistive devices has been described as enabling

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<sup>111</sup> Kyberd et al. (2001)

<sup>112</sup> Lupton & Seymour (2000)

<sup>113</sup> Lupton & Seymour (2000); Larsson Lund & Nygård (2003)

<sup>114</sup> Larsson Lund & Nygård (2003)

<sup>115</sup> Sheldon (2004a)

<sup>116</sup> Barnes (1992)

<sup>117</sup> Clark & Marsh (2002)

<sup>118</sup> Batavia & Hammer (1990); Efring (1999); DiGiovine et al. (2000a); Riemer-Reiss & Wacker (2000); Sheldon & Jacobs (2007a)

<sup>119</sup> Estreen (2005); Olsson (2006)

<sup>120</sup> Fuhrer (2007)

<sup>121</sup> Arnell (1999); Scherer (2002b); ISO 9999:2007 *Technical aids for disabled persons – Classification* (4<sup>th</sup> ed.)

<sup>122</sup> Ryan et al. (2006)

and enhancing a person's "engagement in activities and participation in society through bridging the discrepancy between the individual's abilities and the demands of the environment".<sup>123</sup>

Abandonment, or discontinuance, of a specific device can be defined as "a decision to discard an innovation after previously accepting it", and can exist in one of two forms: (1) replacement (to select an improved version of the device); or (2) disenchantment (rejection of a device due to dissatisfaction). Trialability concerns whether the user is given the opportunity of testing the device prior to making a decision of its value and has been emphasised as an important factor. When trialability is low, the presumptive user must rely on professional guidance concerning the selection of a device. This may imply problems when the professional does not have the knowledge or capability of assisting the presumptive user in making an informed decision.<sup>124</sup> However, persons with disabilities are often marginalised and socio-economically disadvantaged, thus also deprived of possible benefits of technology. The "dependence on others for the funding or maintenance of technological equipment can eradicate or reduce many of its benefits".<sup>125</sup>

Assistive devices do not have the capacity to compensate fully for impairment. In a society without impositions, misconceptions, oppression and prejudices based on bodily constitution or/and function, many items within the field of assistive technology would be rendered obsolete. However, as disability emanates from the incompatibility between person and environment, this can at least be "ameliorated by assistive technology in appropriate instances".<sup>126</sup>

## Useworthiness

Håkan Efring (1999) introduced the term "useworthiness" concerning what makes a specific device worth using or not. Efring's study concerned a robotic arm mounted on an electric wheelchair. He defines useworthiness as "the individual user's assessment of the extent to which the technology meets the user's high-priority needs".<sup>127</sup> A product may be very useworthy but low in usability when the product is complicated or difficult to use, but at the same time meets a high priority need for the user. On the other hand, that a product is used does not imply that the product is worth using, as the user may have no alternative but to use it. The same is true when the product does not fulfil the prioritised needs of the user. User motivation is a significant factor concerning useworthiness, as "a high degree of correspondence between possibilities and needs leads to high motivation and a desire to use the sys-

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<sup>123</sup> Larsson Lund & Nygård (2003)

<sup>124</sup> Riemer-Reiss & Wacker (2000)

<sup>125</sup> Lupton & Seymour (2000)

<sup>126</sup> Cooper (1998a, p. 366-7)

<sup>127</sup> Efring (1999, p. 25)

tem”.<sup>128</sup> The high priority needs involve two components: (1) the desired activity of the user; and (2) the capacity of the device in this activity.<sup>129</sup>

As seen here, it may be argued that the concept of useworthiness is applicable to more sectors than strictly devices, for instance the built environment and societal services. However, concerning research in the field of assistive devices, the concept of useworthiness is still not fully internalised, as, for instance, Samuelsson et al. (2001) discusses assistive devices use in terms of usability. The definition of usability is close to a possible application of useworthiness, as usability comprises the “effectiveness, efficiency and satisfaction” of a particular device.<sup>130</sup> Therefore, “the most advanced application of technology is not necessarily the same as the application of the most advanced technology”.<sup>131</sup>

## Active wheelchairs

The *raison d'être* of a wheelchair is to provide the independence of moving between locations.<sup>132</sup> In this capacity, wheelchairs are used for rather long durations of time, up to 16 hours per day, 365 days per year.<sup>133</sup> Wheelchair mobility can be defined as “the ability, in a self-propelled wheelchair, to move around and overcome obstacles encountered when carrying out daily activities or social roles”.<sup>134</sup> Wheelchairs, as well as assistive technology in general, are intended to support the health and psychosocial functioning of the user.<sup>135</sup>

Internationally, 22 ISO wheelchair standards are approved or under development addressing, for instance, durability, manoeuvrability, safety and transport. However, no standard exists concerning ride comfort.<sup>136</sup> The ISPO<sup>137</sup> Consensus Conference on Wheelchairs for Developing Countries, held in November 2006 in collaboration with, among others, WHO<sup>138</sup>, concluded that a wheelchair can be considered appropriate when it meets the needs of the user. Furthermore, “wheelchair users should be involved in all aspects of wheelchair provision”, as governments are “encouraged to

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<sup>128</sup> Efring (1999, p. 26)

<sup>129</sup> Efring (1999)

<sup>130</sup> Samuelsson et al. (2001)

<sup>131</sup> Childress (2002)

<sup>132</sup> Scherer & Glueckauf (2005); Watson & Woods (2005); Bergström & Samuelsson (2006)

<sup>133</sup> Cooper (1998a)

<sup>134</sup> Routhier et al. (2003)

<sup>135</sup> Scherer & Glueckauf (2005)

<sup>136</sup> Cooper et al. (1996b); Cooper (1998a); DiGiovine et al. (2000a); Sheldon & Jacobs (2007a, 2007b). ISO (International Organization for Standardization) ([www.iso.org](http://www.iso.org)) is an INGO started in 1947 with the purpose of developing and publishing international standards. ISO is seated in Geneva, Switzerland, with member organizations in a total of 157 states. ISO-standards includes the requirement of a wheelchair to withstand 200 000 double-drum cycles and 6 667 curb-drop drops, normally representative of three to five years of use. However, for an active user, it can take a shorter time to reach the calculated amount of strains (Cooper, 1998a).

<sup>137</sup> ISPO is the International Society for Prosthetics and Orthotics ([www.ispo.ws](http://www.ispo.ws)).

<sup>138</sup> WHO is the World Health Organization ([www.who.int](http://www.who.int)).

recognise the right of wheelchair users to choose their wheelchair". Therefore, "users' needs are best met when there is a variety of wheelchair models from which to choose".<sup>139</sup>

The wheelchair has been transformed during the 20<sup>th</sup> century from a cumbersome machine designed for the transportation of patients within hospitals, into today's powerful means of personal mobility.<sup>140</sup> In the 1970s, the lightweight rigid frame wheelchair made its entrance as a result of advances in wheelchair sports, thereafter possible to fit and adjust to individual specifications.<sup>141</sup> Main advances in wheelchair technology have been led by wheelchair users themselves; innovative users began to modify their wheelchairs and then went on to start companies.<sup>142</sup> In 1982, the first Swedish rigid frame wheelchair was introduced.<sup>143</sup> One example of the development of rigid frame wheelchairs since the 1970s is the reduced weight, from ca 16 kg to ca 7-8 kg today due to the introduction of lighter materials. Furthermore, the length has been reduced by ca 15 cm since the early 1980s.<sup>144</sup> Today's wheelchair market offers a range of wheelchair models and colours.<sup>145</sup>

When a person's wheelchair has failed, the user's ability to work, perform daily tasks and move independently is significantly reduced.<sup>146</sup> Thus, failure of a component is a limitation of the user's mobility.<sup>147</sup> To use a wheelchair beyond its planned span of life will result in poor performance and possible injuries.<sup>148</sup> Increased risk of accidents and injuries has been associated with the wheelchair being in disrepair.<sup>149</sup> Even though many wheelchair repairs can be performed by the users themselves,<sup>150</sup> a repair facility should be within the user's vicinity with parts readily available.<sup>151</sup> A Swedish study revealed that 99% of the inspected wheelchairs were in need of acute maintenance. It was concluded that "most wheelchair users are unable to determine on their own when adjustments are needed".<sup>152</sup>

Factors known to influence user attitudes include aesthetics, ease of propulsion, ease of transfer, fit, manoeuvrability, design, size, weight, manoeuvrability and port-

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<sup>139</sup> Sheldon & Jacobs (2007a)

<sup>140</sup> Cooper (1998a); Sapey et al. (2004); Watson & Woods (2004); Woods & Watson (2004, 2005)

<sup>141</sup> Kenward (1971); Kamenetz (1972); Curtis et al. (1995); Karp (1998); Boninger et al. (2000); Norsten (2001); Fröjd et al. (2007)

<sup>142</sup> Brubaker (1988); Cooper (1991, 1998a); Karp (1999); Högborg (2000); Norsten (2001); Corbet et al. (2002)

<sup>143</sup> Handikappinstitutet (1990)

<sup>144</sup> Hobson (1997); Cooper (1998b); Arnell (1999); Norsten (2001); Vogel (2002); Rogers et al. (2003)

<sup>145</sup> Cooper (1998a); Cooper & Cooper (2003)

<sup>146</sup> Cooper & Cooper (2003)

<sup>147</sup> Fay & Boninger (2002)

<sup>148</sup> Cooper (1998a); Cooper & Cooper (2003)

<sup>149</sup> Hansen et al. (2004). For instance defective brakes, frame, tires or wheels.

<sup>150</sup> Fitzgerald et al. (2005)

<sup>151</sup> Mayall & Desharnais (1995)

<sup>152</sup> Hansen et al. (2004). It may be noted that the study concerned all categories of manual wheelchairs.

ability.<sup>153</sup> A wheelchair that does not match the user's abilities, needs, preferences or environment will limit a user's functioning and ultimately cause accidents.<sup>154</sup> For wheelchair users, cosmetics, taste and self image become more important; aesthetics is a functional issue since a wheelchair is an extension of the self and a means of self-expression.<sup>155</sup>

One of the most important aspects of a wheelchair is the seat and cushion, both in terms of static and dynamic performance, distribution of pressure and prevention of pressure ulcers, contractures, increased spasticity, disturbed function of internal organs and impaired mobility. Ultimately, the wrong cushion decreases the user's independence.<sup>156</sup> Even though a width of possibilities exists, objective measurements of matching person, wheelchair and cushion, are not standardised.<sup>157</sup> By individually adjusted measures, back pain and discomfort related to wheelchair seating can be reduced, or even eliminated.<sup>158</sup> However, not even the best cushion is capable of absorbing all pressure; thus, a person using a wheelchair must sometimes relieve pressure, for instance by leaning sideways or forwards.<sup>159</sup> Wheelchair seating and wheelchair mobility are two areas that sometimes are difficult to combine in one wheelchair.<sup>160</sup> For a person with an active lifestyle and varied interests, two or more wheelchairs can be a solution.<sup>161</sup>

A potential problem of the constant strains resulting from wheelchair propulsion is pain and injuries in the wrist, for instance carpal tunnel syndrome.<sup>162</sup> Also, shoulder and neck problems are common among wheelchair users, both as a result of propulsion and from performing transfers in ways less optimised.<sup>163</sup> However, proper

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<sup>153</sup> Mayall & Desharnais (1995); Cooper et al. (1999a); DiGiovine et al. (2000a); Kittel et al. (2002); Rogers et al. (2003); Fitzgerald et al. (2005)

<sup>154</sup> DiMarco et al. (2003); Gavin-Dreschnack (2005)

<sup>155</sup> Batavia (1998); Cooper (1998a); Batavia et al. (2001)

<sup>156</sup> VanSickle et al. (1994, 2000, 2001); Tanimoto et al. (1998, 1999, 2000); Ferrarin et al. (2000); Aissaoui et al. (2001a, 2001b); Gutierrez et al. (2004); Hansen et al. (2004); Monro & Mulley (2004); Clark et al. (2006). Seating problems may increase with older age and longer duration of wheelchair use (Chen et al., 2005; Amsters & Nitz, 2006; Sprigle et al., 2007). Furthermore, a person's posture is affected by choice of cushion (Troy et al., 1997).

<sup>157</sup> May et al. (2003); Sprigle (2007b)

<sup>158</sup> Meiners et al. (2001); Samuelsson et al. (2001). The importance of individualised seating was emphasised as early as 1981 by Nelham (1981). According to Sprigle et al. (2001), more than 200 wheelchair cushion models are commercially available today, thus increasing the possibility of finding a cushion for a breadth of user demands. Several studies have tested different cushions, for instance Tanimoto et al. (1999), finding air-filled cushions giving an even pressure distribution, and Shaw (1998) testing the so called 'egg-crate cushion'.

<sup>159</sup> Gilsdorf et al. (1990, 1991)

<sup>160</sup> Samuelsson et al. (2001); Samuelsson et al. (2004)

<sup>161</sup> Mayall & Desharnais (1995)

<sup>162</sup> Boninger et al. (1996); Veeger et al. (1998); Fay et al. (1999a, 1999b); Koontz et al. (1999); Boninger et al. (2000); Shimada et al. (2001)

<sup>163</sup> Boninger et al. (2000); Veeger et al. (2002); Nawoczenski et al. (2003); Kirby et al. (2004c); Finley et al. (2005); van Drongelen et al. (2005a, 2005b). Furthermore, three-dimensional (3-D) kinematic



fitting of the wheelchair can improve the user's mode of propulsion, thus possibly reducing risks of pain and injury.<sup>164</sup> Shoulder problems may be more common among women than men, which points to the need for proper fitting.<sup>165</sup>

The main objective in prescription is to select a wheelchair that best allows the user to carry out daily activities and social roles.<sup>166</sup> Scherer et al. (2007) describes the desired outcome as a user satisfied with the device, who performs needed and desired activities and participates in a variety of roles and events in varied settings "where the lack of an appropriate device was a critical limiting factor for performance and participation".<sup>167</sup> A dilemma in prescription is a traditional view on users as patients, subject to expert assessment and prescription and not as people with a right to express preferences or allowed the possibility to choose.<sup>168</sup>

Wheelchair prescription requires knowledge in many areas, for instance mechanics, anatomy, physiology, kinesiology and technology. Moreover, knowledge concerning available products is needed due to the constant expansion of available products. It is vital to allow the user to try different models as a wheelchair is an extension of the user's unique body. However, the most important factor is the user's personal priorities.<sup>169</sup> As a prescriber you have to understand the client, i.e. "put yourself in the mind of the client".<sup>170</sup> However, even though the user relies on the prescribers, users must recognise that they are the ones who will bear the consequences.<sup>171</sup> In the US, approximately 30% of assistive devices are discarded within the first year.<sup>172</sup> The most important reason is lack of user involvement in selection.<sup>173</sup>

In Sweden, prescriptions of wheelchairs are a responsibility of mainly occupational therapists (OT), attending adjustments and repairs when needed, as well as providing information and assistance in maintenance, and documentation of the process and items prescribed.<sup>174</sup> Prescription of assistive devices in Sweden has been described as a five step process: (1) estimate the needs; (2) try out, adapt and choose a product; (3) possibly adapt the product; (4) instruct, train and inform; and (5)

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analysis has been proposed as a means to gain a further understanding of the forces involved (Davis et al., 1998).

<sup>164</sup> Boninger et al. (2000); Kirschblum et al. (2007). A proper fitted wheelchair combined with efficient training have been shown to further improve a user's mechanical efficiency, thus decreasing shoulder problems (de Groot et al., 2005b).

<sup>165</sup> Boninger et al. (2003)

<sup>166</sup> DiGiovine et al. (2000a); Routhier et al. (2003)

<sup>167</sup> Scherer et al. (2007)

<sup>168</sup> Sapey et al. (2004)

<sup>169</sup> Cooper (1991); Batavia (1998); Larsson & Samuelsson (1999); Batavia et al. (2001); Samuelsson et al. (2004)

<sup>170</sup> Mayall & Desharnais (1995, p. 21)

<sup>171</sup> Batavia et al. (2001)

<sup>172</sup> Scherer & Glueckau (2005). I have not been able to locate any statistics concerning the abandonment of prescribed wheelchairs in Sweden.

<sup>173</sup> Scherer (2002b)

<sup>174</sup> Hedberg-Kristensson & Iwarsson (2003); Hansen et al. (2004)

follow up and evaluate function and benefit.<sup>175</sup> However, a need for increased knowledge and developments concerning individual solutions in prescribing active wheelchairs in Sweden has been emphasised.<sup>176</sup> Although some users in Sweden may be dissatisfied, satisfaction may still be rated high on a general level.<sup>177</sup>

According to Routhier et al. (2003), improvements of wheelchair prescription procedures can involve development of an assessment tool considering: (1) the user's profile; (2) the wheelchair; (3) the environment; (4) the daily activities and social roles; and (5) the assessment and training received.<sup>178</sup> A recent review failed to identify any published standards concerning wheelchair prescription.<sup>179</sup> However, an example of a general model for the provision of assistive devices is the MPT-model, Matching Person and Technology.<sup>180</sup> The MPT-model utilises a form of checklist instrument in assessing a user's goals and preferences and uses this information when determining the potential benefit of a certain technology. It thereafter measures the impact of the technology for the user.<sup>181</sup> Focus in the prescription process is the individual as "a unique user of a particular device".<sup>182</sup> The MPT-model emphasises three reciprocal components: (1) user preferences; (2) critical features of the technology; and (3) environment and psychosocial setting in which the technology is used. These components may each contribute to user satisfaction.<sup>183</sup> Thus, each of the three components in the MPT can contribute to either a negative or a positive influence on a user's attitudes towards a wheelchair. The opportunity of supplying a user with a device supporting optimal use is reduced if there are too many negative influences. Ultimately, this can lead to abandonment and/or a severely affected quality of life, as "on average, one-third of assistive technologies are abandoned by their users".<sup>184</sup>

In the assessment process, evaluation of the effectiveness of a device and the impact of training over time must be integrated. The user needs a proper education in use and maintenance of the wheelchair.<sup>185</sup> Training of wheelchair skills is important,

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<sup>175</sup> Hjälpmedelsinstitutet (2006)

<sup>176</sup> Bergström & Samuelsson (2006)

<sup>177</sup> Brandt (2005)

<sup>178</sup> Routhier et al. (2003)

<sup>179</sup> DiMarco et al. (2003)

<sup>180</sup> Scherer & Cushman (2001); Scherer (2002a, 2002b); Scherer & Glueckauf (2005); Scherer et al. (2005). The MPT has been described as an ICF-focused assessment system, as the environmental dimension is stated as a parameter (Scherer & Glueckauf, 2005).

<sup>181</sup> Cooper (1998a)

<sup>182</sup> Scherer (2002a)

<sup>183</sup> Cooper (1998a); Scherer & Glueckauf (2005); Scherer et al. (2005)

<sup>184</sup> Scherer & Cushman (2001)

<sup>185</sup> Batavia (1998); Cooper (1998a); Samuelsson et al. (2001); Kittel et al. (2002); DiMarco et al. (2003)

as many activities in everyday life become easier to perform.<sup>186</sup> In this process, the importance of peer-to-peer support has been emphasised.<sup>187</sup>

## Prosthetic hands

What makes the human hand unique is the easy opposition of the thumb to the four other fingers.<sup>188</sup> The human hand has 22 degrees of freedom and a grip force exceeding 500N (age 20-25). The range of a joint is typically about 100° and each finger has a tapping frequency of about 4.5/second with a force of 1-4N. The total number of sensors exceeds 17 000 and provides a grasp stable against slip or external load.<sup>189</sup> The detailed motor function of the hand is controlled by memories and learnt ‘motor programs’, classifying objects in classes based on density, and adjust muscle power already before gripping an object.<sup>190</sup> A prosthetic hand can only partly replace function (e.g. myoelectric prostheses) and restore outer appearance (e.g. cosmetic prostheses).<sup>191</sup> Nevertheless, multiple attempts to construct prosthetic hands have been made throughout history. One difficulty in developing upper limb prostheses is the relatively small size of the field; manufacturers may not be so interested in this small market segment due to high costs and low profits.<sup>192</sup> However, one explanation for the continuing attempts to construct prosthetic hands can be that a prosthesis does not only consist of the pieces of wood, plastic, metal, leather or other materials joined together, as “it is also the very idea that you can *replace*”.<sup>193</sup>

A person with an acquired amputation of one hand can usually perform 90% of daily activities without (and the rest with) assistive devices or special arrangements.<sup>194</sup> Some persons with upper limb amputations have no need for prosthetics or other ‘treatment’, whereas other persons may require a substitute of some sort.<sup>195</sup> Myoelectric hands have been developed since the end of World War II.<sup>196</sup> In 1958, researchers in the Soviet Union built the world’s first EMG-controlled electric prosthetic hand for mid-forearm amputations.<sup>197</sup> The basic concept of a myoelectric hand is that the electric activity generated by a contracting muscle is amplified and

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<sup>186</sup> Coolen et al. (2004); Best et al. (2005); Kilkens et al. (2002, 2005a, 2005b, 2005c). One example of a concentrated training program is the Wheelchair Skills Training Program (WSTP) (Kirby et al., 2004a). Another example is the Wheelchair Circuit (Kilkens et al., 2004).

<sup>187</sup> Kittel et al. (2002)

<sup>188</sup> Kyberd & Pons (2003)

<sup>189</sup> Ridley (1997); Zecca (2003)

<sup>190</sup> Childress (1985); Olsson (1997)

<sup>191</sup> Zecca et al. (2003); Kargov et al. (2004); Yang et al. (2004)

<sup>192</sup> Childress (1973)

<sup>193</sup> Stiker (1999, p. 123-4, original emphasis)

<sup>194</sup> Davidson et al. (2002); Bhaskaranand et al. (2003)

<sup>195</sup> Lundborg (2004)

<sup>196</sup> Bottomley (1965); Silcox et al. (1993); Light & Chappell (2000); McLean & Scott (2004); Meier (2004)

<sup>197</sup> Bottomley (1965); Almström et al. (1981); Silcox et al. (1993)

used for the control of the flow of electricity from a battery to a motor, in turn moving the fingers of the hand.<sup>198</sup> Myoelectric control is normally achieved by means of one or two electrodes reading the EMG signals from antagonistic muscle groups. However, a prosthetic device may fail at any given time.<sup>199</sup>

Today, most myoelectric hands possess one degree of freedom, and utilise a high grip force to ensure stable prehension. In order to achieve more than one (or two) grip patterns, more than one or two degrees of freedom are required.<sup>200</sup> Lack of more than one degree of freedom has been mentioned as a cause of prosthesis abandonment.<sup>201</sup> User demands on prostheses include, for instance, improved cosmesis<sup>202</sup>, lower weight<sup>203</sup>, and better comfort during use and easy to put on (don) and take off (doff).<sup>204</sup> Other requirements include a design requiring less visual attention during operation, has prehension feedback and the possibility to execute several movements simultaneously.<sup>205</sup> The prosthesis should be perceived as a part of the natural body and replicate sensory-motor capabilities.<sup>206</sup> Kyberd et al. (1998a) emphasises durability, ease of cleaning, light weight, longevity of operation and suitability for driving motor vehicles.<sup>207</sup> Uellendahl et al. (2006) identifies comfort, function and appearance as the primary goals in upper limb prostheses fitting.<sup>208</sup> Reviewing user surveys, Poulton et al. (2003) conclude that a prosthesis that does not make life easier for the user is likely to be rejected. Therefore, a functional prosthesis must offer real advantages in order to be accepted before a cosmetic prosthesis.<sup>209</sup>

In Sweden, studies concerning persons with Thalidomide-induced limb deficiencies during the 1960s and 1970s revealed that upper limb prostheses may be more of a hindrance than actual assistive devices in most situations.<sup>210</sup> Except for being a hindrance during activities in everyday life, prosthetics may also affect a person's body image and self image negatively and be perceived as rough, solid and plastic foreign objects. One person interviewed by Paulsson (1995) even uses the term "instrument of torture".<sup>211</sup> Any given prosthesis has disadvantages as it is an encumbrance, a warm, constricting and sometimes uncomfortable device. Even though there are

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<sup>198</sup> McLean & Scott (2004)

<sup>199</sup> Shurr & Michael (2002)

<sup>200</sup> Light & Chappell (2000); Pylatiuk et al. (2004)

<sup>201</sup> Light & Chappell (2000)

<sup>202</sup> Herder et al. (1998); Kyberd et al. (1998a); da Cunha et al. (2000); Weir et al. (2001b); Pylatiuk et al. (2004)

<sup>203</sup> Carrozza et al. (2004); Pylatiuk et al. (2004)

<sup>204</sup> Herder et al. (1998); Shurr & Michael (2002)

<sup>205</sup> Dhillon et al. (2004); Farrell et al. (2005)

<sup>206</sup> Carozza et al. (2001, 2004); Kyberd et al. (2001); Marks & Michael (2001); Sebastini et al. (2003); Pons et al. (2004)

<sup>207</sup> Kyberd et al. (1998a)

<sup>208</sup> Uellendahl et al. (2006)

<sup>209</sup> Poulton et al. (2003). Compare, for instance, the cosmetic prosthesis with the contradiction in terms of a cosmetic wheelchair – an example of different perspectives on assistive devices.

<sup>210</sup> Paulsson (1995)

<sup>211</sup> Paulsson (1995, p. 136-7)

potential advantages, for instance concerning cosmesis and functional assistance, “only the individual can decide whether the advantages outweigh the disadvantages”.<sup>212</sup>

One example of a new approach to prosthetic design is a colourful terminal device (a non-anthropomorphic prosthetic hand), the WILMER prehensor. All mechanical parts are covered in a cosmetic cover available in almost any colour, highly appreciated among children. To use a brightly coloured prosthetic prehensor can be a clear statement of personal uniqueness, and the design can be the opposite of concealing one’s difference by wearing a cosmetic device.<sup>213</sup>

### Assistive devices provision in Sweden

The societal role of law is to regulate behaviour.<sup>214</sup> The objective of the health care system, of which assistive technology is a part, is that individuals with disability can be fully active members of society.<sup>215</sup> In Sweden, the parliament legislates, the government statutes and the authorities form provisions. Legislation, statutes and provisions are all legally binding. There is also a system of guiding documents, for instance common advice from authorities and the UN standard rules for persons with disabilities. The Swedish political system is based on strong and independent municipalities and counties.<sup>216</sup> Within their respective fields of responsibility, they are relatively free to decide upon taxes and the detailed content of specific services.

The Swedish Health and Medical Care Act<sup>217</sup> (HsL) is based on the obligation of the Medical Service System to supply the necessary medical care. This means that the patient has no right to demand a specific medical treatment; decisions based on HsL cannot be appealed. Instead, the medical care system is obligated to supply what it deems medically necessary. The HsL is a framework law, and regulations concerning the details are a responsibility for, among others, the National Board of Health and Welfare (*Socialstyrelsen*) and the Medical Products Agency (*Läkemedelsverket*).<sup>218</sup>

As a result of the handicap reform in 1994, full responsibility and some resources concerning provision of assistive devices were transferred to the municipalities after having been a county responsibility since 1862.<sup>219</sup> The specific content of the transfers of responsibility were made subject of local agreements. These agreements were not regulated in detail concerning the division of responsibility and the tax shift between the municipalities and the counties. As a result, the goals and content of the

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<sup>212</sup> Day (1990)

<sup>213</sup> Hilhorst (2004); Plettenburg (2006)

<sup>214</sup> Jones & Marks (2004)

<sup>215</sup> Brandt (2005)

<sup>216</sup> Sweden consists of 290 municipalities and 21 county councils.

<sup>217</sup> HsL: Hälso- och sjukvårdslagen, SFS 1983:763

<sup>218</sup> Rönnberg (2005)

<sup>219</sup> Blomquist & Nicolaou (2007). The matter is also discussed on an enclosed DVD.

municipal supply of assistive devices were neither discussed nor investigated concerning dimensioning, resources or responsibilities.<sup>220</sup> Thus, responsibilities may still be unclear. For instance, according to both anecdotal reports and a bachelor dissertation in Occupational Therapy<sup>221</sup>, one potential problem concerning electric wheelchairs is that the municipality is responsible for the drive line, and the county for the rest of the wheelchair. This may cause problems when something needs maintenance or repair.<sup>222</sup>

Assistive devices are not defined in the Swedish legislation. However, regulations exist on the matter of assistive devices provision. The handicap reform clarified the responsibility for the counties and municipalities to provide assistive devices required for the individual, alone or with the aid of another person, to manage for instance ambulation and function in the home and in the vicinity of the home, and to participate in normal leisure and recreation activities. Some, but not all, assistive devices are medical-technical devices. These are defined in the Law on Medicine Technical Products, LMTP (SFS 1993:584) as products defined by the manufacturer to be used to: (1) establish, prevent, supervise, treat or ease a disease (e.g. ventilators); (2) establish, supervise, treat, mitigate or compensate an injury or impairment (e.g. hearing aids and wheelchairs); and/or (3) examine, alter or replace anatomy or physiologic process (e.g. prostheses).<sup>223</sup> Thus, in Sweden wheelchairs and prostheses are seen as medical products<sup>224</sup>, and as such, treated as a part of the medical care system, thereby not separating disabilities from temporary medical conditions. Normally, municipalities are responsible for technical aids used in everyday life, such as active wheelchairs, whereas counties are responsible for prostheses, etc.<sup>225</sup>

Personnel qualifications concerning the prescription of assistive devices, together with the responsibility of following up on the devices and how they are used, is not regulated. Instead, there is a responsibility for the municipality or county to provide 'competent personnel' in order to supply 'good care'. Most commonly, occupational therapists, physiotherapists, district nurses, speech therapists and physicians are authorised, but other personnel categories may be included. Prescription is supposed to be based on the user's whole life situation, and the choice of product is to be made together with the user based on her/his individual demands. However, these formulations, 'as good as possible' and 'made together with the user' do not in any way imply that the user may choose a device. In practice, the prescriber decides, and the user has no formal right to complain. The availability of a certain device may differ depending on place of residence, and even though a specific device is available

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<sup>220</sup> Larsson et al. (1994)

<sup>221</sup> The bachelor dissertation: Nilsson, J. (2004) *Bråkarens delaktighet under förskrivningsprocessen av elrullstol*. Kandidatuppsats, Avd f Arbetsterapi, Lunds Universitet. The dissertation can be downloaded via <http://www.arb.lu.se/uppsatsdb/default.asp>

<sup>222</sup> Whether similar problems can also be found concerning other types of assistive devices remains unclear.

<sup>223</sup> Hedberg-Kristensson & Iwarsson (2003); Blomquist & Nicolaou (2007)

<sup>224</sup> I.e. as "medicintekniska produkter" (SFS 1983:763)

<sup>225</sup> Larsson et al. (1994); NSH (2003). However, differences may occur.

in theory (on a local list), it may prove impossible to obtain.<sup>226</sup> Due to the constant introduction of new products, it may be difficult for occupational therapists to keep up with the latest technology and products.<sup>227</sup> Cooperation and interaction between counties and municipalities regarding assistive devices assortment and potential fees are not regulated.<sup>228</sup> However, in a survey from 2003, the Swedish National Confederation of Persons with Disabilities (DHR) found that the supply of assistive devices was complicated due to decentralisation and widespread responsibilities, in turn making it difficult to find someone with an actual responsibility.<sup>229</sup> Only 35% of counties and municipalities report of any political discussion concerning assistive devices.<sup>230</sup>

A basic principle of the Swedish policy is that most devices are supposed to be supplied without charge or an economic needs test.<sup>231</sup> Nevertheless, Blomquist (2006) found an increase in fees and large variations regarding technical aids. These fees can vary between different parts of the same county, as well as between different counties. Some municipalities have chosen to include the fees for technical aids in the municipal purchase cost maximisation.<sup>232</sup> In 80% of the municipalities, no fees are involved in the prescription or supply of assistive devices.<sup>233</sup> A prescribed assistive device is still owned by the service provider (municipality or county) and borrowed by the user. Thus, the user is supposed to return the device when it is no longer needed.<sup>234</sup> Furthermore, when a user moves from one municipality to another, the device is supposed to be returned and another prescribed in the new municipality. Routines for these returns are specified in the Swedish Handicap Institute document "List of, and Routines for, Management and Invoice Concerning Assistive Devices in the Event of Moving between Counties and Municipalities within Assistive Devices Centrals, or Comparable".<sup>235</sup> This document contains specified regulations, for instance, rule no 3: *the county shall seek to attain that the user is not left without assistive devices*; and rule no 6: *assistive devices attached to the body (e.g. prostheses) are brought when moving over the county borders without payment due to the insignificant recycling value*.<sup>236</sup>

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<sup>226</sup> Paulsson & Winnberg-Lindqvist (1997); NSH (2003); Lindgren (2006); Svensson et al. (2007)

<sup>227</sup> Batavia (1998)

<sup>228</sup> NSH (2003); Svensson et al. (2007)

<sup>229</sup> Rörelsehinderförbundens hjälpmedelsprojekt (2003); De Handikappades Riksförbund ([www.dhr.se](http://www.dhr.se))

<sup>230</sup> Blomquist (2006)

<sup>231</sup> Lundgren-Lindqvist et al. (2001); Brandt (2005)

<sup>232</sup> Blomquist (2006)

<sup>233</sup> SOU 2004:83 Hjälpmedel

<sup>234</sup> Svensson et al. (2007)

<sup>235</sup> Hjälpmedelsinstitutet (2008) "Lista och rutiner för hantering och fakturering av hjälpmedel vid flytt mellan landsting och kommuner inom hjälpmedelscentralerna/motsvarande", dated 2008-02-26.

<sup>236</sup> Hjälpmedelsinstitutet (2008) Rule no 3: "Landstingen skall eftersträva att patienten/brukaren ej blir utan hjälpmedel". Rule no 6: "Kroppsburna hjälpmedel (proteser, etc.) medtages vid flytt över länsgränserna utan betalning eftersom hjälpmedlen har ringa återanvändningsvärde".

The Swedish Handicap Institute estimates that approximately 130 000 persons in Sweden utilise wheelchairs (manual and electric).<sup>237</sup> The number of wheelchairs sold in 2004/05 and reported to the Swedish Handicap Institute was 18 787. Of these, 1 579 were active wheelchairs. Not all wheelchairs sold in Sweden are reported; only wheelchairs prescribed within the public system are expected to be reported. Statistics from manufacturers concerning actual sales has proven difficult to obtain. Thereto, wheelchairs and rollators of other origin than through the regular channels, non-tested by the Swedish Handicap Institute, have been spotted for sale in hardware stores.<sup>238</sup>

In general, one impediment concerning wheelchair prescription is the budgetary system. A government-funded system may utilise standards resistant to changes regarding types and models possible to prescribe. The result is that new devices are approved only after an expensive and tedious process.<sup>239</sup> In Sweden, choices regarding the local selection of assistive devices are guided by recommendations by the Swedish Handicap Institute. One role of the Institute is to test and approve assistive devices, normally by commission of manufacturers.<sup>240</sup> Some tests, e.g. of manual wheelchairs, are accredited by SWEDAC, the Swedish Board for Accreditation and Conformity Assessment.<sup>241</sup> From the list of recommended models each municipality/county may establish a local list containing a selection of the models recommended. Concerning active wheelchairs, i.e. 12 22 03 AB<sup>242</sup>, 17 models from five distributors/manufacturers are included in the list of recommendations.<sup>243</sup> The local lists tend to contain fewer models due to, for instance, economic reasons.<sup>244</sup> However, no legal hindrances have been located regarding prescription of non-approved models. The Swedish Handicap Institute approval may therefore serve other purposes, e.g. as a marketing argument.<sup>245</sup> Comparing the Swedish and Danish markets for active wheelchairs, the Danish equivalent of the Swedish Handicap Institute, the Danish Centre for Assistive Technology (*Dansk Hjaelpemiddels Instituttet*), has a list

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<sup>237</sup> Hjälpmedelsinstitutet (2006)

<sup>238</sup> The chain of hardware stores in question (Harald Nyborg) have been advertising wheelchairs both in printed material and in their internet store ([www.harald-nyborg.se](http://www.harald-nyborg.se)). Whether these devices are actually assistive devices or not, seen from a regulatory point of view, remains unclear.

<sup>239</sup> Brubaker (1988); Rogers et al. (2003)

<sup>240</sup> NSH (2003); Hellberg (2004); Rönnerberg (2005); Blomquist (2006)

<sup>241</sup> SWEDAC is the organization in Sweden responsible for contacts with ISO.

<sup>242</sup> The ISO classification code, where 12 means mobility assistive devices, 22 means manual wheelchairs, 03 means manual rear wheel drive wheelchairs, and AB is a Swedish national category implying active wheelchairs. The categories are somewhat changed in the 4<sup>th</sup> edition from March 2007 (Hjälpmedelsinstitutet Webb-HIDA).

<sup>243</sup> Some of the 17 models are also available in, for instance, short models or with alternative angle of the front part of the frame. In the Webb-HIDA (<http://80.80.24.87/>), these are counted as two models.

<sup>244</sup> Wressle & Samuelsson (2004)

<sup>245</sup> Handbok för hälso- och sjukvård (2004)



of 43 models from 15 distributors/manufacturers, as compared to the Swedish HI list of 17 models from five distributors/manufacturers.<sup>246</sup>

When a citizen is in contact with a civil servant, e.g. a prescriber of active wheelchairs, the meeting can be described as asymmetric, i.e. not on equal terms. The most obvious difference is that the civil servant is there in a professional role, and the citizen is there as her-/himself. The meeting is not a voluntary activity, as the bureaucracy has a monopoly of social service, and the citizen is dependant on the result. Furthermore, a citizen is connected to a certain office due to place of living, and not allowed to visit any other office.<sup>247</sup> Previous studies have shown relatively high levels of dissatisfaction with societal services in general.<sup>248</sup> Although the social security system in Sweden has allocated significant resources, the “present state of affairs often creates frustration and disappointment on the part of the disabled person”, for instance due to the complexity of the service delivery system with insufficient information and co-ordination.<sup>249</sup> Förhammar (2004) concludes that Swedish disability politics cannot be described as consistent, and that persons with disabilities and their organisations have had a rather small influence when it comes to shaping Swedish disability politics.<sup>250</sup>

## Disability and assistive devices in everyday life

Everyday is “a series of ‘methodic appearances’ through which ‘doing being ordinary’ is mundanely, methodically and reflexively accomplished”.<sup>251</sup> Everyday life is not only banal, but also so mundane that it can be described as the essence, yet beneath the radar of domination and power relations.<sup>252</sup> Everyday life is profoundly related to all social relations and activities, the lived experience of multidimensional social fields of practice, i.e. daily occurrences where social relations are (re-)produced, and activities performed or desisted from. Everyday life takes its shape and form in the sum total of all relations and activities that make the person a whole.<sup>253</sup> Everydayness can be defined as “experiences that appear to be firmly em-

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<sup>246</sup> The Danish equivalent of 12 22 03 AB is 12 22 03-04 (Dansk Hjaelpemiddels Institutet, [www.hmi.dk](http://www.hmi.dk) and Hjaelpemiddelbasen, [www.hmi-basen.dk](http://www.hmi-basen.dk)). In Denmark, this category includes individually manufactured wheelchairs, i.e. custom made for a specific user much in the same way as a prosthesis is individually fitted. This category of wheelchairs is absent in the Swedish list. In comparison, Sweden has a population of approximately 9.2 millions, and Denmark 5.4 millions (Nordiska Rådet, i.e. Nordic Council of Ministers, [www.norden.org](http://www.norden.org)).

<sup>247</sup> Hall (2001); Krantz & Larsson (2003)

<sup>248</sup> Hetzler (1994)

<sup>249</sup> Nordgren et al. (2003)

<sup>250</sup> Förhammar (2004)

<sup>251</sup> Sandywell (2004)

<sup>252</sup> Shields (2002)

<sup>253</sup> Burkitt (2004)

bedded in the known rituals of practical life separated from the open realm of events and temporal flux”.<sup>254</sup> Everydayness is the usual and the commonplace normal run of things, experiences of what happens in its most typical form today the same way as yesterday and most often also tomorrow, i.e. “the positive continuity of endless repetition”.<sup>255</sup> In this study, everyday life is separated from the concept of ADL (Activities of Daily Living), as the latter is more of an instrument possible to use for clinical evaluation concerning, for instance, a person’s capacity to manage certain activities.<sup>256</sup>

In everyday life, the use of assistive devices may allow a person to acquire a higher degree of independence. However, the use of assistive devices is also known to affect the attitudes from others during interaction. Therefore, in the following, the use of assistive devices will be discussed from two perspectives, namely a functional perspective and a social perspective. The functional perspective of assistive devices consists of a biologically based understanding of how a person with a disability can achieve activities beyond the capacity of her or his body by means of applying a device to lengthen the personal capacity to the degree normally considered in range of a person without disability.

## Stigmatisation

To have a disability and to use an assistive device may be experienced as a stigma, defined by Erving Goffman (1990a) as “an attribute, either physical or psychological, that makes a person different from others and therefore less desirable”.<sup>257</sup> Zygmunt Bauman (2007) concludes that “an unfit body breaks and defies the rule that is promoted as universally binding and presented as amenable to all who try hard enough, and is felt therefore to be not only dysfunctional, but also aesthetically offensive”.<sup>258</sup>

Goffman (1990a) proposes three main types of stigmas: (1) abominations of the body; (2) blemishes of character; and (3) tribal stigmas. Abominations of the body concerns physical deformities or marks, e.g. facial deformities or physical disabilities. Blemishes of character concern personality traits, e.g. criminals, liars or other negative traits. Tribal stigma refers to having an ethnic or minority group background. Stigmatisation implies a devalued social identity in a specific context. However, some stigmatising attributes are so powerful that they become the master status, the core identifying personal attribute.<sup>259</sup> A person with a stigmatising attribute may be: (1) discredited (easily noticeable attribute, attempt to manage tensions involved in social interactions); or (2) discreditable (concealable attribute, strive to control expo-

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<sup>254</sup> Sandywell (2004)

<sup>255</sup> Sandywell (2004)

<sup>256</sup> Hulter Åsberg (1990)

<sup>257</sup> Goffman (1990a)

<sup>258</sup> Bauman (2007)

<sup>259</sup> Goffman (1990a); Yang et al. (2007)

sure).<sup>260</sup> There is a difference between a stigma and a stereotype, insofar as a stereotype can be either favourable or unfavourable, whereas a stigma is always unfavourable.<sup>261</sup>

To be labelled as stigmatised or deviant can mean that a person becomes more observant of other people's reactions. This may contribute to the development of a situation consciousness, leading to the assessment of self in advance regarding the impression that is made in various contexts.<sup>262</sup> Deviants can be seen as the exception that proves the rule, i.e. provides the possibility for 'normal' persons to define the common identity. Thus, deviations are extremely valuable when establishing distinctions by which the concept of 'us and them' is understood.<sup>263</sup> One argument against the notion of a fixed signifier, e.g. as deviant, is the constant reiteration of norms in society and stigmatisation as a discursive construction.<sup>264</sup>

A stigma emerges from the discrepancy between the virtual social identity (i.e. how a person is characterised by society) and actual social identity (the actual attribute possessed).<sup>265</sup> A person's identity as stigmatised is constructed through affective, behavioural and cognitive processes – each focusing on social or situational determinants of stigmatisation.<sup>266</sup> This is the 'moral career', i.e. when an individual internalises the general standpoints, thus gaining knowledge of particular stigmas and their respective effects. When a particular attribute emerges, e.g. illness, a person moves from a normal to a discreditable status, and if their illness is revealed in a wholly different context, their contextual status shifts to discredited. Transition from discreditable to discredited depends on control of identity information.<sup>267</sup> Therefore, "stigma occurs as a new social identity is assumed through interaction (i.e. 're-identifying') with socially constructed categories"; stigmatisation is both a social and a subjective process since a stigma can be both social and relational in nature.<sup>268</sup>

Stigma can be enacted or experienced. Enacted stigma are episodes of stigmatisations that have occurred in the past, whereas experienced stigma refers to the feeling of shame emanating from a potential stigma and the fear of being exposed to future (enacted) stigmatisation.<sup>269</sup> Experienced stigma may cause greater suffering and more anxiety than enacted stigma,<sup>270</sup> and can be referred to as "felt stigma".<sup>271</sup> Stigma con-

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<sup>260</sup> Taub et al. (2004)

<sup>261</sup> McLaughlin et al. (2004)

<sup>262</sup> Åsbring & Närvänen (2002)

<sup>263</sup> Duedahl (2005)

<sup>264</sup> Shildrik & Price (1996)

<sup>265</sup> Goffman (1990a)

<sup>266</sup> Yang et al. (2007)

<sup>267</sup> Goffman (1990a)

<sup>268</sup> Yang et al. (2007)

<sup>269</sup> Scambler (1984); Green et al. (2007); Luoma et al. (2007)

<sup>270</sup> Åsbring & Närvänen (2002)

<sup>271</sup> Gray (2002); Green et al. (2007)

sciousness is grounded early in life and concerns the individual's expectance of being stereotyped.<sup>272</sup>

Self-stigma, also referred to as 'internalised stigma', is the negative feelings and thoughts emerging from identifying oneself with a group of similarly stigmatised persons.<sup>273</sup> Stigma can increase stress, uncertainty and vigilance. In a further perspective, stigmatisation can lead to intellectual underperformance.<sup>274</sup> Stigmatised persons have been found to monitor social interactions more vigilantly, and recall more details about the interaction than others.<sup>275</sup> There are differences between (1) being born with a stigma (origin outside individual control), and (2) obtaining a stigma later in life (somewhat individually controllable origin).<sup>276</sup>

Phantom acceptance is when a person lives in the belief that she or he has a greater personal acceptance of a stigma than what is really the case. If the phantom acceptance is confronted, this can lead to an attitudinal crisis, i.e. the interactant has no idea of how to react.<sup>277</sup> For instance, persons with stigmas are often encouraged to achieve a 'good adjustment', i.e. to accept their new selves as they are, but still withhold from situations or activities where non-stigmatised persons could feel uncomfortable in their presence. One function fulfilled by phantom acceptance is to protect the non-stigmatised while the stigmatised obtains the idea that they are accepted. This provides a basis for 'phantom normalcy'.<sup>278</sup>

Minor bodily stigmas can be defined as "small physical imperfections that make us fear we stand out and might be rejected", and although evident to others, they are rarely severe enough to interrupt social interaction or become the focus of attention. Nevertheless, the stigma bearer may emphasise its existence and thereby produce anxiety and distress. However, an attribute that one person perceives as a minor bodily stigma may by another person be seen as a major stigma.<sup>279</sup> To manage a minor stigma can be experienced as more urgent during changes in a social context due to the perceived need to control information. The latter may include both how to conceal and how to reveal.<sup>280</sup> Minor bodily stigmas are a part of everyday life, but something interactants feel unsure about how to relate to. This may increase the double shame for the holder of a minor bodily stigma, i.e. not only feeling shame for the stigma *per se*, but also feeling shame for feeling shame because of such a rather trivial blemish.<sup>281</sup>

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<sup>272</sup> Pinel (1999); Pinel (2002); Brown & Pinel (2003)

<sup>273</sup> Herek (2007); Luoma et al. (2007)

<sup>274</sup> Inzlicht et al. (2006)

<sup>275</sup> Shih (2004)

<sup>276</sup> Oswald (2001)

<sup>277</sup> Kaufman & Johnson (2004)

<sup>278</sup> Goffman (1990a)

<sup>279</sup> Ellis (1998)

<sup>280</sup> Sutherland (1982); Iphofen (1990)

<sup>281</sup> Ellis (1998)

## *Disability and stigmatisation*

In discussions concerning language and disability, issues are based on the discrimination in everyday life experienced by persons with disabilities.<sup>282</sup> Language tends to reflect attitudes and stereotypes.<sup>283</sup> Among persons with disabilities, the term “disabled” has been discussed, and a common complaint has been that no alternative terms have been found that, at least, describe disability neutrally.<sup>284</sup> This discussion is present also in other languages, „der Begriff ‚Behinderung‘ beinhaltet weiterhin ein großes Stigma”.<sup>285</sup>

Feelings of stigmatisation are influenced by the perceived commonality of the particular stigma.<sup>286</sup> Uncertainty and uneasiness concerning attitudes among others toward the disability, rather than the experiences gained, have been found to constitute problems for persons with disabilities. Thus, the uncertainty constitutes an additional disability on top of the one already possessed by the person.<sup>287</sup> However, the social meaning of disability depends very little on the degree of functional loss or limitation, as the ways in which disabilities are socially constructed have been shown to primarily depend on perceptions generated, sustained or changed in everyday life.<sup>288</sup>

For a person with a disability, the impairment is more or less pervasive in different situations, but still constitutes a basic condition of life.<sup>289</sup> It is a daily task to relate to starrng and other attitudes enhancing the perceived stigma; the disability is likely to be the most obvious external characteristic.<sup>290</sup> However, to stare can be a result of an interactant being taken by surprise by the presence of a disability, and although starrng is considered socially rude, a conflict can emerge between the desire to stare and to avoid starrng, resulting in discomfort. This discomfort can then be avoided by avoiding the evocation of this stickiness, i.e. the person with a disability.<sup>291</sup>

The public perceptions of disability include the belief that persons with disabilities live in a constant tragedy, have a negative self image and that their experiences of life are negative.<sup>292</sup> Persons with disabilities are oppressed by “the imperative to ‘overcome’ in some superhuman fashion in order to be afforded basic acknowledgement”.<sup>293</sup>

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<sup>282</sup> Barnes (1993)

<sup>283</sup> Lipson & Rogers (2000)

<sup>284</sup> Longmore (1985)

<sup>285</sup> Steadward (2000)

<sup>286</sup> Lipson & Rogers (2000)

<sup>287</sup> Viemerö & Krause (1998)

<sup>288</sup> Susman (1994)

<sup>289</sup> Peterson et al. (2006)

<sup>290</sup> Goffman (1990a); Lenney & Sercombe (2002); Taleporos & McCabe (2002); Peterson (2006)

<sup>291</sup> Lenney & Sercombe (2002)

<sup>292</sup> Peterson et al. (2006)

<sup>293</sup> Swartz & Watermeyer (2008)

There is a difference between being disabled from birth and acquiring a disability later in life, insofar as persons belonging to the latter group are deprived of functions previously had and forced to adapt to life on new terms.<sup>294</sup> For a person with a disability, the fact that others may have difficulties in separating the person from the disability might mean that he or she is treated as someone totally disabled.<sup>295</sup> When transitioning from non-disabled to disabled, communication patterns and relationships with the non-disabled majority are altered. New communication strategies involve patterns of impression management designed to facilitate seeing persons with disabilities as ‘persons first’, i.e. pointing to the contextual irrelevance of the disabled status. A person with a disability may have to struggle to be seen as normal, to have the disability be part of normality, i.e. as an insignificant part of oneself.<sup>296</sup>

The group of persons using wheelchairs is only one of many sub-groups within the whole population of persons with disabilities. Despite this, wheelchairs have become the very symbol of the idea of disability.<sup>297</sup> A person using a wheelchair for ambulation can in many cases be ignored and/or avoided, and invisible and/or ‘othered’, i.e. defined as disabled and wheelchair-bound. However, for a person who, for instance, uses a wheelchair for longer distances but has the ability to walk a few meters, the question of disabled or not disabled may prove contextually problematic when transgressing boundaries, i.e. leaves an interactant in a situation where taken-for-granted definitions and distinctions are collapsed.<sup>298</sup>

From a historical point of view, disability has been seen as a static state of existence based on illness and/or injury.<sup>299</sup> Persons with disabilities have been closed out from the public space, i.e. some citizens are more expected in the public environment than others.<sup>300</sup> Persons using wheelchairs face embarrassing contingencies due to the physical environment being unfriendly to this type of mobility.<sup>301</sup> A recent study from the UK showed that 61% of wheelchair users feel disabled due to the way in which public places are designed.<sup>302</sup> When measuring participation among persons using wheelchairs, measures need to be device-specific and reflect the impact of use of various types of mobility devices.<sup>303</sup>

Wheelchair users can sometimes be treated as open persons in some contexts, i.e. possible to address at will.<sup>304</sup> Thereby, persons using assistive devices are othered in much the same way as, for example, celebrities, persons whose private lives can be read about in special magazines. Users of assistive devices may be concerned that

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<sup>294</sup> Braithwaite (1990); Peterson et al. (2006)

<sup>295</sup> Peterson et al. (2006)

<sup>296</sup> Braithwaite (1990); Watson (2002)

<sup>297</sup> LaPlante (2003)

<sup>298</sup> Shildrik & Price (1996)

<sup>299</sup> Meyers et al. (2002)

<sup>300</sup> Peterson et al. (2006)

<sup>301</sup> Cahill & Egglestone (1994)

<sup>302</sup> Bromley (2007)

<sup>303</sup> Harris (2007)

<sup>304</sup> Cahill & Egglestone (1995)

interactants can view them as inferior as a result of assistive devices. These experiences reflect the interactants' understanding of a person using an assistive device as based on a medical understanding of normality. In order to protect the self from these prejudices, users may attempt to conceal dependency, difficulties and limitations, and even withdraw from certain activities.<sup>305</sup>

According to Cooper (1998), a person defines her/his own disability, i.e. the personal definition of what it means to have a disability differs from person to person.<sup>306</sup> To adapt to using a wheelchair in everyday life implies not only a physical adaptation, but also an emotional adaptation of one's self image to include the wheelchair.<sup>307</sup> As a device, "the wheelchair has, for most of its history, been a design that segregated instead of integrated", thus implying the struggle among wheelchair users to be identified based on their personal identity and not on the ascribed meaning of an assistive device.<sup>308</sup>

Assistive devices can leave their user in a form of stickiness, since assistive devices on one hand signal the failure of the body and the departure from the world of the able-bodied and over to another form of existence. On the other hand, assistive devices may prove to be the only way of getting out of bed and into the world, and, ultimately, as devices restoring the possibility to lead an active life, i.e. as devices turning inability into ability and creating mobility out of immobility.<sup>309</sup>

For a person with an artificial limb, it may be difficult to 'come out' or 'open up' to another person since it is impossible to predict the reaction of the other person: "once they get over the fact of the limb and they take it, you either accept or reject them depending on that".<sup>310</sup> A given prosthesis may represent a restoration of independence and embody ability for one person, whereas for another person (or the same person at another time) the same prosthesis may represent disability. Thus, the personal construction of a prosthesis is not only individual, but also situational/contextual.<sup>311</sup> Females have been found to rate prosthetic appearance as the most important concern after comfort.<sup>312</sup> Prosthesis use does play a social role, and the ability to conceal enable users to avoid stigmatisation. Concealing provides a possibility to establish oneself contextually, without the construction of self based on the non-existing limb.<sup>313</sup> Concealing may be more difficult for women than for men due to societal images of perfection.<sup>314</sup> A prosthesis can be central in the presentation

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<sup>305</sup> Larsson Lund & Nygård (2003)

<sup>306</sup> Cooper (1998a)

<sup>307</sup> Larsson Lund & Nygård (2003)

<sup>308</sup> Cooper (1998a)

<sup>309</sup> Wilson (2005)

<sup>310</sup> Gallagher & MacLachlan (2001)

<sup>311</sup> Gallagher (2004)

<sup>312</sup> Nielsen et al. (1989)

<sup>313</sup> Murray (2005)

<sup>314</sup> Winchell (1996a)

of self to others, insofar as the same person can react differently to the person with the prosthesis depending on whether the prosthesis is worn or not.<sup>315</sup>

Prosthetic embodiment is when a prosthesis becomes an incorporated part of the user.<sup>316</sup> ‘Psychoprosthetics’ are psychological factors in the adaptation to a prosthetic device, and the prosthetically enhanced body is constituted by the body and the attached prosthetic device.<sup>317</sup>

Both men and women with physical disabilities experience discrimination and prejudice. However, women with physical disabilities encounter more interpersonal barriers than men with comparable physical disabilities.<sup>318</sup> In a study concerning women with disabilities in Sweden, it was stressed that they are doubly disabled, both by being women and by having a disability.<sup>319</sup> Women with disabilities face more disadvantages than men with disabilities,<sup>320</sup> as “disabled women are either attractive in spite of their impairment or unattractive because of their impairment”.<sup>321</sup> In research concerning disability, gender and personal experiences among women with disabilities has been a neglected issue. Furthermore, men with disabilities have been considered representative for the disabled population.<sup>322</sup> In general, women are more often than men judged by appearances. Combined with a physical disability, this can lead to self-doubt, shame and lower self-esteem<sup>323</sup>, i.e. women are not only forced to cope with societal images of perfection, but are also stigmatised because of their disabilities. One example may be the repelling effect of assistive devices on the male ideal of female flawlessness.<sup>324</sup>

### *Socialisation to stigmatisation*

According to Barron (1997), women growing up with physical disabilities may see their bodies as not ‘up to scratch’. From an early age, they are implicitly told that their bodies need to be repaired by means of habilitation and training with the purpose of gaining more ‘normal’ body functions. Thus, when the need for training is stressed, the argument is normalisation of a body in need of repair.<sup>325</sup>

Among younger persons with disabilities, the amount of required assistance does not appear to be linked with autonomy in everyday life.<sup>326</sup> When children’s stigma consciousness levels get higher, they may become more likely to confirm stereotypes

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<sup>315</sup> Murray (2005)

<sup>316</sup> Gallagher (2004)

<sup>317</sup> Gallagher (2004); Murray (2005)

<sup>318</sup> Taub et al. (2004)

<sup>319</sup> Harris & Wideman (1988); Helmius (2001); Taub et al. (2004); Thomas (2006)

<sup>320</sup> Fine & Asch (1988); Barron (1997a, b); Crawford & Ostrove (2003); Harjunen (2004); Magnus (2004); Reinikainen (2004); Zitzelsberger (2005); Strahan et al. (2006); Thomas (2006)

<sup>321</sup> Morris (2001)

<sup>322</sup> Barron (1997b); Thomas (1999)

<sup>323</sup> Barron (1997a); Taub et al. (2004)

<sup>324</sup> Fine & Asch (1988)

<sup>325</sup> Barron (1997a)

<sup>326</sup> Barron (1997b)



about their group.<sup>327</sup> Persons perceived as belonging to a stigmatised group can encounter situations where anything they say or do may in fact confirm negative group stereotypes. This stereotype threat refers to a fear of being reduced to merely a stereotype. Stigma is in itself ego depleting, and when coping with a specific stigma, the coping process may in fact weaken a person's ability to regulate and control behaviour in areas not related to the stigma.<sup>328</sup>

Young persons with disabilities do not have the same possibilities or choices as their non-disabled peers, for instance due to diminished access to cultural and consumption activities.<sup>329</sup> In one study, Skär (2003) found that adolescents with physical disabilities had no or very few relationships with friends of the same age without disabilities. Relationships to adults were described as ambivalent or asymmetric, as "adults were simultaneously helpful and supportive while over protective and dominant".<sup>330</sup>

A Swedish study showed that children with mobility disabilities were less satisfied with their relationships with friends at school than children without disabilities. Furthermore, children with mobility disabilities were less popular among other children and had a lower capability of taking social initiatives.<sup>331</sup> The social division of children with disabilities affects their self image insofar as human needs of companionship and being confirmed as a person may be unsatisfactory fulfilled. Lack of confirmation can lead to inhibited behaviour, low self-confidence, and feelings of despondency.<sup>332</sup> Most important for these children were the same things as for all children has, namely to feel closeness and security etc. It was not as important to look normal in the sense of looking like everyone else by means of prostheses etc. The struggle to make children look normal was the struggle of the adults, not of the children themselves.<sup>333</sup>

Compared with persons with disabilities in general, women whose disabling condition emerged during adolescence may be more vulnerable to negative body image self-appraisal.<sup>334</sup> The date of onset of a physical disability in a person's life is significant in influencing the representation of self, as the earlier the onset, the more likely are expressions of a specific 'disability identity'.<sup>335</sup> Many persons with congenital or early onset disabilities are not primarily socialised within mainstream culture, due to having been cut off from this culture.<sup>336</sup>

A physical disability is not just a practical inconvenience, but also a social and emotional barrier leading to more or less obvious alienation. Especially during ado-

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<sup>327</sup> Pinel (1999); Zimbardo (2007)

<sup>328</sup> Inzlicht et al. (2006)

<sup>329</sup> Hughes et al. (2005a)

<sup>330</sup> Skär (2003)

<sup>331</sup> Nylén (2004). This corroborates earlier findings, e.g. Jarkman (1996).

<sup>332</sup> Peterson et al. (2006)

<sup>333</sup> Paulsson (1995); Peterson et al. (2006)

<sup>334</sup> Ben-Tovim & Walker (1995)

<sup>335</sup> Ville et al. (1994)

<sup>336</sup> Lipson & Rogers (2000)

lescence, this becomes increasingly clear for the young person with a physical disability.<sup>337</sup> Congenital or early onset disabilities may affect sexual development, as lack of privacy and means of being independent in everyday life can imply a lack of normal sexual experiences.<sup>338</sup> However, existing research has emphasised a view of children with disabilities as passive and dependent by employing an individual model of disability. By doing so, the experiences of the children themselves have been excluded from research.<sup>339</sup> This exclusion has later been addressed by Connors & Stalker (2007), who found that children aged 7 to 15 experience disability in four ways in terms of: (1) impairment; (2) difference; (3) other persons' behaviour towards them; and (4) material barriers.<sup>340</sup>

### Body image and self image

The presence of a visible physical disability influences the impressions other form of a person. These impressions have a tendency to extend beyond the disability and to include social characteristics and personality.<sup>341</sup> A physical disability is likely to have a negative impact on a person's body image and body esteem, as persons with disabilities face more negative feedback due to being physically different and have lower levels of social inclusion.<sup>342</sup>

The relation between the body and the self has been discussed by, for instance, René Descartes, who emphasised the duality of body and mind, i.e. that the mind exists only in time and is present in every part of the body, whereas the body exists in both time and space and is divisible. Thus, as Descartes puts it: "Although the whole mind seems to be united to the whole body, nevertheless, were a foot or an arm or any other bodily part amputated, I know that nothing would be taken away from the mind", and, to be a 'self' is to be distinguished from the other.<sup>343</sup> Furthermore, what is closest to ourselves is sometimes what scares us the most, i.e. threatens our distinctions.<sup>344</sup>

Body image can be defined as "that picture or scheme of our own body which we form in our minds".<sup>345</sup> Today, body image is thought of as a wider concept than when first described in neurological terms, i.e. perception of limb position in space and movement.<sup>346</sup> The term 'body image' refers to the perceptions a person has of

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<sup>337</sup> Peterson et al. (2006)

<sup>338</sup> Glass & Soni (1999)

<sup>339</sup> Morris (1997); Priestly (1998)

<sup>340</sup> Connors & Stalker (2007)

<sup>341</sup> Gething (1992)

<sup>342</sup> Rybarczyk et al. (1995); Taleporos & McCabe (2001); Gannon & Nolan (2007). Body esteem is the overall evaluation, positive or negative, of one's body and bodily appearance (Taleporos & McCabe, 2001).

<sup>343</sup> Garber (1998, 2003) quoting Descartes.

<sup>344</sup> Shildrik (1999). Distinctions understood based on Bourdieu (1984).

<sup>345</sup> Schilder (1950)

<sup>346</sup> Yuen & Hanson (2002)

her/his body.<sup>347</sup> Body image is a multifaceted psychological experience a person has of her/his physical appearance, i.e. the perceptions of, and attitudes towards, self, including behaviours, feelings, beliefs and thoughts.<sup>348</sup> Body image is a dynamic construction.<sup>349</sup> As such, the concept of body image is not limited to the actual looks, but also contains how a person thinks she/he looks; the mental picture of one's physical self. The situational impact of body image is comprised of two dimensions, the first being the personal importance of body image, and the second the degree of personal satisfaction with one's body image.<sup>350</sup>

Any visible bodily difference can have a profound impact on a psychological level for the person concerned. An acquired difference in one's bodily construction, e.g. a non-congenital disability, changes the appearance, integrity and functioning of the body and sets up a series of psychosocial, emotional and perceptual reactions, and ultimately the loss of self-identity, thus altering the body image and psychosocial well-being.<sup>351</sup> However, after an initial period after the onset of disability, the person adjusts and gets a more positive body image.<sup>352</sup> Dissatisfaction with one's body image can interfere with daily functioning, and lead to depression, negative self-esteem, social introversion and anxiety.<sup>353</sup> Self-esteem reflects the cognitive appraisal of competence regarding areas deemed important.<sup>354</sup> Body image can include the concept of stigma and exclusionary social ideals and norms.<sup>355</sup>

Body image is related to how a person with a disability has integrated the behavioural aspects of the disability into his or her total life pattern, not only regarding the physical loss, but also the loss of self-identity. An acquired disability is hereby seen as affecting a person's body image. However, the more subjective experiences are often more psychologically powerful than the more objective ones. After having acquired a disability, and being faced with the problem of regenerating ones body image, the regenerating process is often referred to as coping mechanisms. More precisely, these are strategies used by a person in order to manage thoughts and feelings associated with threats or challenges to the body image.<sup>356</sup> Persons with disabilities encounter numerous biased attitudes among people without disabilities, and their bodies are subjected to the values of a society that looks at them as less valuable and as inferior to those considered to uphold the embodiment of normality.<sup>357</sup>

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<sup>347</sup> Breakey (1997b)

<sup>348</sup> Winchell (1996a, b); Flannery & Faria (1999); Cash (2004); Pruzinsky & Cash (2004); Rudiger et al. (2007)

<sup>349</sup> Ramachandran (1998); Flannery & Faria (1999); Desmond & MacLachlan (2002); Rudiger et al. (2007); van den Berg & Thompson (2007)

<sup>350</sup> Sarwer & Crerand (2004); Rieves & Cash (1996)

<sup>351</sup> Flannery & Faria (1999); Yuen & Hanson (2002); Cash (2004); Rumsey & Harcourt (2004)

<sup>352</sup> Frank (1988); Taleporos & McCabe (2002)

<sup>353</sup> Sands & Wettenhall (2000)

<sup>354</sup> Rubenfeld et al. (1988)

<sup>355</sup> Taleporos & McCabe (2002)

<sup>356</sup> Breakey (1997b); Yuen & Hanson (2002); Cash (2004); Melnyk et al. (2004); Rumsey & Harcourt (2004)

<sup>357</sup> Rybarczyk et al. (1995); Winchell (1996a); Winchell (1996b); Edwards & Imrie (2003)

A person with limb loss may have different body images, one when wearing a prosthesis and another one when not, and altered when wearing different types of prosthetic devices.<sup>358</sup> A person's body image is not limited to the person and the body, but can be extended and include external objects such as a wheelchair or a prosthesis, i.e. embodiment (defined as the physical expression of an abstract idea).<sup>359</sup> Any given prosthesis may for one user embody disability and prohibition of certain functions and roles, and for another embody ability in terms of enablement of certain physical functions and social roles.<sup>360</sup> Hence, whether the cause of the limb loss is congenital or acquired, using a prosthesis is something that requires both a physical (re-)adjustment and a psychological acceptance<sup>361</sup>.

Having a negative body image may affect women more than men, for instance their perceived sexual attractiveness.<sup>362</sup> It has been shown that men with disabilities have a greater tendency than women with disabilities to engage in affective and sexual experiences.<sup>363</sup> Body image may be influenced by traditional gender roles.<sup>364</sup> However, when comparing levels of body image satisfaction among female wheelchair athletes and female athletes, no significant differences were found.<sup>365</sup>

## Handling stigmatisation

There are mainly three processes for handling stigma described in earlier research: (1) compensation; (2) strategic interpretations of the social environment; and (3) focusing on multiple identities. Shih (2004) suggests coping and empowerment to account for the consequences of adopting one, two or three of these strategies in order to handle a stigma: "A coping model predicts that overcoming stigma is a draining process, while an empowerment model proposes that overcoming stigma is an energising and empowering experience". However, the perspective of empowerment as a form of stigma-handling strategy has not been emphasised in earlier research to the same extent as coping.<sup>366</sup> Thus, stigma may be understood not only as a burden, but also as something to gain strength and learn valuable life lessons from when confronting adversities caused by stigma and stigmatisation, i.e. as an empowering factor.<sup>367</sup>

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<sup>358</sup> Winchell (1996a, b); Breakey (1997a)

<sup>359</sup> Featherstone & Turner (1995); Winchell (1996a, b); Breakey (1997b); Flannery & Faria (1999); Yuen & Hanson (2002); Price (2006)

<sup>360</sup> Desmond & MacLachlan (2002)

<sup>361</sup> Pillet & Didierjean-Pillet (2001)

<sup>362</sup> Ben-Tovim & Walker (1995); Rieves & Cash (1996). However, an emerging disability may affect both men and women in these matters (Ide, 2004).

<sup>363</sup> Rodarte & Muñoz (2004)

<sup>364</sup> Flannery & Faria (1999)

<sup>365</sup> Sands & Wettenhall (2000)

<sup>366</sup> Shih (2004)

<sup>367</sup> Goffman (1990a); Shih (2004); Oyserman & Swim (2001)

When a person with an invisible stigma enters a context known to be negative towards the stigma, the person may alter actions and manners in order to not be outed as stigmatised. This mechanism can be referred to as “role-flexing”.<sup>368</sup> To camouflage is to adapt in a situation, i.e. the specific ways chosen to adapt may vary between situations.<sup>369</sup> Passing can protect privacy, to not be seen as an open person, to shield oneself from the sometimes invasive curiosity of the ‘normals’, from embarrassment and concern. Thus, concealing can be seen as “a means of not disrupting the flow of the moment and not attracting undue attention to self”.<sup>370</sup>

Feelings of guilt derived from attempts to manage stigma by means of concealment and social withdrawal can be directly related to fear and deception. However, withdrawal and concealing can transform a concealed stigma into one manifested through disruption of social interaction. This may develop into a negative, self-amplified mechanism, as increased despair can lead to further isolation.<sup>371</sup>

Discreditable persons can experience anxiety about exposure to enacted stigma. This can exist in two forms: (1) being exposed to too much consideration from other people; and (2) being socially excluded.<sup>372</sup> Ways of managing stigmatising reactions from others includes deflection and normalisation. Deflection is the attempt to shift focus from the stigma. Normalisation is the attempt to lessen undesirable effects.<sup>373</sup> One way of emphasising one’s autonomy as a person with a disability, is advocacy, i.e. emphasising a stigmatised status and opposing negative treatment.<sup>374</sup>

### *Coping*

Previous research in stigma-coping has concerned a variety of groups considered stigmatised, e.g. African-Americans,<sup>375</sup> African-American gay and bisexual men,<sup>376</sup> persons with Cervical dystonia,<sup>377</sup> co-workers with disabilities (e.g. AIDS, cerebral palsy and stroke),<sup>378</sup> persons with epilepsy,<sup>379</sup> gays and lesbians,<sup>380</sup> HIV-related stigma,<sup>381</sup> women with hysterectomy,<sup>382</sup> persons involved in on-line close relation-

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<sup>368</sup> Della et al. (2002)

<sup>369</sup> Hansson (2006)

<sup>370</sup> Lingsom (2008)

<sup>371</sup> Letkemann (2002)

<sup>372</sup> Åsbring & Närvänen (2002)

<sup>373</sup> Goffman (1990a); Taub et al. (2004)

<sup>374</sup> Ville et al. (1994); Taub et al. (2004); Peterson et al. (2006)

<sup>375</sup> Clark et al. (1999); Mallet (2003)

<sup>376</sup> Della et al. (2002)

<sup>377</sup> Ben-Shlomo et al. (2002)

<sup>378</sup> McLaughlin et al. (2004)

<sup>379</sup> Suurmeijer et al. (2001)

<sup>380</sup> Kaufman & Johnson (2004)

<sup>381</sup> Pryor et al. (1999)

<sup>382</sup> Elson (2003)

ships,<sup>383</sup> male college students with physical disabilities,<sup>384</sup> persons with obesity,<sup>385</sup> older caregivers,<sup>386</sup> persons with spasmodic torticollis<sup>387</sup> and stress<sup>388</sup>.

Coping is the constantly changing behavioural and cognitive efforts and activities undertaken to manage, master, tolerate, reduce or minimise external (environmental) and/or internal (intrapsychic) demands perceived to represent potential threats, existing harm or losses, appraised as taxing or exceeding the resources of the person. Coping is the thoughts and behaviours that people use to manage the internal and external demands of situations that are appraised as stressful,<sup>389</sup> i.e. situations where internal and/or environmental demands tax or exceed the individual's adaptive resources and can consist of interrelated variables and processes rather than one isolated variable possible to measure and correlate with an outcome of a specific strategy.<sup>390</sup> Coping can be: (1) problem-focused or behavioural (taking action and addressing the cause); and (2) emotion-focused or cognitive (addressing the emotions and mental strategies).<sup>391</sup> The nomenclature of problem-focused and emotion-focused coping may be complemented with meaning-focused coping (cognitive strategies utilised to manage a stressful situation) and a social dimension (seeking social support).<sup>392</sup>

Two sets of goals are proposed in the coping process, i.e. lower-order goals serving the purpose of achieving the higher order goals. One example may be a higher order goal, e.g. to preserve one's identity (passing as normal, i.e. a strategic goal), and lower order goals as means to achieve it, (concealing a stigma, i.e. a tactic goal).<sup>393</sup> Coping efforts, or functions, can complement each other and be exercised proactively and/or reactively.<sup>394</sup> Proactive coping consists of five stages: (1) resource accumulation, (2) recognition of potential stressors, (3) initial appraisal, (4) preliminary coping efforts, and (5) elicitation and use of feedback concerning initial efforts undertaken.<sup>395</sup>

The engagement coping response predicts better adjustment than disengagement coping strategies. Engagement coping can be divided into primary and secondary strategies. Primal control coping, or active coping, may include an attempt to directly change a stressful situation by means of, for instance, problem solving, emo-

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<sup>383</sup> Wildermuth (2001)

<sup>384</sup> Taub et al. (1999)

<sup>385</sup> Mallet (2003); Puhl & Brownell (2003)

<sup>386</sup> Kristensson Ekwall et al. (2007)

<sup>387</sup> Caldwell (2001)

<sup>388</sup> Latack & Havlovic (1992); Livneh et al. (1996)

<sup>389</sup> Folkman & Lazarus (1980); Lazarus & Folkman (1984); Folkman och Lazarus (1985); Compas et al. (2001); Folkman & Moskowitz (2004)

<sup>390</sup> Lazarus & Folkman (1984); Folkman & Lazarus (1985); Lazarus et al. (1985); Folkman & Moskowitz (2004)

<sup>391</sup> Folkman & Lazarus (1980); Folkman & Moskowitz (2004)

<sup>392</sup> Folkman & Moskowitz (2004)

<sup>393</sup> Lazarus (1991); Lazarus (2006)

<sup>394</sup> Lazarus (1991); Mallet (2003); Newby-Clark (2004); Lazarus (2006)

<sup>395</sup> Aspinwall & Taylor (1997)

tional expression and emotional regulation. Secondary control strategies may include an adaptation to the current situation by means of, for instance, distraction, acceptance and positive thinking.<sup>396</sup>

A person's coping skills repertoire (pre-defined set of tactical dispositions), is a dynamic construction based on previous experiences.<sup>397</sup> Any given form of coping may be effective in one context but ineffective in another.<sup>398</sup> Functions changing over time and contexts can be regarded as a process, relatively stable functions as a trait or a style.<sup>399</sup> The way a person copes with a particular stressor has an effect on the emotions that the person experiences.<sup>400</sup> Women and men use different coping strategies due to differing internalised dispositions.<sup>401</sup> Women with disabilities have been found to use spirituality and active use of technology as coping strategies.<sup>402</sup> Personal traits may affect a person's choice of coping strategy. For instance, optimists tend to adopt active coping strategies, whereas pessimists tend to adopt passive strategies. In general, pessimists experience higher stress levels than optimists.<sup>403</sup> A person constructs relational meaning from the relationship between the person and the environment based on the amalgamation of appraised personal goals, resources and beliefs about the self and the world, and the social and physical environment.<sup>404</sup> Emotional intelligence has been shown to function as a coping resource.<sup>405</sup>

A specific form of coping is body image coping and consists of three strategies: (1) avoidance; (2) appearance fixing; and (3) positive rational acceptance. The latter is considered the most adaptive coping strategy and can be for instance empowerment via peer-to-peer networks.<sup>406</sup> Avoidance can be either social (entire contexts, e.g. public places) or situational.<sup>407</sup>

For a stigmatised person, a vast array of responses is at hand towards the stressor.<sup>408</sup> Responses can include, but are not limited to, emotional, cognitive, biological and behavioural responses.<sup>409</sup> Persons coping do not respond in only one way; often several ways are tried and feedback on each and everyone is constantly evaluated.<sup>410</sup> Furthermore, the same person may use different responses based on the specific stressor and situation.<sup>411</sup>

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<sup>396</sup> Connor-Smith & Compas (2004)

<sup>397</sup> Chia & Holt (2006)

<sup>398</sup> Lazarus & Folkman (1984)

<sup>399</sup> Lazarus (2006)

<sup>400</sup> Folkman & Lazarus (1988)

<sup>401</sup> Puhl & Brownell (2003); Chia & Holt (2006)

<sup>402</sup> Banks (2003)

<sup>403</sup> Iwanaga et al. (2004)

<sup>404</sup> Lazarus (2000)

<sup>405</sup> Saklofske et al. (2007)

<sup>406</sup> Kaufman & Johnson (2004); Melnyk et al. (2004); Shih (2004)

<sup>407</sup> Letkemann (2002)

<sup>408</sup> Goffman (1990a)

<sup>409</sup> Miller & Kaiser (2001)

<sup>410</sup> Lazarus & Folkman (1984)

<sup>411</sup> Miller & Kaiser (2001)

For a person with a stigma, prejudice and discrimination are specific sources of stress not perceived by persons without the specific stigma. Apart from being exposed to stigmatisation, a stigma (being discreditable) can also lead to stress based on the ambiguity of whether an event including negative attitudes is based on the stigma itself, or something else. Thus, a stigmatised person may be exposed to the double stress of not knowing if the stress was discriminatory or not.<sup>412</sup> Also, other persons may question whether a stressful event was in fact based on prejudice or discrimination, thus diminishing the experience and devaluing the person stigmatised.<sup>413</sup>

According to one review, the religious/spiritual dimension of coping is unclear, as some studies showed positive results, others showed non-significant results, and yet others showed negative results, whereas one study even found religious coping to be a disadvantage.<sup>414</sup>

Among persons with traumatic upper limb amputations, coping styles may be predictors of psychosocial well-being; avoidance showed a strong association with psychological distress and low levels of adjustment.<sup>415</sup> The loss of a body part and the death of a loved person bear many similarities regarding the perceived grief caused by the loss.<sup>416</sup> In a study of coping after transfemoral amputation among younger persons in Sweden, informants did not feel prepared for exposure to people staring and asking intimate questions.<sup>417</sup> Ways of coping influence the amount and form of phantom limb pain experienced by amputees.<sup>418</sup> Especially, catastrophising has been emphasised as a negative coping strategy.<sup>419</sup>

Among persons with spinal cord injuries, there is a relationship between quality of life and coping strategy, as acceptance and social reliance are connected with higher quality of life.<sup>420</sup> Persons indicating internal control reported acceptance and fighting spirit coping strategies resulting in increased well-being, whereas external control and a social reliance coping strategy was related to poorer well-being.<sup>421</sup> Another study found downward contrast (forming a positive response vs. others worse-off) and upward identification (forming a positive response vs. others better-off) to be frequent, and downward identification and upward contrast less frequent, the latter related to depression.<sup>422</sup>

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<sup>412</sup> Miller & Kaiser (2001)

<sup>413</sup> Clark et al. (1999)

<sup>414</sup> Thuné-Boyle et al. (2006)

<sup>415</sup> Desmond (2007)

<sup>416</sup> Maguire & Parkes (1998)

<sup>417</sup> Sjö Dahl et al. (2004)

<sup>418</sup> Hill et al. (1995)

<sup>419</sup> Jensen et al. (2002); Whyte & Carroll (2004)

<sup>420</sup> Elfström et al. (2005)

<sup>421</sup> Elfström & Kreuter (2006)

<sup>422</sup> Buunki et al. (2006)



## *Empowerment and agency*

Empowerment is a multi-dimensional social process that assists persons in gaining control of their lives and gives them the capacity to implement issues perceived as important.<sup>423</sup> ‘Multi-dimensional’ implies an occurrence on various levels, e.g. person, group and community. ‘Social’ implies the occurrence in relation to others. ‘Process’ implies that development occurs as a person works her/his way through life.<sup>424</sup> Empowerment can give voice to personal and/or collective dissatisfactions with, for instance, societal support concerning assistive devices. Dissatisfactions can be associated with social exclusion, invisibility and lack of power concerning one’s destiny.<sup>425</sup> Empowerment is linked to the concepts of self-efficacy and locus of control and often accompanied by a commitment to challenge injustice and oppression.<sup>426</sup> However, the concept of empowerment has been criticised for being used as a synonym for ‘enabling’ – empowerment must be accompanied “by a commitment to challenging and combating injustice and oppression”.<sup>427</sup>

‘Agency’ is the capacity to act in ways not determined by social structures, i.e. a situated process where an individual simultaneously reflects on past, present and future implications of possible actions.<sup>428</sup> Agency has been used as a core concept in theories of human practice, i.e. theories seeking to explain the development of patterns of action and behaviour in social contexts. Thus, agency and context are intertwined, although not conjoined, matters.<sup>429</sup> Applying the dramaturgic perspective of Goffman (1990b), context can be described as the stage, and agency as the dynamic script of the actor/agent.

Agency is the result of internalised symbolic structures rather than solely an element of anticipation in interaction.<sup>430</sup> In the words of Chu & Robey (2008), “the basic appeal of agency is the restoration of concepts such as free will, rational choice, and praxis to social theory”, thus, ultimately, the power to act in a way not solely predetermined by interactional factors, but on the basis of personal values, ideology and past experiences, i.e. practice based on being a thinking human being; the interactional outcome of *cogito ergo sum*.

One of the “most influential contributors to an understanding of practice”<sup>431</sup> is Pierre Bourdieu. According to Bourdieu, practice is based on the logics of habitus. Habitus can be described as the internalised social experiences, memories and pat-

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<sup>423</sup> Baistow (1994); Herrenkohl et al. (1999); Page & Czuba (1999); Summerson Carr (2003)

<sup>424</sup> Page & Czuba (1999)

<sup>425</sup> Baistow (1994)

<sup>426</sup> Ward & Mullender (1991); Patton (1997); Breeding (2008)

<sup>427</sup> Ward & Mullender (1991)

<sup>428</sup> Chu & Robey (2008)

<sup>429</sup> Dryden & Still (2007)

<sup>430</sup> Bryant & Schofield (2007)

<sup>431</sup> Chu & Robey (2008)

terns of behaviour that are consciously or unconsciously embedded in a human being. Habitus is shaped by previous experiences, and guides actions and behaviours.<sup>432</sup>

So, how are agency and empowerment related? Both concern the execution of control over one's life, as agency is the internalised capacity to act in a way not contextually determined, and empowerment is a process supporting the gaining of control. Thus, it can be argued that empowerment is the process of strengthening one's habitus, whereas agency can be the contextual externalisation of empowerment.

One specific form of stigma management is empowerment via peer-to-peer networks, i.e. with persons exposed to similar stigmatisation.<sup>433</sup> This is found in a variety of stigmatised groups, e.g. women with chronic fatigue syndrome and/or fibromyalgia,<sup>434</sup> African-American gay and bisexual men,<sup>435</sup> persons with facial disfigurement,<sup>436</sup> epilepsy,<sup>437</sup> obesity,<sup>438</sup> and Phantom Limb Pain (PLP) after amputations.<sup>439</sup>

Peer-to-peer support can offer a field where information can be shared among peers, where matters of collective importance for persons exposed to similar stigmatisation can be openly discussed, and where support can be gained from others in the same situation. This field can be regarded as a type of private sphere, which can in turn be seen as a back region.<sup>440</sup> Thus, it may be hypothesised that the concepts of peer-to-peer support and a back region are connected insofar as the back region represents the context and peer-to-peer support the exercised agency therein. Manns & Chad (2001) give an example of this in a study concerning persons with paraplegia and quadriplegia. If a bladder or bowel accident occurs, no explanations or excuses are needed, and the lack of need thereof has been described as creating a 'comfort zone'.<sup>441</sup>

Another arena emphasised in previous research as important for empowerment among persons with disabilities is disability sports.<sup>442</sup> In a study concerning females with disabilities taking part in sports, it was found that sports can serve as a means of gaining a more positive body image, as well as a means of empowerment in other areas of life.<sup>443</sup>

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<sup>432</sup> Bourdieu (1984, 1991, 1992); Broady (1989); Källström (1994)

<sup>433</sup> Nielsen et al. (1989); Nielsen (1991); Legro et al. (1999); Kerr & McIntosh (2000); Compas et al. (2001); Gallagher & MacLachlan (2001); Miller & Kaiser (2001); Kaufman & Johnson (2004); Shih (2004); Veith et al. (2006)

<sup>434</sup> Åsbring & Närvänen (2002)

<sup>435</sup> Della et al. (2002)

<sup>436</sup> Robinson et al. (1996)

<sup>437</sup> Suurmeijer et al. (2001)

<sup>438</sup> Puhl & Brownell (2003)

<sup>439</sup> Mortimer et al. (2002)

<sup>440</sup> Goffman (1990a, b); Della et al. (2002); Åsbring & Närvänen (2002); Kaufman & Johnson (2004)

<sup>441</sup> Manns & Chad (2001)

<sup>442</sup> Taub et al. (1999); Banta (2001); Page et al. (2001); Berger (2004); Wickman (2008)

<sup>443</sup> Sands & Wettenhall (2000)

## Occupations – the *raison d'être* of assistive devices?

Everyday life is the field, to use a term from Bourdieu, where meaning is created and re-created, and activities are performed or desisted from, i.e. the core arena of human life. One model highlighting the perspective of occupations in everyday life is the Value and Meaning in Human Occupations (ValMO) model.<sup>444</sup> Persson et al. (2001) propose “a tentative structure for describing occupation, allowing for analysis in a lifelong panorama as well as for the immediate experience a person acquires from performing a single occupation”. In the following, this tentative structure will be described.<sup>445</sup>

An occupation consists of a person performing a task in an environment. Occupational value is a prerequisite for meaning and consists of three dimensions: (1) concrete value; (2) symbolic value; and (3) self-reward value. Concrete value is the dimension concerning concrete and visible aspects of occupational value, characterised by tangible outcomes in the form of a product that “brings satisfaction to the doer through, improved or newly acquired capacities and skills, as well as the avoidance of negative consequences”.<sup>446</sup> Symbolic value is the dimension concerning less obvious values (compared to concrete value) that are of symbolic importance. Symbolic value consists of three interacting levels: (1) personal level (specific for each person, based on her/his unique experience and background); (2) cultural level (specific for each (sub-)culture, e.g. the Western cultural hemisphere or philatelists); and (3) universal level (where similar symbolically loaded occupations are performed in different cultures, e.g. dancing and performing rituals).<sup>447</sup> Self-reward value is the dimension concerning the immediate rewards gained from the experience of an occupation, “in a self-reward occupation the person chooses to perform an occupation because he or she simply enjoys doing it”.<sup>448</sup> When concentrated, an occupation can be a Flow experience, regarded as fruitful in itself.<sup>449</sup> Self-reward value may, however, also include non-Flow states, for instance philosophising while soaking in a bath.

This triad structure – concrete, symbolic and self-reward value – can be seen from separate but interacting perspectives: macro, meso and micro. A macro perspective consists of a life course level of the structure of values, and can be described

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<sup>444</sup> Persson et al. (2001); Erlandsson & Persson (2005)

<sup>445</sup> If not otherwise stated, the description of ValMO is based on Persson et al. (2001). Furthermore, the term ‘activity’ is used in a broad sense (i.e. ‘activity’ can imply ‘occupation’), whereas the term ‘occupation’ is used solely when referring to a ValMO specific definition, for instance concerning occupational categories.

<sup>446</sup> Persson et al. (2001)

<sup>447</sup> The personal level is, in my understanding, related to Bourdieu’s concept of habitus (Bourdieu, 1984, 1991, 1992). Both are based on a person’s unique experiences and background, and consist of everything that the person has experienced in every situation so far, thoughts, ideals, etc., i.e. every aspect of what makes a human being specific.

<sup>448</sup> Persson et al. (2001)

<sup>449</sup> Csikszentmihályi (2004)

as consisting of four occupational categories: (1) maintenance; (2) work; (3) play; and (4) recreation, in short: M, W, P and R, respectively. A fifth category is sleep (S), although not considered an occupation *per se*. The meso perspective consists of the single occupation contained in a one day occupational pattern, whereas the micro perspective consists of the single occupations' actions and operations.

The triad of concrete, symbolic and self-reward value can be described as the hub of all occupational performance, and "continuously creates a personal and unique repertoire of occupations, dynamically changing through the life course".<sup>450</sup> This occupational repertoire consists of the above mentioned categories M, W, P, R (and S). Maintenance occupations are the basic occupations of preserving oneself, for instance eating, travelling, making lunch and paying the bills. They can be described as the foundation of existence, thus providing the ability to take part in other occupations, i.e. everyday activities. Work occupations are production-focused, performed in order to support one's existence, for instance generating wages. Another example can be education as a means of qualifying for work. Play occupations are occupations that, *per se*, are experienced as joyful and satisfying. They allow persons to transcend everyday roles, as well as use their imagination in everyday existence. Recreational occupations are not obligations or duties, as they are performed because persons like to perform them. They differ from play occupations insofar as being more relaxing, allowing the person to just be, for instance philosophising in a hammock a hot summer's day. Sleep is not considered an occupation in the ValMO model, as it is an unconscious process that cannot be directed or influenced, and a prerequisite for other occupations. A single occupation may belong to any of the four categories based on its ascribed value.

In every occupation, seemingly pertaining to one of the four categories, elements from the other categories may reveal themselves, for instance, elements of play within a maintenance occupation. Thus, the occupational value outcome of the categories of occupations is not pre-determined, as "they may vary from person to person, from situation to situation, as well as from time to time".<sup>451</sup>

From a life-course (macro) perspective, each individual creates a unique individual life course. From a macro-perspective, meaning is constructed, discovered or created from life-experiences. Everything a person achieves (or chooses to desist from), contributes to the shaping of the person's self-concept and identity. In turn, a person's identity "determines the meaning attached to an occupation".<sup>452</sup> From a meso-perspective, smaller sections of the person's life-course repertoire are focused and can, theoretically, be sliced out of the life-course repertoire. The meso-level can be seen as consisting of two levels. The first is the thin section of life being pulled out, representing a specific time-span, for instance a day. The second is the level of a single occupation of the occupational repertoire, for instance going to a café with a friend after work, discussing plans for the weekend. From a micro-perspective, two

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<sup>450</sup> Persson et al. (2001)

<sup>451</sup> Persson et al. (2001)

<sup>452</sup> Persson et al. (2001)

sub-levels are found. The first level is an *action*, for instance having a cup of coffee, whereas the second section are the *operations* of an action, for instance gripping the cup of coffee in order to lift it to the mouth.

All occupations are individually meaningful as long as they are coherent with a person's occupational continuity. It is the interaction between macro, meso and micro perspectives that ultimately determines an occupation's meaningfulness.

The ValMO model could provide a theoretical framework for understanding the structure and value of everyday life including use of assistive devices, for instance upper limb prostheses and wheelchairs, which will be exemplified in the discussion section below.

# Aims

The overall aim of this thesis is to discuss the personal and interactional meaning of disability and assistive devices in everyday life. The specific aims are:

- To present prescriber-perspective data and analyse prescribers' experience of factors influencing the prescription of active wheelchairs. (Study I)
- To describe experiences and aspects of importance in relation to active wheelchair provision among experienced users in Sweden. (Study II)
- To develop a grounded theory regarding stigma-handling strategies used in everyday life by women aged 20 to 30 with dysmelia (transversal upper limb reduction deficiency). (Study III)

# Methods and materials

## Context

The research was carried out in Sweden. Study I comprised a specific population in a predefined context, whereas studies II and III were not dependent on the geographical location of the interviewees within Sweden. The population in study I consisted of 1 992 persons from seven counties<sup>453</sup>: Jönköping, Västra Götaland, Örebro and Östergötland (located in the central parts of Sweden), Norrbotten and Västerbotten (located in northern Sweden), and Skåne (located in southern Sweden). These seven counties encompass 149 municipalities, chosen in order to ensure comprehensive variation in all nine categories within the classification of municipalities proposed by the Swedish Association of Local Authorities and Regions. This classification is based on structural parameters, for instance, number of inhabitants, economic structure and degree of urbanisation. The number of municipalities within each category were calculated for both the sample utilised in this study and the total number of municipalities. The deviations within each of the nine categories comparing the selection and the total were between -4 and +3 percentage points. The sample included 51% of the municipalities (149 of 290), and consisted of 47% of the Swedish population (4 252 312 of 9 103 551). This is shown in table 2, and figure 1 (below).

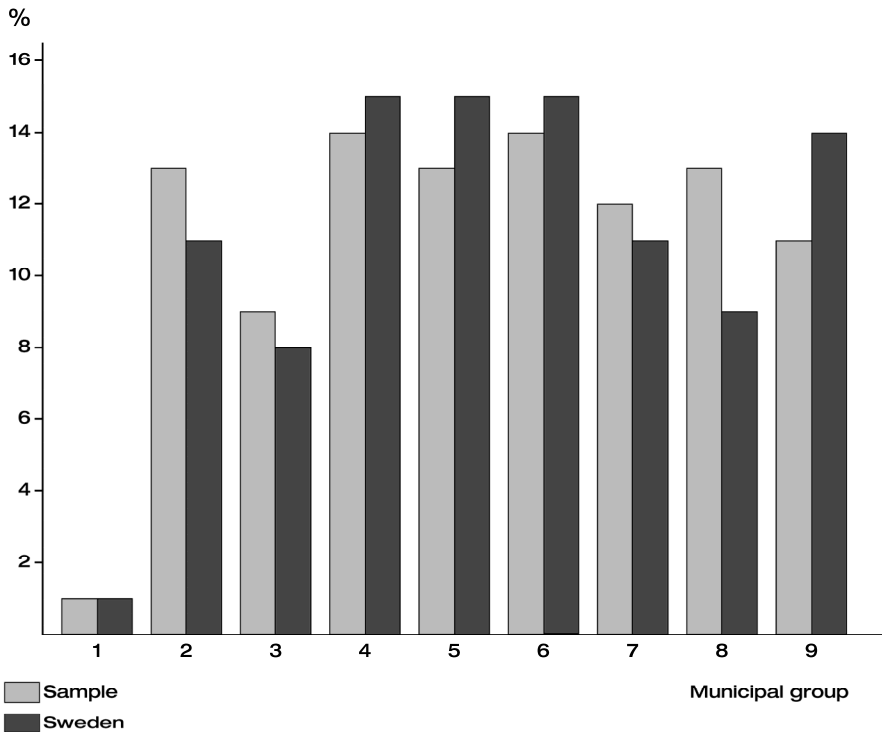
**Table 2: Comparison of municipalities and counties in Sweden and sample, respectively**

	Municipalities		Counties	
	Sweden	Sample	Sweden	Sample
<i>N</i>	290	149	21	7
Mean size	31 392	28 539	433 502	607 473
Median size	15 251	14 068	273 511	331 247
Std. Deviation	60 474	50 964	484 378	526 966
Inhabitants	9 103 551	4 252 312	9 103 551	4 252 312
Percentiles	25	9 964	8 538	239 098
	50	15 251	14 068	273 511
	75	32 421	29 396	318 477

**Source:** Statistics Sweden: The population in the country, counties and municipalities Sept. 30, 2006

<sup>453</sup> In Swedish: "Landsting" or "Region", i.e. county councils, here referred to as counties.

**Figure 1: Municipalities by group in the sample and in Sweden as n (group sum) of N (total: 149 and 290), respectively**



In comparison, the mean size of municipalities in Sweden is 31 392, and in the sample 28 539 (9% smaller). The median size is smaller, 15 251 in Sweden, and 14 068 in the sample (8% smaller). The reason is that the sample of 7 counties, with a total of 149 municipalities, gives an average of 21 municipalities per county, whereas Sweden, with 21 counties and a total of 290 municipalities, gives an average of 14 municipalities per county. Thus, the number of inhabitants in the sample is divided between larger numbers of municipalities, resulting in a lower sum per municipality, i.e. the average size of the counties in the sample is slightly larger than the average size of the counties in Sweden. As has been shown, the included counties and their respective municipalities may constitute a representative sample, given the Classification of Municipalities, 1 Jan 2005.



## Design

This thesis consists of three studies, each with its own study design. Study I utilises a quantitative, statistics-based design; study II a descriptive qualitative design; and study III a grounded theory design. This is presented in table 3 (below).

	Study I	Study II	Study III
<b>Design</b>	Descriptive	Descriptive qualitative	Grounded theory
<b>Sample, n</b>	278	11	4
<b>Women, n (%)</b>	256 (92.1)	3 (27)	4 (100)
<b>Age, md (range)</b>	46 (24-63)	41 (25-52)	n.a. (20-30)
<b>Inclusion criteria</b>	Working with active wheelchair prescription	(1) Experienced active wheelchair users (2) Working full-time (3) Comprehensive social life and activities (4) Absence of drug abuse or cognitive affects	(1) TULRD (2) Female (3) Age 20-30
<b>Data collection</b>	Questionnaire	Semi-structured interviews	Semi-structured interviews, observations, and in-group printed/online material
<b>Analysis</b>	Descriptive statistics Chi2-test	Descriptive qualitative	Grounded theory

## Sample and population

In this thesis, the sample consisted of persons within the sphere of physical disability, more specifically (a) persons with personal experience of physical disability; or (b) persons working with service supply for persons with physical disabilities. From these two main groups, three groups were chosen as subjects: (1) persons supplying active wheelchairs (study I); (2) experienced users of active wheelchairs (study II); and (3) Women aged 20-30 with dysmelia (transversal upper limb reduction deficiency) (Study III).

The first group of subjects consists of persons working with supplying active wheelchairs (study I). Potential respondents were recruited by personal communication with key persons (personal directors) in each particular organisation. The prescriber population is presented in table 4 (below). It may be noted that 71% (198 of 278) of the respondents were (a) female; (b) occupational therapists; and (c) working in municipalities.

The second group of subjects is experienced users of active wheelchairs (study II). In general, an experienced user of active wheelchairs only differs from a societal normality due to utilising a wheelchair for ambulation. An experienced user can be a

**Table 4: The prescriber population (study I)**

	<i>n</i>	(%)
<b>Sex</b>		
Male	21	(7.6)
Female	256	(92.1)
No answer	1	(0.4)
<b>Education</b>		
Occupational therapist	235	(84.5)
Physiotherapist	24	(8.6)
Other	13	(4.7)
No answer	6	(2.2)
<b>Employer</b>		
Municipalities	221	(79.5)
Counties	43	(15.5)
Other	11	(4.0)
No answer	3	(1.1)
<b>Years in occupation</b>		
<5	105	(37.8)
6-15	101	(36.3)
>16	62	(23.1)
No answer	10	(3.6)
<i>Range 0-41</i>		
<i>(mean: 10.5; sd: 8.9; md: 9.0)</i>		
<b>Age (years)</b>		
No answer	26	(9.4)
<i>Range 24-63</i>		
<i>(mean: 45.2; sd: 10.6; md 46.0)</i>		

person who has passed primary rehabilitation, and has gained a width of experiences of living with a wheelchair as primary mode of mobility. It is presumed that the number of years as a wheelchair user is less important than the width of experiences gained. An experienced user has high skills of wheelchair utilization, not by means of negotiating extreme environmental obstacles, but on a level where wheelchair utilization in everyday life is performed without specific concentration.

Criteria for being included as an active and experienced user are: (1) at least half time employment, but preferably full time; (2) consider oneself to live an active life with a width of family and leisure activities; and (3) to perceive oneself to be post rehabilitation, having landed in a re-shaped everyday life. These criteria are based on persons within this group possibly having accumulated a width of experiences of active wheelchair use and provision. Another criterion was absence of cognitive affect and/or drug abuse.

After establishing inclusion criteria, key persons in disability organizations were contacted. They were informed on inclusion criteria, suggesting persons who were later contacted by the first author, and fulfillment of criteria validated. This form of community recruitment was complemented with respondent referrals (i.e. snowball sampling). Eleven respondents, eight male and three female, aged between 25 and 52 (md: 41; mean 38.6), and between three and 40 (md: 23) years of wheelchair experience were included, in the citations referred to as numbers 01 – 11. Four were civil servants, three were teachers/lecturers, two were students, one was an economist and one worked with computers. Cause of impairment was spinal cord injuries. It is presumed that persons using active wheelchairs can be known to each other, for instance from sports clubs, athletics teams, and organisations. Therefore, comprehensive measures have been undertaken in order to preserve the anonymity of respondents. For instance, no indications are given concerning brand, model, type of cushion, or detailed wheelchair configuration. Furthermore, place of residence is only presented as “Sweden”. By employing this degree of bowdlerization, it is hypothesised that anonymity is preserved.

The third group of subjects (study III) was defined and selected based on gender, dysmelia and age. In all, sources of information were:

- nine interviews with four participants and three supplementary conversations with two of the interviewees;
- participation in two camps organised by *Svensk Dysmeliförening* (*Swedish Association of People with Dysmelia*), where conversations were held with five participants during the first camp;
- articles in ten issues of *Dysmelibladet* (*the Dysmelia Newsletter*, produced bi-annually by *Svensk Dysmeliförening*);
- the dysmelia (educational) film entitled “*Precis som alla andra... nästan*” (“*Just like everyone else... almost*”) produced by *Svensk Dysmeliförening*;
- the website of *Svensk Dysmeliförening*;
- two reports from conferences arranged by the Scandinavian dysmelia organisation;
- conversation with the chairman of *Svensk Dysmeliförening* (Stig Jandrén);
- two visits to an orthopaedic technician, the first with one of the interviewees (to adjust her prosthesis), the second as an informative meeting with an orthopaedic technician;
- an essay by Maria Gardsäter (2004), written from a personal perspective of growing up with dysmelia, thus used as a primary data source.

## Data collection

### Statistical data (study I)

A postal questionnaire was constructed for this study by the first author and a senior researcher<sup>454</sup> according to the following steps: (1) A large number of potentially usable questions were formulated drawing on previous research, including the MPT model; (2) Questions and scales were discussed and selected; (3) A discussion was held with a panel consisting of two senior researchers and one junior researcher; (4) A questionnaire was formulated using revised questions from the panel discussion; (5) The questionnaire was discussed with (i) prescribers, and (ii) users of active wheelchairs, and (6) revised in accordance with those discussions; (7) Reliability and internal consistency were discussed and resulted in minor revisions; (8) A final check for misspelling etc., and edited in its final form. The final questionnaire contained 18 questions focusing on active wheelchair prescription as well as some background data. All 18 questions were close-ended with the possibility to write a comment.

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<sup>454</sup> Kjell E. Eriksson, PhD, Lund University

Five questions (01, 15, 16, 17 and 18) in the questionnaire were attitude-based, whereas questions (02-14) were fact-related. The fact-related questions referred to external factors outside the personal control of the prescriber, for instance, municipal regulations concerning the choice of colour of the wheelchair. The attitude-based questions concerned, for instance, the importance ascribed by the prescriber to the user's possible choice. This allowed comparisons of the attitude-based answers with background variables to detect possible differences based on place of work, age, sex, education, etc. Answers to the fact-based questions were based on conditions at the prescriber's place of work, not the personal sphere of the prescriber. Therefore, comparisons with background variables of the prescribers might be less valid.

The prescribers of active wheelchairs were also included in the study population of another project. So, in order to contain the costs of data collection, the *prescription* questionnaire was co-distributed with a questionnaire for that project, the *Rights*-project. The two questionnaires then had the background questions in common. Responders were first faced with the common background questions, thereafter the *Rights*-project questionnaire and then the prescriber questionnaire. This sequence was chosen since the common part and the *Rights*-project questionnaire were both aimed at the total population, whereas the prescriber questionnaire was aimed at a subset of the population only. The time used for completing the questionnaires (the *Rights*-project and the prescriber questionnaire) was in the range of 30 to 45 minutes.

The two postal questionnaires were accompanied by an introductory letter, emphasising the importance of the studies and describing how to fill out each questionnaire. The letter also stated that there were no legal obligations attached and that the prescriber questionnaire was intended for persons working with active wheelchair prescription only. Reminders were sent two and five weeks after the initial distribution to the respondents who had not returned the questionnaire. After the final reminder, the returned questionnaires were scanned. Each returned questionnaire had been given a serial number used for keeping track of possible reminders. To ensure the anonymity of the respondents, the process was blind, i.e. a secretary kept track of the serial numbers on the outside of the answering envelopes and kept track of reminders, i.e. never saw the questionnaires. The persons responsible for scanning the questionnaires opened the envelopes, but were not, however, given access to the list of names and corresponding numbers. During the scanning, each questionnaire was given a new serial number.

## Interview data (study II)

Data was gathered by means of employing semi-structured open-ended interviews guided by an interview guide. Initially, an interview guide was constructed with a width of possible aspects. However, after two pilot interviews, it was found that the initial interview guide did not serve its purpose as a list of things to remember to ask due to its complexity. The revision concerned (1) a total reconstruction, leading to a

more loosely constructed guide, and (2) the usage of a short form concerning name, age, occupation, years using wheelchair, and current wheelchair model. It was found that the discussion emanating from the question of model of wheelchair lead to data emanating; thus, the recording of the interview was started before the short form was being filled. This was done from the fourth of the eleven interviews. The interview guide consisted of themes concerning aspects of personal experiences of wheelchair prescription and utilization. Each interview started with a basic question of “what do you do when you need a new wheelchair”.

During each of the interviews, ideas emerged about what to ask next when following up on specific issues. For instance, concerning the role of sports, it was found that this served a role as a source of information concerning news on the international wheelchair market. This was revealed after a follow up question concerning differences of sports wheelchairs and everyday active wheelchairs, leading to what brands and models of active wheelchairs were utilised by athletes from other countries, in turn revealed information on news and product development. Initially, sports was included as a possible way of gathering information concerning the personal development of wheelchairs skills, but this proved to be of a lesser perceived importance than as a source of increased knowledge in, for instance, active wheelchair optimization. In general, follow-up questions aimed at being based on the interviewers understanding of key issues in what was said, rather than as a direct response to the last sentence spoken. This was achieved by returning to the notes on key aspects, written by the interviewer during the interview. Attempts were also made to ensure the interviewer had understood what the respondent meant by means of detailed follow up questions pertaining to the steps of the respondent’s line of argument and content of what was said, i.e. as a way of back-tracking the content from the notes made. Finishing each interview, the respondent was asked if something needed to be supplemented. This aimed at giving the interviewee more control of the content of the interview.<sup>455</sup>

Interviews were digitally recorded utilizing an mp3-recorder with and without external microphone(s) and preamp, or a mini-DV camera (utilizing only the audio recording capacity), utilizing the internal stereo microphone or an external mono microphone. The original sound files were kept for reference purposes, and copies used when (1) converting all mp3 files to wav file format (16 bit 44.1 or 48 kHz); (2) ‘washing’ the sound files, applying noise reduction, equalization, high-pass and low-pass filters, and noise gate before compression and level optimization; (3) transcribing the interviews verbatim using software playback and word processor simultaneously.

My personal experiences as a wheelchair user (not mentioned when recruiting respondents) proved helpful during the interviews. A common ground of understanding emerged due to shared knowledge of wheelchair use. For instance, one of the first respondents immediately expressed a feeling of relief when noticing the interviewer using a wheelchair and said it was great due to ‘speaking the same language’.

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<sup>455</sup> Beazley et al (1997)

This was understood as having a common terminology, thus not needing to explain every detail of importance concerning the wheelchair. However, this also served as a reminder of the need to handle these issues in the following interviews, for instance by means of attempting to employ an enhanced naivety. This episode also increased awareness (as a form of reflexivity) of potential researcher bias.

Consent from the interviewees was obtained in accordance with valid ethical guidelines. Valid Swedish legislation was followed when conducting the study.<sup>456</sup>

### Qualitative data (study III)

Within a grounded theory study, the process of analysing data begins with open coding during the collection of data. Thus, it is difficult to describe the data collection and the data analysis as separate phases. However, here an attempt is made to discuss issues pertaining to the data itself, and not as a part of the analysis process.

When the idea of a study concerning dysmelia emerged, a first step was to attempt to gain an initial understanding by means of a search on the Internet. One of the first websites found was that of *Svensk Dysmeliförening*. Thereafter, two interviews were performed, each beginning with the question of “what is it like to have dysmelia?”, a question seemingly naïve, but at the same time providing a way to gain an understanding of dysmelia based on views among the respondents.

Following the first two interviews, contacts were made with *Svensk Dysmeliförening*. This was in line with the concept of theoretical sampling, as one of the interviewees emphasised this organisation’s importance for her sense of empowerment. The contacts with *Svensk Dysmeliförening* proved helpful in gaining a more thorough understanding of e.g. prosthetic technology, growing up with dysmelia and empowerment; i.e. the beginning of a thematic understanding of strategies. In the first contacts with *Svensk Dysmeliförening*, the chairman had the function of gate-keeper, granting access to *Dysmelibladet*, the dysmelia film, the essay<sup>457</sup> and the first visit to the summer camp. Thereafter, interviews were performed with two more respondents. During each interview, ideas emerged about what to ask next. This is one ingredient in theoretical sampling.<sup>458</sup> For the subsequent interviews, more specific questions were also generated aiming at increasing saturation, e.g. concerning the function and use of prostheses, and specific situations and activities. This was to some extent based on ideas emerging from *Dysmelibladet*, as well as on the conference reports and the dysmelia film. The chronology of the data collection process can be seen in figure 2.

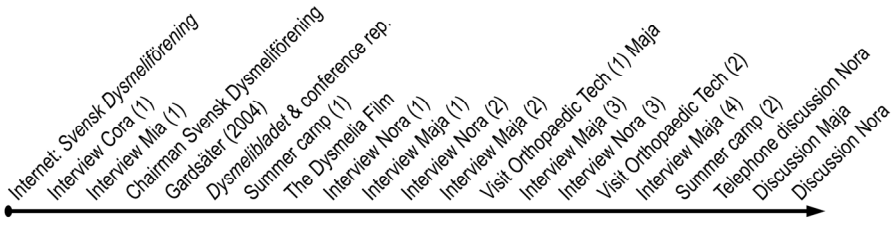
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<sup>456</sup> SFS 2003:460 Lagen om etikprövning av forskning som avser människor; Gustafsson et al (2006)

<sup>457</sup> Gardsäter (2004)

<sup>458</sup> Glaser (1978)

**Figure 2: Chronology of the data collection process (study III)**



Concluding each interview, a question was asked whether something needed to be supplemented, aiming at giving the interviewee more control of the content of the interview.<sup>459</sup>

## Data analysis

### Statistical analysis (study I)

Descriptive statistics were computed. Moreover, for a set of questions the null-hypotheses that the answers were the same irrespective of (a) years in profession and (b) the number of users responsible for, respectively, were tested, employing the chi-square test.<sup>460</sup>

### Descriptive qualitative analysis (study II)

Textual analysis has been discussed by, for instance, Burnard (1991, 1996). Definitions of core themes within qualitative content analysis have been discussed by, for instance, Graneheim & Lundman (2004), providing definitions and deeper insights into the concepts and terminology (including, but not limited to, the manifest and latent levels of content, the unit of analysis, the meaning unit, text condensation, abstraction, content area, code, category and theme). Qualitative content analysis seeks to link themes and issues in the interview data forming a system of categories from which the subject can be understood. Constant comparisons are utilised as a means of understanding data in relation to other data; permeated with the data

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<sup>459</sup> Beazley et al. (1997)

<sup>460</sup> Altman (1991). Furthermore, all calculations were performed using SPSS versions 12.0 and 14.0; Service Provisioning System Software, SPSS Inc., Chicago, IL

analysis.<sup>461</sup> During and after each interview, notes and memos were made. These were used noting emerging ideas concerning categories in the data.<sup>462</sup>

The analysis focuses the manifest content of the interview transcripts; each transcript constituting the unit of analysis. Before continuing, each part of the transcripts was provided a number to keep track of the interview from which it emanated. The units of analysis were then divided into meaning units, each concerning a specific subject or emerging code as a form of heuristic marker pertaining to active wheelchair prescription. Each meaning unit was placed in a cell of a continuing table in a word processor document. Only thereafter, the text was condensed into a new column in the textual data table, attempting to preserve contextual markers during the coding.<sup>463</sup> However, textual data is by definition detached from its original context; the interview data has been separated from the interview.<sup>464</sup>

The condensed text was aggregated into groups, or clusters, pertaining to a thematic understanding, i.e. the process of abstraction. The creation of categories was performed by clustering pieces of content sharing a common thread, thereby constructing a new table from the clustered pieces. Each piece (meaning unit) was still kept within its own cell, but the cells were grouped together. A category can refer to a descriptive, or manifest, level of content, i.e. answers the question of “what”. A theme can be a thread of the underlying meaning on a more interpretative level when the latent content is focused, answering the question of “how”.<sup>465</sup>

### **Grounded theory (study III)**

Data selection was guided by theoretical sampling, i.e. the process of collecting data aimed at generating a grounded theory. During this process of sampling, data was collected, coded and analysed, thus guiding the decision of what subsequent data to collect and where to find these data. The aim was to develop the emerging theory by checking and refining emerging conceptual categories by gathering further data.<sup>466</sup>

The main source of data was the interviews, as they gave a deeper understanding of strategies in everyday life. Also, the natural reciprocity of the interviews provided possibilities to follow up on specific matters directly. However, the other material contributed largely to the emerging understanding, i.e. to generating ideas of what to ask in the subsequent interviews. It can be assumed that the emerging theory would have been less substantial without this material, as it contributed to the thematic understanding of main issues within the dysmelia community. This can be described as triangulation, i.e. the combination of multiple data sources used to overcome bias emanating from utilising one single type of data. In detail, triangula-

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<sup>461</sup> Glaser & Strauss (1967)

<sup>462</sup> Burnard (1996)

<sup>463</sup> Graneheim & Lundman (2004)

<sup>464</sup> Burnard (1996)

<sup>465</sup> Graneheim & Lundman (2004)

<sup>466</sup> Glaser (1978)



tion aimed at confirmation (of non-bias) and completeness (ensuring a comprehensive analysis etc.).<sup>467</sup>

The formulation of the grounded theory began with open coding. Consistent with the grounded theory concept “all is data”<sup>468</sup>, every component in the data collection process – pertaining to the process itself or to the informational content – was used in the analysis, i.e. no data was excluded. A comparative approach was used together with a conceptual analysis, the latter by continuing memo-writings and open coding of the material. Transcripts from the interviews, the film, the articles in *Dysmelibladet*, the conference reports, etc., were coded line-by-line, as well as the memos from visits to the summer camps and the orthopaedic technician. This was done by asking a set of questions about “what is happening here”, “what category could this be”, etc., thus maintaining the theoretical sensitivity. Memo-writing contributed to the development of codes and categories based on the transcribed material. Line-by-line coding was done by sorting and categorising events in the data, thereby assisting in generating concepts representing underlying patterns. Each piece of data was coded and analysed separately before the next part of the process was approached, a “circular methodological cycle”.<sup>469</sup> This functioned as a continuing review process, since comments were received from the respondents within every segment of the process. Furthermore, fit, relevance, workability and modifiability may thus have increased, as the emerging themes were constantly compared to each other, i.e. a process of constant comparativeness. Continuing through the process, concepts were then compared with other concepts, thus leading to the core *adapting stigma-handling strategies to situations in everyday life*. After this, selective coding was performed in a search for variables relating to the core concept. As such, the core concept served as a major factor in further data collection and theoretical sampling, e.g. the latter interviews. To deepen the understanding of the material, it was coded once more searching for categories relating to the core.

Validity may be less of an issue in a grounded theory than: (1) fit (the concepts fit the represented incidents); (2) relevance (captures the real concern of the participants); (3) workability (explains, with variations, how the problem is solved); and (4) modifiability (possibility to alter when new data are added).<sup>470</sup> Parts of the latter interviews served as a form of discussion regarding the emerging core. The respondents expressed an interest in this as a possibility to understand how the interviewer understood dysmelia, i.e. the emerging theory was discussed involving e.g. the fit of the theory, its relevance and workability.

Theoretical memos in the form of both text and figures were produced during the data analysis. Memos were written when anything substantial concerning the analysis emerged. This way, a large collection of memos was created. During the sorting and systematisation of these memos, relationships between categories and

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<sup>467</sup> Curtin & Fossey (2007)

<sup>468</sup> Glaser (1998)

<sup>469</sup> Chicchi (2000)

<sup>470</sup> Glaser (1998)

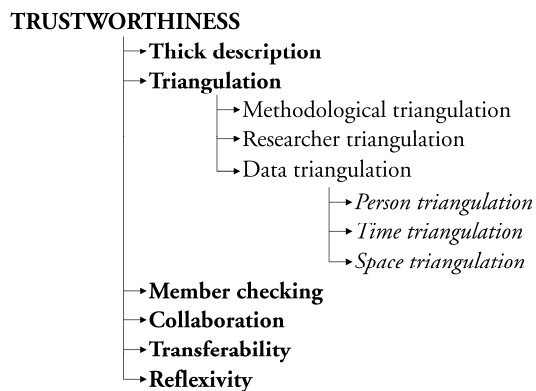
core were sought and noted. In the final stage, the memos were formed as an emerging grounded theory. After the formulation of the substantive theory, a search for, and review of, relevant literature was performed. This was done in line with Glaser’s (1978) advice to try to avoid reading the literature until a framework of understanding has been formed. The literature formed another source of data, thus integrated into the process of constant comparativeness. The literature added an understanding of the theory in relation to a social relational model of disability.<sup>471</sup> The collection of data ended when saturation had increased significantly, i.e. when the most recent data were generating a less substantial contribution to the emerging theory.<sup>472</sup>

## Trustworthiness in qualitative research

A basic assumption of qualitative research is that reality may be interpreted in a variety of ways, and that our understanding depends on the subjective interpretations of the interpreter.<sup>473</sup> One aspect of qualitative studies is trustworthiness, defined by Curtin & Fossey (2007) as “the extent to which the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation”. According to Graneheim & Lundman (2004), “trustworthiness of interpretations deals with establishing arguments for the most probable interpretations”. Therefore, findings presented with a rich or thick description may allow a reader to search for other interpretations, thus increasing trustworthiness.<sup>474</sup>

Curtin & Fossey (2007) argue that one way of determining the degree of trustworthiness of a qualitative study is by applying six detailed considerations: (1) evidence of ‘thick description’; (2) triangulation; (3) member-checking; (4) collaboration between researcher and researched; (5) transferability; and (6) and reflexivity. Triangulation includes two sub-levels. The proposed structure of trustworthiness is shown in figure 3.

**Figure 3: The structure and levels of trustworthiness** (adapted from: Curtin & Fossey, 2007)



<sup>471</sup> Thomas (1999)

<sup>472</sup> Glaser (1978)

<sup>473</sup> Graneheim & Lundman (2004)

<sup>474</sup> Graneheim & Lundman (2004); Curtin & Fossey (2007)

Graneheim & Lundman (2004) discuss trustworthiness in terms of credibility, dependability and transferability. Credibility concerns the focus of research, selection of context, the participants and the approach to gathering data. For instance, including participants with varying experiences (e.g. age, gender and other relevant perspectives) “increases the possibility of shedding light on the research question from a variety of aspects”,<sup>475</sup> and, furthermore, observers with varying experiences and perspectives can contribute to a richer variation. The latter can be understood as triangulation.<sup>476</sup> Dependability can concern change or instability over time regarding the phenomenon being studied, and alterations emanating from the decisions of the researcher during the process of analysis, according to Graneheim & Lundman (2004), an issue related to the concept of time triangulation from Curtin & Fossey (2007). Transferability can be proposed by the researcher(s), but, ultimately, the reader understands the degree of transferability of the findings. A contributing factor of transferability is “a clear and distinct description of culture and context, selection and characteristics of participants, data collection and process of analysis”, combined with “rich and vigorous presentation of the findings together with appropriate quotations”.<sup>477</sup> The latter can be a part of a ‘thick description’.<sup>478</sup>

In grounded theory, issues related to trustworthiness can be: (1) fit (concepts fit the represented incidents); (2) relevance (captures the real concern of the participants); (3) workability (explains, with variations, how the problem is solved); and (4) modifiability (possibility to alter when new data are added).<sup>479</sup>

As seen, issues concerning trustworthiness can be labelled differently and categorised utilising different nomenclatures, but many key issues remain similar across terminologies. In the following, where trustworthiness concerning studies II and III are discussed, the terminology utilised is mainly based on Curtin & Fossey (2007), but incorporates issues from Glaser (1998) and Graneheim & Lundman (2004). The reason is pragmatic: (1) Curtin & Fossey (2007) encompasses a larger number of levels concerning triangulation; and (2) triangulation was used as one vital means of ensuring a wide spectrum of data in study III. Trustworthiness pertaining to study II is discussed based on Curtin & Fossey (2007) and Graneheim & Lundman (2004), as Glaser (1998) focuses grounded theory, whereas study II is based on qualitative content analysis.

A thick description provides a detailed description of both the context and other circumstances surrounding the studied phenomena. By providing this, “the meaning and importance of behaviours and events can be fully understood”.<sup>480</sup> A thick description involves a rationale for the chosen method, a clear description of the re-

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<sup>475</sup> Graneheim & Lundman (2004)

<sup>476</sup> Curtin & Fossey (2007)

<sup>477</sup> Graneheim & Lundman (2004)

<sup>478</sup> Curtin & Fossey (2007)

<sup>479</sup> Glaser (1998)

<sup>480</sup> Curtin & Fossey (2007)

search process, full documentation of the data collection process, details on the data generated and a specified analysis process description. In study III, attempts were made to provide a thick description concerning these components. For instance, the choice of a grounded theory approach was guided by a relative lack of previous studies focusing on ways of handling visible differences in the form of dysmelia among women, as compared with questions concerning attitudes at large, male perspectives and other types of possible stigmatisation. The description of the data collected, and the process of open coding, was aiming at providing all the necessary details of the context and nature of the subject in question. In study II, the thick description aimed at providing a widened understanding of experiences among experienced users of the process of active wheelchair prescription, and the wheelchair itself. The thickness consist of, among other components, the provision of a comprehensive set of contextual descriptions and quotations from the interviewees. One general problem in studies concerning personal experiences can be the lack of information of the context in which these experiences are made. In order to provide such information, quotations can be a vital component.

Triangulation is the combination of multiple theories, methods, data sources and observers used to overcome bias emanating from single *modus operandi* studies. In detail, triangulation serves the purposes of confirmation (of non-bias) and completeness (ensuring a comprehensive analysis, etc.), for instance as a possible way of enhancing the fit and relevance of an emerging grounded theory. Triangulation can be a combination of data triangulation, researcher triangulation and methodological triangulation. Data triangulation includes utilising a variety of sampling sources and strategies in order to maximise the range of data ensuring a more complete understanding. Data triangulation consists of time triangulation (the collection of data at different time intervals), space triangulation (the collection of data from two or more settings, thus ensuring consistency of data across spaces) and person triangulation (the collection of data from more than a single level of persons, for instance individuals, groups, communities, organisations, etc.).

In study II, triangulation was ensured by, for instance, reduction of potential researcher bias by means of inviting two co-analysers to each generate their own category system from the data. This was done independently and without information concerning neither the first author's, nor the other co-analyser's system. Curtin & Fossey (2007) refers to this as researcher triangulation, serving the purposes of confirming non-bias and completeness, thus ensuring a comprehensive analysis. The two new lists of categories were then discussed and compared with the first. This resulted in a common ground of understanding and relating the categories to each other, in turn forming the basis of the presentation of the results interpreted from the aim of this study.

In study III, data triangulation was ensured by means of employing a wide spectrum of data sources, for instance interviews, printed material, conversations with male and female persons with dysmelia, conversations with prosthesis professionals, web sites, a film, and an essay concerning growing up with dysmelia. Interviews and conversations took place at different time intervals and at different locations (e.g. the

respondent's home, cafés, camps organised by the *Dysmeliföreningen* and via telephone) over the course of a longer time span. Person triangulation was achieved by the breadth of the data, for instance from the *Dysmeliföreningen*, individuals, elected officials within the *Dysmeliföreningen*, and groups of persons at camps organised by the *Dysmeliföreningen*.

Ultimately, researcher triangulation aims at enhancing trustworthiness, defined by Curtin & Fossey (2007) as "the extent to which the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation". According to Graneheim & Lundman (2004), "trustworthiness of interpretations deals with establishing arguments for the most probable interpretations". Trustworthiness can include, but is not limited to: (1) evidence of 'thick description'; (2) triangulation; (3) member-checking; (4) collaboration between researcher and researched; (5) transferability; and (6) and reflexivity.<sup>481</sup> Reflexivity concern the direct acknowledgement by the researcher of the fact that the researcher is an active participant in the process of research, as well as being explicit about personal biases, assumptions and values. My personal experiences as a wheelchair user can be seen as a form of potential bias. However, combining personal awareness with a thorough researcher triangulation, every means possible was used attempting to handle this potential bias.

Researcher triangulation in study III by means of using co-analysts might have contributed to the analysis. However, when the analysis was conducted, neither resources nor time was available. Instead, the circular methodological cycle<sup>482</sup> was emphasised and served as a constant reviewing process in data collection and analysis.

Methodological triangulation is the application of two or more research methods or approaches within one study. This can be both across-method (for instance both qualitative and quantitative approaches) and within method (for instance participant observation, interviews and written material). As mentioned earlier concerning study III, a breadth of data sources was utilised, thus making it possible to describe as within method methodological triangulation. These data were gathered by means of interviews, observations, printed material, on-line material, a film and conversations with persons with dysmelia and a professional orthopaedic engineer. Study II is based on interview data emanating from interviews performed by the main author. Due to study II being a qualitative descriptive study, the within method triangulation was not as wide as in study III.

Member checking concerns the involvement of participants in the process of analysing data in order to ensure congruency with participant experiences. The interview process in study III included a recurring process in the form of two of the respondents being interviewed a total of nine times. Combined with supplementary conversations on the telephone, in real-life and using e-mail, this resulted in increased saturation. This also served as a form of discussion regarding the emerging core. The respondents expressed an interest in this as a possibility to understand how

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<sup>481</sup> Curtin & Fossey (2007)

<sup>482</sup> Chicchi (2000)

the interviewer understood dysmelia, i.e. the emerging theory was discussed involving e.g. the fit of the theory, its relevance and workability. According to Curtin & Fossey (2007), the degree of collaboration between participants and researchers can contribute to “privilege the perspectives, views and experiences of the research participants”. The recurring interview process of study III, and the conversations with the respondents in study II, served the purpose of gaining a better understanding of the data generated, thus increasing the collaboration between the researcher and the respondents.

Transferability concerns the possibility to transfer findings within one context or concerning one phenomenon into another context or another phenomenon. Although study III focuses on women with a specific form of concealable stigma, applicability and modifiability may be discussed regarding gender and other concealable stigmas based on differently constructed bodies. One example of a concealable deviation, i.e. one that constitutes a discreditable status, is *Alopecia Areata*, autoimmune loss of hair possible to conceal with a wig. It can be assumed that hairlessness may be experienced in a similar way as dysmelia – both constitute a (potentially) discreditable deviation and both are concealable. Hairlessness may be more stigmatising for women than men, since cultural norms regarding femininity are narrower than comparable norms concerning masculinity, and women, more often than men, are judged by their appearances. Thus, in a possible wider application of the model, it may be hypothesised that applicability depends on a stigma being concealable and intersecting with gender. Transferability of the findings in study II may be discussed in terms of other assistive devices or other groups of users, and experiences among users in, for instance, Scandinavia. However, transferability may be more difficult to obtain with a qualitative descriptive study than with a study made utilising a grounded theory approach, due to the latter aiming at producing a theory or hypothesis.

Reflexivity concerns the direct acknowledgement by the researcher of the fact that she or he is an active participant in the process of research, as well as being explicit about personal biases, assumptions and values, as they may influence the research process. In study III, my personal experiences as a wheelchair user was clearly addressed and discussed in relation to concealable and non-concealable deviations from a situated normality. Study II concerned the prescription of wheelchairs, and my own experiences within the field of wheelchair utilisation in everyday life proved helpful during the performing of the interviews, as a common ground for the discussion emerged as terminology and specific details were known by both the interviewer and the interviewed from the first second. For instance, one of the interviewed persons immediately expressed a feeling of relief at seeing the interviewer use a wheelchair when opening the door. This interviewee said that it was great to have a common terminology and not need to explain every detail of importance concerning the configuration of the wheelchair or other aspects pertaining to common in-group knowledge.

## Ethical considerations

Consent from the interviewees was obtained in accordance with valid ethical guidelines. Valid Swedish legislation was followed when conducting this study.<sup>483</sup>

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<sup>483</sup> SFS 2003:460 Lagen om etikprövning av forskning som avser människor; Gustafsson et al. (2006)

# Results

## Study I

The experience of prescription of active rigid-frame ultra light-weight wheelchairs was reported, using data on 278 prescribers in Sweden. Data was collected by means of a questionnaire and interpreted within the theoretical framework of MPT: Matching Person and Technology. This framework contains three reciprocal components: (1) user preferences; (2) critical features of the technology; and (3) environment and psychosocial setting in which the technology is used.

Within the framework of the MPT-model, user preferences and the aesthetics, appeal, design and appearance of the assistive device are considerable factors in wheelchair selection and important for the perceived quality of an assistive device. To acknowledge user preferences is closely related to empowerment. According to the results, user preferences were not taken into full consideration in the majority of answers. In many cases, the user had a limited choice, even between colours and models.

Almost every respondent stated that the wheelchair is important for the self image of the user, and all but one of the respondents emphasised the importance of the wheelchair for the user's quality of life. Thus, when comparing the respondents' answers concerning the importance of user preferences with the regulatory system in which they are working, it seems that regulations may constitute a barrier in prescription. It may be hypothesised that regulations can be a larger problem in the group with the longest work experience since members of this group tend to emphasise cost-related issues as well as ascribe the least importance to the design and colour of the wheelchair, but still emphasise their influence on the user's perceived self image and lifestyle.

The prescribers were responsible for the prescription of a variety of assistive devices, out of which active wheelchairs were one. This suggests that prescribers possessed a wide, but not that profound, basis of information regarding critical features of the technology. This view is supported by, for instance, the MPT-model and previous research: professionals working with prescription may be unaware of effective processes in matching the person and the device, and the particular role of technology in this match. Information about news and technical developments was seldom obtained from independent sources, implying a strong role for manufacturer marketing.



A majority stated that they lacked knowledge concerning alternative rear wheels, i.e. Spinergy Spox and Decon Spider. This may be due to the low quantity of annually prescribed active wheelchairs, just over one per year and prescriber. Nevertheless, this indicates a lack of specialised knowledge about wheelchair optimisation. Thus, even though prescribers may consider themselves informed, and even though longer time in the line of work and more users responsible for may imply a higher degree of information, the overall knowledge may be less substantial. A possible lack of knowledge regarding critical features of the technology may be a barrier in the prescription of active wheelchairs.

Prescription of active wheelchairs was a less common work task among the prescribers in this study. This task includes how to facilitate specific demands set by the environment in which the wheelchair is used. Nevertheless, a higher cost may be accepted when adapting a wheelchair for the physical environment in which the user lives, although one in ten respondents states local regulations as a hindrance for adaptations. However, adaptations based on user demands, e.g. colour, may be less possible, despite its importance being stated in the attitude-based questions, especially within the group with shorter time working. This leads to the assumption that demands set by physical factors are emphasised over the psychosocial.

An active user may need two or more individually adjusted wheelchairs to facilitate different environmental demands. However, almost one in four of the prescribers were hindered by local regulations to prescribe more than one active wheelchair per user, whereas almost half are entitled to prescribe double wheelchairs on a regular basis. This implies a breadth regarding local regulations, an assumption supported by Hedberg-Kristensson & Iwarsson (2003) and Blomquist (2006), who find variations in both quality and quantity between different parts of the healthcare and prescription system.

Regulations limit the assortment of models and designs possible to prescribe. Thus, regulations influence the components of the MPT model, i.e. (1) user preferences can be within or beyond regulations; (2) critical features of the technology are supplied or withheld in wheelchair prescription; and (3) the environment and psychosocial setting may set demands within or beyond regulations. Therefore, by using the framework of the MPT model, regulations can be identified as a possible barrier to assistive technology prescription and use.

The barriers identified and discussed in this study were the results of political decisions concerning the societal organisation of prescription, e.g. regulations and the work of the prescribers. However, Blomquist (2006) indicates that only 35% of county councils and municipalities have had any political discussions concerning regulations. Therefore, in a wider perspective, the MPT model can be seen as a micro-level of prescription (matching person and technology), and the regulatory perspective as a meso-level (regulating the availability of the technology). By combining the two levels, the interaction between prescription and the regulatory control thereof has been discussed. However, the existence of micro- and meso-levels demand the existence of a macro-level: in this case the political level where regulations are decided. Nevertheless, the macro-level was excluded from this study as it is com-

prised of the formulation of the regulatory framework, and not of the execution of prescriptions therein.

One possible limitation is that the data in this study includes only about 20% (291) of the prescribed active wheelchairs (1 579) in Sweden during 2004/05. The data covers prescribers in seven counties, together representing 47% of the Swedish population. If prescription were evenly distributed geographically within the Swedish population, data would cover 47% (737) of the prescribed wheelchairs. One component in a possible explanation can be that some prospective respondents may have been missed even though the process of recruiting respondents was thorough, i.e. the question remains whether we searched in the right places. Other possible explanations include, but are not limited to: (1) the number of prescribed active wheelchairs per capita is not proportional to the population in each county in Sweden; (2) the number of prescribed active wheelchairs during a single year is not proportional to the mean number of wheelchairs prescribed during a normal year; (3) the counties in the data have widespread restrictions regarding prescriptions, thus prescribing a non-proportionate number of active wheelchairs; (4) persons using active wheelchairs tend to settle within other counties. Which one, or what combination of, these possible causes can explain the difference is impossible to conclude – we can only speculate.

Prescribers in this study emphasise self image, design, appearance and aesthetics as important when prescribing active wheelchairs. However, regulations and other limitations, e.g. a narrow local list of possible models and colours, may constitute a barrier when optimising the critical features of the wheelchair in accordance with user preferences and environmental demands. Another barrier may be lack of practice due to few annual prescriptions, as well as lack of information regarding news and product developments in the wheelchair market. This is underlined since the major source of information is direct marketing from manufacturers. Thus, even though prescribers want to prescribe the best possible active wheelchair for the user, they may lack the possibility to do so due to: (1) lack of practice and specialised knowledge; and (2) narrow regulations.

## Study II

The aim was to describe the experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced users in Sweden. A thematic qualitative content analysis approach was utilised, based on eleven interviews with experienced users of active wheelchairs. Through this approach, themes and issues in the interview data was linked, forming a system of categories from which the subject was understood.

Inclusion criteria were: (1) at least half time employment, but preferably full time; (2) consider oneself to live an active life with a width of family and leisure activities (e.g. sports or other hobbies); and (3) to perceive oneself to be post reha-

bilitation, having landed in a re-shaped everyday life. These criteria are based on persons within this group possibly having accumulated a width of experiences of active wheelchair use and provision. Another criterion was absence of cognitive affect and/or drug abuse. Eleven respondents, eight male and three female, aged between 25 and 52 (md: 41; mean 38.6), and between three and 40 (md: 23) years of wheelchair experience were included in this study. Cause of impairment was spinal cord injuries.

In short, interviewees experienced the prescription process as continuing negotiations with the prescriber. During this process, feelings of injustice and unfairness were frequent, associated with feeling insecure within the system. Aspects of importance concerning the wheelchair were support of physical and social functioning, respectively. Physical function was that the wheelchair should be easy to handle, provide comfortable seating and stand high strains in order to be trusted to function. Social function was to support the identity and self image of the user and provide personal autonomy.

From a user perspective, the process of wheelchair provision can be seen as a triad of relations between the wheelchair user, prescriber, and sales representative. The goal of the wheelchair user was to obtain an optimal wheelchair. The goal of the sales representative was described as proposing a wheelchair optimised for the user, thus also in many cases more expensive, for instance concerning choice of rear wheels. It was noted that the goal of the user in this negotiation (to obtain an optimal wheelchair) and the goal of the sales representative (to sell) appear intertwined concerning optimization.

Informants did not expect the prescriber to have neither a cost cut goal nor a rehabilitating or health promoting goal; they considered themselves rehabilitated already. The informants experienced the prescriber's goals to be in conflict with their own. Informants expected the prescriber to have expert knowledge of technical aspects. This can be a role conflict for the prescriber, i.e. to simultaneously have a health promoting rehabilitating perspective that is not requested, and a cost cutting perspective that might contradict what the user deems optimal for his wheelchair. Instead, the sales representative fulfilled this expected role of the prescriber by supplying technical expertise.

The division of power within the complex of active wheelchair supply is not equal. The prescriber has the mandate to decide on the prescribed wheelchair. This power imbalance is not easily changed, but, what can be changed is the organization of wheelchair provisioning – every prescriber does not have to be expert in every type of assistive device. On a general level, societal organization of assistive devices supply is arranged to facilitate the demands of persons with long-standing, sometimes progressing, diseases, but does not facilitate the demands of persons with stable conditions (i.e. 'healthy disabled'); everyone has been treated from a rehabilitation and health promotion perspective. One way of lessening this problem is to identify the group of 'healthy disabled' and their needs, and locate/construct an alternative track through the system, a track with optimal wheelchair provisioning as its only goal.

Until the mid 1990's, specialised assistive devices centres existed within each county, but after assistive devices becoming a municipal responsibility, the centres were closed and competence disappeared. This can add to problems experienced by experienced users. For persons with a more general demand of assistive devices supply, combined with rehabilitation and health promotion, today's municipal system can be sufficient. In sum, it is proposed that the specific group of experienced users is identified, and prescription of active wheelchairs organised in a way that meets the demands of this specific group. Due to the size of the group, supply can be organised on a regional rather than a local level in order to enable provision based on specialised knowledge.

Differences described by the interviewees between in-group and out-group attitudes towards the wheelchair can be discussed in Goffman's (1990) terms of back stage and front stage, i.e. the back stage being where information can be exchanged freely among peers, and the front stage being where self is presented to others, i.e. out-group persons. For instance, front stage, technical aspects could be emphasised from a perspective of physical function; social aspects often left aside. Back stage, particular aspects are ascribed a certain value among peers, for instance having a certain model of rear wheels, or a wheelchair that is properly maintained. Persons not members of the in-group are neither aware, nor know of the existence, of these values. According to the informants, outsiders tended to react on the wheelchair *per se* as signalling absence of autonomy and agency. Among peers, social capital emerged from the functional value of the optimised wheelchair and the skills of the user as means of agency, where user skills were understood and evaluated based on individual prerequisites, for instance function based on level of SCI (Spinal Cord Injury). In sum, a person's agency can be understood based on both a physical level of ambulation based on personal prerequisites and optimization of the wheelchair, and a social level of self image, identity and social functioning in everyday life. Thus, the combination of physical and social aspects is vital when optimizing a wheelchair as a means of agency.

For an experienced user, the wheelchair has become integrated into the user's body image – a person's mental picture of her/his body. This was seen in a person's body image as a dynamic construction based on internal and external stimuli, understood as the compatibility between the actual and mental pictures of the body. The body image of a wheelchair user can be affected by, for instance, attitudes and values projected back stage concerning aspects of the wheelchair and parts thereof, as the wheelchair can be a means of expressing ones self. However, this was not mentioned as an aspect expressed to ones prescriber during a process of prescription. Instead, the negotiation was mainly kept on a technical level by the interviewees, a level where prescribers were unable to respond due to lack of knowledge. Questions could therefore be raised whether users have realistic expectations regarding the prescribers' resources to meet demands of an optimal wheelchair. In addition, prescribers are not technicians; prescribers have a health promotion view on their work as a prime level of competence. From the view of the prescriber, the user's view of optimization may have seemed to concern the wheelchair having the best technical qualities of, for

instance, weight, maintenance and durability. This may have left the prescriber, guided by a budget, judging how the user's demands harmonised with what was deemed needed to enable a sufficient functional and meaningful everyday life (i.e. health promoting aspects). Equipment with technical qualities considered to enable an everyday life more functional and meaningful than what was judged necessary would probably be denied after being properly negotiated by the prescriber.

For a wheelchair user, prescription can be a process of negotiating ones basic needs. Efring (1999) discusses assistive devices and needs as based on the desired activity of the user and the capacity of the device in this activity. The desired activity defined by the user, what remains to be negotiated with the prescriber is the capacity of the device. The optimal wheelchair fulfilling these demands can be a wheelchair with a high degree of useworthiness, i.e. a device perceived as not only possible to use, but also worth using due to the qualities of the device corresponding with the user's needs. 'Needs' have been discussed by, for instance, Hallström & Elander (2001), utilizing a definition by Georg Henrik von Wright, i.e. as something "bad for the person to be without". By not recognizing perceived needs, the prescriber was seen as exercising power, repressing the functioning of the user. However, prescribers are an executive part of the municipal organization, not the ones making the rules they are following.

However, it is emphasised that users may also be satisfied with the prescribed wheelchair, feeling secure and having their needs met within the system. This can be when a user has expectations on a level corresponding to what the system can offer. A possible explanation is that demands may increase with increased interest and knowledge in wheelchair matters – a user becoming increasingly interested and gaining knowledge of what is possible to achieve with an optimised wheelchair, e.g. in terms of agency, perceives a need for the optimization.

Some users had abandoned the public system of prescription as a consequence of not being met by sympathy for ones expressed needs. Instead, the personal financial capacity was used to obtain an optimal wheelchair, or complementing a prescribed wheelchair with other rear wheels, etc. This can be seen in Bourdieu's (1984, 1991, 1992) terms as a transformation of economic capital into social capital, where ones financial assets are used as means of gaining a higher degree of social capital valid among peers back stage, where matters of, for instance, rear wheels are ascribed a certain value. Consequently, a person without the financial capital is unable to obtain the social capital desired. On a general level, abandonment of the public system raises the question of financial differences within the group of users when a person's need of an optimal wheelchair becomes less important than her/his financial strength.

There is a risk that my personal experience as a wheelchair user has affected the interviews and the analysis of the interview transcripts. To balance this risk, two co-analyzers also generated their own category system from the data, i.e. researcher triangulation. The first co-analyzer (PhD in Occupational Therapy) had experiences from a prescribing perspective, and the second co-analyzer (Professor, PhD in Caring Sciences) had experiences from a caring science perspective. Through compre-

hensive discussions, an increased awareness emerged where the included perspectives added to a wider understanding of the subject. Furthermore, personal experience of wheelchair use mainly proved positive concerning the possibility to gain a more thorough understanding of key issues, at the same time as increasing awareness of potential researcher bias *per se*. Other means of triangulation employed in order to enhance trustworthiness included attempts to make a 'thick description' by providing extensive quotes from the interviews and a comprehensive description of the research process. Ultimately, triangulation aims at enhancing trustworthiness, i.e. establishing arguments for the interpretations most probable (Graneheim & Lundman 2004).

Concluding, experienced users of active wheelchairs were not satisfied with active wheelchair prescription. The process was described as negotiating ones needs of an optimised wheelchair as a means of physical and social functioning. The counterpart in this negotiation, the prescriber, was perceived to have a low level of knowledge concerning important aspects of the wheelchair from both physical and social perspectives, and was working within a cumbersome system of budgets and regulations. Prescribers emphasised a health promotion focus instead of a user requested technical focus. This left the user feeling insecure within the system. As a consequence, a question can be raised whether users have realistic expectations regarding the prescribers' resources to meet their needs of an optimal wheelchair. Another question can be raised concerning prescribers' knowledge of the social function of active wheelchairs, i.e. prescribers' access to, and use of, back stage information in wheelchair prescription. Efforts by the prescribers to express and utilise knowledge of these conditions, purposes and norms therefore seem highly warranted. Even in a changed organization, to accomplish a better fit and satisfaction within the prescription process in the future, users, in turn, have to inform the prescriber about everyday life and personal needs.

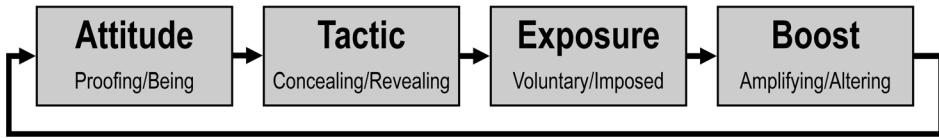
## Study III

The aim was to develop a grounded theory regarding stigma-handling strategies used in everyday life by women aged 20 to 30 with dysmelia (TULRD). The basic question for this study was: What strategies (patterns of behaviour) are used by women with dysmelia (TULRD) between 20 and 30 in everyday life, and how are these strategies constructed? The study shows an adaptation of stigma-handling strategies to situations in everyday life by women aged 20 to 30 with dysmelia (TULRD). In short, strategies are comprehensive patterns of behaviour aiming at controlling information about one's status as deviating from normality. In the following, this is described in more detail.

The core in the proposed model of understanding is: Women aged 20 to 30 with dysmelia *adapt stigma-handling strategies to situations in everyday life*. Strategies are understood as comprehensive patterns of action based on both contextual demands

and (habitual) expectations of interactional response, i.e. as means to achieve higher order goals. ‘Habitual’ implies that the expectations may be based on earlier experiences. A strategy that minimises micro-stress and, consequently, maximises personal well-being, is chosen. Strategies may vary between contexts as well as over time and phases in life. Categories within the core, i.e. the construction of a strategy, are shown in the model, figure 4, and will be discussed below.

**Figure 4: Model of understanding (study III)**



In the model of understanding, *Attitude* constitutes expectations based on previous experiences of contextual reactions to a stigma, i.e. lower order goals, thus a starting point for choice of tactics. *Proofing* is striving to be recognised by emphasising other factors of self as more significant; *being* is striving to be recognised with dysmelia as a part of normality. *Tactic* refers to specific patterns of behaviour. *Concealing* is a tactic aiming at delaying exposure by means of blending in; thus not being noticed as deviating from the contextual normality. *Revealing* is promoting, or not bothering about, exposure. *Exposure* is the *voluntary* or *imposed* outing as deviating from the contextual normality, thereby being exposed to interactants’ attitudes and possible prejudices. After exposure, the relative importance of dysmelia in a given context may diminish, although rarely completely vanish. *Boost* is the interactional outcome, i.e. experiences had during the process, *amplifying* or *altering* attitudes. In the following, these terms will be discussed more extensively.

Individual awareness of deviating from an *ad hoc* normality can imply an accentuation of: (1) proofing; or (2) being, i.e. the attitude is based on previous experiences of contextual reactions and can serve as a starting point for the choice of action in a given context. Proofing is striving to be recognised (despite dysmelia) by emphasising other factors as more significant, e.g. by over-achieving and thereby not giving interactants an excuse for seeing one as deviating. Being is striving to be recognised with dysmelia as a part of normality. Thus, proofing can imply higher stigma consciousness than being. A proofing attitude might imply concealing, although nothing hinders a person with a proofing attitude from emphasising revealing, and vice versa, since the choice of tactics is also based on contextual input, as will be discussed later.

In many contexts, the person with dysmelia is alone in being different. Except from being exposed to attitudes and questions, none of the interviewees considered themselves disabled; they did not need assistive devices and managed all desirable activities, although sometimes with an alternative *modus operandi*. Thus, physical limitations can be considered a smaller problem than a non-mainstream body image. On the other hand, medical professionals may consider dysmelia as something treat-

able, implicitly telling the person with dysmelia that 'your body is not good enough as it is', which is experienced as negative feedback upon not only the body but on one's person, thereby boosting a negative body image and lower self-esteem.

One arena for empowering a being attitude may be activities arranged by *Dysmeliföreningen*. These activities aim at empowerment and increasing knowledge for persons with dysmelia and families with children with dysmelia. Activities arranged by *Dysmeliföreningen* can be a back region, an arena where matters regarding dysmelia can be openly discussed among peers.

Two interactional tactics were found: (1) concealing the missing hand by the use of long sleeves, prostheses for cosmetic reasons, body-language and choice of activities; (2) revealing the absence of a hand, although this has a higher cost in terms of self-esteem in many contexts. Revealing may be more common in contexts where the relative importance of dysmelia has faded or where the attribute is not a stigma. The choice of tactic may be induced by habitual expectations combined with an interactional response, i.e. a dynamic construction based on previous experiences. Thus, attitudes can be thoughts before and during interaction (and after, affected by the interaction, thus reactive). Attitudes may constitute a starting point and a re-shaping reference, although not necessarily the actual course of events, as attitudes affect tactics in the actual appearance, which in turn affect attitudes, an assumption supported by Goffman (1990b).

Concealing a deviation from an *ad hoc* normality is not being obliged to explain, as concealing assists in focusing abilities, not disabilities. Prosthetics may conceal dysmelia and facilitate activities. However, none of the interviewees using prosthetics say that they really need them; activities are often more easily performed without them. A prosthesis may work as a means of establishing a status as non-deviating in a new context; however, once the status is established, the prosthesis may be abandoned since the need to conceal *per se* fades away.

One of the respondents stated that she does not use a cosmetic prosthesis for her own sake, but for others, as the cosmetic prosthesis looks better. This was underlined as she does not see camouflaging her dysmelia as primary, but does not feel comfortable without prosthesis. This implies that a person with dysmelia can have one body image when using a prosthesis, and another when not. In this way, the body image can be altered when wearing different types of prosthetic devices. The opposite can be to view the prosthesis as a tool, utilised in specific situations. Dysmelia may be concealed in order not to be a constant topic of conversation, reducing the person to something that is not there, i.e. the missing body part. A choice to wear a cosmetic prosthesis is understood as concealing one aspect of self that is mostly unimportant, yet has the potential to become the centre of every new interaction.

Exposure occurs when others become aware of an agent deviating from what is considered normal in the particular context. However, it may be hypothesised that exposure exists in two forms: (1) voluntary, when a person emphasises a revealing tactic; (2) imposed, when a person emphasises a concealing tactic and is exposed unintentionally. The first is an example of individual choice; the latter is a contex-



tual effect. However, both result in contextual reactions, thus the proposed model of understanding focusing on exposure *per se*. Nevertheless, when a person with a disability is exposed, the person is in many contexts stigmatised, i.e. discredited. Concealing can delay exposure and (temporarily) grant a status of being discreditable, thus establish a contextual status not based on deviation.

In general, after the interactants have become aware of the dysmelia, they do not think of the person with dysmelia as being like everyone else. The earlier in life the person with dysmelia realises this, the earlier it is possible to understand these reactions as socially constructed prejudices and fears of something unknown. It is then possible to develop one's own ways of meeting these reactions. Sometimes reactions can be negative and disrupt the normal flow of everyday life, and sometimes the reaction is neutral. None of the interviewees said that they could predict how anyone is going to react. Many persons who meet someone with dysmelia for the first time respond with questions about pain. This might be because the absence of a hand is associated with a traumatic event; interactants sometimes try to understand by relating to how they would feel if they suddenly were to lose a hand.

The outcome of an interaction is here referred to as a boost, i.e. experiences had during the process, enforcing attitudes and the choice of tactics in another context. A boost can have two forms of effect: (1) strengthening the present attitude, i.e. amplifying; (2) enforcing a change in attitude, i.e. altering.

To be exposed to others' valuations is a major component of having dysmelia; dysmelia constitutes something interactants feel obliged to relate to. In general, interactants tend to see the person with dysmelia as either 'abnormal', 'deformed' and 'disabled', or as 'cool', 'amazing' and 'capable'. Either way, the person with dysmelia is generally seen as special. She or he seldom gets a neutral reaction and is rarely left alone, since by having dysmelia, she or he can be perceived as being an open person. The interviewees talked about withdrawing from activities where they risked being treated differently and about situations where they instead became over-achievers. In general, the interviewees felt that they should at least manage what others did, and if not, everyone would presume it was because of the missing hand. One of the interviewees said that this could be because many persons with dysmelia have low self-esteem, and either over-achieves to prove themselves, or the contrary, desist from desirable activities.

After exposure, interactants gradually re-emphasise other aspects – the contextual importance diminishes, although rarely vanishes. However, it can be hard to be partly included and partly excluded from the group, and to be commented, looked at, and subject to prejudices and negative attitudes. As stated earlier, to be exposed is to be looked at based on deviation and not on other, perhaps more relevant, aspects. The contextual reactions focus on deviation, thereby stigmatising by accentuating an aspect of self and identity that the deviating person sees as less important. This can be a boost underlining a more proofing attitude. To be exposed can also boost the opposite: the context does not regard the deviation as a stigma, or even as a deviation. For a person with a more proofing attitude, the latter may imply an altering

boost. This can be in a back region or in any context that does not deem a person discreditable as an automatic consequence of dysmelia.

One surprising finding was based on my own personal experiences as a wheelchair user. A wheelchair, seen in relation to an upper limb prosthesis, is by nature more difficult to conceal. The stigma associated with wheelchair use may be more obvious than with dysmelia, since a wheelchair to some extent draws more immediate attention. Despite this, the energy invested in concealing dysmelia (if concealing was chosen as a tactic) was in some cases major. This implies that the concealability of a specific deviation from an *ad hoc* normality is a factor regarding choice of strategy.

On a general level, study III indicates that dysmelia can promote creativity in terms of finding alternative ways of performing activities, and that some activities may be more easily performed without prosthetics. A part of the explanation may be that prosthetic training aims at teaching the person with dysmelia to perform tasks in a two-handed manner – despite prosthetic devices being rough imitations of the human hand in terms of dexterity and sensorial feedback. Nevertheless, prosthetic usage was in many cases maintained. This indicates that self image is valued higher than usability regarding useworthiness; the latter defined as the importance of a technical aid in the life situation of the user, i.e. worth using or not. One reason may be that experiences of stigmatisation are the reference, not the practical implications. This assumption is underlined as women with dysmelia in this study want to be seen on the same terms as everyone else, i.e. without prostheses, concealing, etc., as dysmelia is something mostly unimportant, but at the same time has a potential to become the centre of every new interaction. According to Thomas (1999), personal experiences of living with impairment are shaped by the interaction between (and accumulation of) impairment effects and disability. As such, the social relational model is a tool with which dysmelia can be explained as a form of social oppression requiring the person to adapt a certain strategy in order to handle the undermining of the psycho-emotional well-being. Performance of activities is a smaller problem than contextual attitudes. With this in mind, it can be proposed that dysmelia is less of a disability than it is a construction of the body that draws attention.

Furthermore, findings concerning a concealing tactic may be discussed from the perspective of either a medical or a social model of disability. A medical model implies that disability is a problem of functioning based on personal shortcomings, whereas a social model implies that disability emerges in the discrepancy between individual functioning and contextual constructions, i.e. that it is based on physical and social barriers of society. One emerging question is whether dysmelia constitutes a disability, whether it is *a priori* seen as restricting activities as a result of impairment. Data suggest that practical performances of activities implicated by the impairment *per se* are of less importance. Therefore, it can be argued that dysmelia is a social disability: it is something that interactants relate to as a deviation from an *ad hoc* normality, a stigmatising construction of the body. However, unwanted attention may also be the result of curiosity from an interactant, experienced by the person with dysmelia as stigmatising.

# Discussion

This chapter begins with a discussion of the results of studies I-III. Thereafter, a societal perspective concerning the role of assistive devices, disability and difference is discussed. Finally, and with an increased level of abstraction, a structure is proposed for understanding issues pertaining to assistive devices, tools, disabilities, occupational value, and useworthiness of assistive devices and utilisation thereof on an individual level, i.e. the social construction of assistive devices and the utilisation thereof in everyday life.

Studies I and II both concern matters of assistive devices provisioning in Sweden, more specifically, prescription of active wheelchairs. The perspective of study I is the perspective of the prescriber, whereas the perspective of study II is experiences among experienced users.

In study I, manufacturers are identified as the key source of information for the prescriber concerning technical and other aspects of active wheelchairs. In study II, the manufacturer is perceived as the key supplier of knowledge concerning technical aspects of the wheelchairs. Thus, it can be proposed that manufacturers have a strong role supplying knowledge and expertise in active wheelchair prescription.

Users perceive the prescriber as lacking knowledge concerning active wheelchairs (study II), whereas prescribers consider themselves to lack practice and specialised knowledge (study I). Therefore, enhanced knowledge and practice among prescribers seems highly warranted in the future. Nevertheless, prescribers emphasise much of the same goals as the users in study II; both emphasise social and personal, as well as technical and physical, functioning as central roles for an optimal wheelchair. Users in study II experience the process of prescription as a negotiation with the prescriber concerning the optimal wheelchair as a means of social and physical function. However, when users perceive the negotiation as causing feelings of insecurity due to lack of predictability of the outcome, prescribers sees regulations and narrow assortment as factors hindering the prescription of an optimal wheelchair. The budget was perceived by users as a hindering factor, but was not identified in study I as a factor of importance among prescribers. The reason is unknown – I can only speculate.

On a general level, hinders in wheelchair supply can be regulations and legislation failing to meet other demands on active wheelchairs than strictly physical (mechanical) function. The official objective of assistive devices provisioning in Sweden is that individuals with disability should be granted the possibility of being fully

active members of society and living active and independent lives.<sup>484</sup> Social and personal aspects of the wheelchair are not taken into consideration due to not having any explicit functional (mechanical) implications, thus not acknowledged in wheelchair prescription. In the light of study III, this not the case concerning all forms of assistive devices. For instance, provision of a device with an intended function based on cosmetic appearance alone is not unusual concerning hand prostheses. The purpose of a cosmetic device can be social and personal function, whereas physical functioning can be less emphasised, nonetheless present.<sup>485</sup>

For a person with dysmelia (study III), management of activities in everyday life did not pose any major problems, use or no use of assistive devices. However, others reactions toward being different were ascribed importance. To have dysmelia and use a prosthesis may actually imply the existence of two stigmata; first, the body being different due to dysmelia in itself, and second, the use of prosthesis.

Compared with using a wheelchair, having dysmelia is a less obvious difference – dysmelia can be concealed. For a wheelchair user, the wheelchair is rather difficult to conceal. Interactional effects emanating from wheelchair use are visible, thus present, from the first encounter. Dysmelia is less obvious, and may therefore lead to two first impressions, i.e. first being ascribed a status as normal (while dysmelia not revealed), and second, after exposure, as deviating, i.e. revelation forces reinterpretation.<sup>486</sup> This reinterpretation implies an attitudinal change of the interactant, searching for a habitual clue on how to handle (or cope with) the altered understanding of reality.<sup>487</sup> The latter can be seen in the light of what Bauman (2007) discussed of the unfit body as “not only dysfunctional, but also aesthetically offensive”, i.e. something located outside established distinctions.

What can make the appearance of something outside established distinctions being perceived as threatening? One component of a possible explanation can be Sigmund Freud’s notion of the ‘uncanny’. In the words of Landsberg (1995), an ‘uncanny’ sensation “is produced by an encounter with something which is simultaneously familiar and unfamiliar; the sensation of the uncanny comes from the ‘return of the repressed’”.<sup>488</sup> The encounter leaves the interactant in vain before the unknown, not knowing its further implications and meanings. In other words, the interactant is searching for a way to cope with the occurrence of the hitherto unpredictable; the un-thought. Until then, stigmatisation can strengthen ones definition of self within established distinctions. Another possible outcome is the relative importance of the deviation in the specific context diminishing with time due to habit-

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<sup>484</sup> Proposition 1999/2000:79

<sup>485</sup> Compare, for instance, with the *contradictio in adjecto* of a “cosmetic wheelchair”.

<sup>486</sup> It can be proposed that this major redefinition of the person can be a unique interactional effect of a less obvious deviation from normality, i.e. as the deviation is ascribed a higher importance than the absence thereof, and at the same time does not immediately imply a master status.

<sup>487</sup> Nevertheless, it can not be ruled out that the reinterpretation does not lead to a redefinition due to the deviation not being perceived as a deviation but a part of normality.

<sup>488</sup> Freud, Sigmund (1959) “*The uncanny*”, pp 368-407 in *Collected Papers*, Vol IV. New York: Basic Books. Quoted in: Landsberg (1995).

ual expansion – the deviation is no longer a major deviation, thus no longer constituting a presumptive master status. This can be when the interactant applies a coping strategy, i.e. behavioural and cognitive efforts and activities undertaken to facilitate demands from the not yet habituated. However, despite efforts by the person deviating to convince the interactant of the deviation *per se* being unimportant, the uncanny may cause remaining interactional effects.<sup>489</sup>

## A societal perspective on assistive devices

Assistive devices are not just means of compensating for impairments. For instance, one idiosyncrasy of wheelchairs is the dual nature of its use, as wheelchairs are medical products designed to meet medical needs, and the majority are funded and prescribed within a medically based model of understanding. However, as described by Sprigle (2007a), wheelchairs are also functional, as their use and importance are defined by the users, thus a broad spectrum of activities in various environments. It can be proposed that the two ways of defining wheelchairs, the medical and the personal, are in many parts incommensurable – a wheelchair enhances function and improves occupational independence, but may also be perceived as having a negative impact on a person's life if not enabling the person full participation, according to Chaves et al. (2004). A wheelchair may be seen as both an impediment and a prerequisite for social inclusion and participation, i.e. at the same time as a wheelchair may be seen as stigmatising, it is in many ways a prerequisite for moving around in society. Thus, a wheelchair has an impact on the body image of the user, i.e. it is something in most situations unimportant, but which still has the potential of becoming the unspoken centre in many interactions; a wheelchair may be something interactants can feel an obligation to display their feelings about.

Assistive devices may in general be means of reducing disabling barriers, thus (physically or otherwise) enabling participation. Assistive devices are also means of supporting self-realisation and the desired lifestyle or self image of the user. An active wheelchair does not only have to be mechanically proficient; there are also lifestyle-related values to be considered, e.g. the colour, the shape and the image. Emphasised by, for instance, Lupton & Seymour (2000), assistive devices can be seen as both tools for executing tasks, utilised when assisting bodily function (physical perspective), and as contributors to the presentation of body and self to others, i.e. parts of a user's body image and self image (social perspective). This Janus-face, or duality, can be described in terms of assistive devices being simultaneously enablers/disablers of individual execution of will on every level of a person's occupational repertoire

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<sup>489</sup> However, the interactant being the one applying a coping strategy in this example does not exclude the possibility of the person deviating from the contextual normality also applying a coping strategy, for instance if the interactant has difficulties with coping. The latter can be described as a form of coping with the other not coping.

(the ValMO-model), and enablers/disablers on a social and higher order needs level due to assistive devices serving as reminders of the existence of disability, i.e. signalling difference and opening for stigmatisation. Nevertheless, there are other ways of perceiving difference, and already in 1859, Charles Darwin concluded that variation is positive and serves the good of the species, and also that variation leads to flexibility concerning shifting environments and conditions.<sup>490</sup> Furthermore, by definition, “the congenital is normal but differs from the norm”<sup>491</sup>, and Snyder & Mitchell (2006) find this to be valid also concerning disabilities, as “variations are a feature of biological elasticity rather than a discordant expression of a ‘natural’ process gone awry”.<sup>492</sup>

The only person who can decide whether a specific assistive device is an enabler or a disabler in relation to the physical and social perspectives on assistive devices utilisation, is the person using (or not using) the device. Using another term, this can be described as useworthiness, i.e. according to Efring (1999), the assessment of how a specific device meets the high-priority needs of the user. In this case, “needs” can be the desired activity of the user combined with the capacity of the device in the desired activity, thus encompassing both a physical and a social perspective. Thereto, “needs” can be understood in the sense proposed by von Wright as something “bad for the person to be without”<sup>493</sup>; and therefore, assistive devices as both means of achieving this “something” and, perhaps, the “something” in itself, if utilisation is rendered impossible by a non-functioning, or even non-existent, device.

Occupational value can be used when understanding useworthiness, i.e. the combined dimensions of concrete, symbolic and self-reward value emanating from the utilisation of a specific (assistive) device in a specific activity and context of everyday life. Concerning hand prostheses, the degree to which a device assists in the physical performance of activities can generally be described as low, following a low concrete occupational value, but as a means of granting the user a contextual status as discreditable, and not immediately discredited, its useworthiness may nevertheless be high, as will its symbolic value. Many studies of degree of prosthesis utilisation among persons with dysmelia seem to focus the degree of prosthesis use, and not on how, or in which activities, the prosthesis is actually used. There is a difference between using a prosthesis for gripping and for manipulating, insofar as gripping is to hold and keep an object in a given state, i.e. to secure its position in space, whereas manipulating is the utilization of a held object in order to affect the position or shape of another object, for instance as a tool. Active wheelchairs, on the other hand, can be described as quite the opposite. The possible gain from wheelchair utilisation is, from a perspective of physical participation, possible to describe as a binary func-

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<sup>490</sup> Darwin (1998)

<sup>491</sup> Canguilhem G (1998). *Le normal et le pathologique*. In: Collection Quadrige. Ed. PUF, 91-92. Quoted in: Snyder & Mitchell (2006).

<sup>492</sup> Snyder & Mitchell (2006, p. 70). This theme is also found within the context of popular culture, for instance the X-Men trilogy.

<sup>493</sup> Hallström & Elander (2001)

tion (either it is, or it is not), even though a wheelchair, on a social level, can be stigmatising. Despite in some situations being a signal of a discredited status, user-matched active wheelchairs can be perceived as high in useworthiness. Therefore, utilisation (or non-utilisation) of an assistive device can be described from two dimensions: (1) degree of activity/occupational support (as a physical enabler/disabler); and (2) degree of self image and body image support (as a social enabler/disabler). These two dimensions can be related to the ICF insofar as the degree to which a device can support activity can be a response to the difficulties in executing activities due to an impairment; the degree to which a device can support self image and body image can assist the individual involvement in life situations and be a way to overcome restricted participation.

The function of an assistive device can also be described in Rodenbeck's (n.y.) terms of anticipatory and retroactive function/meaning, insofar as an assistive device can be retroactive regarding the function of the body (restore/replace an impairment) and anticipatory in regard to the world (preparing before situations where utilisation supports participation). Thus, both a physical and a social perspective may include anticipatory, as well as retroactive, components.

Within the ValMO model, an occupation consists of a person performing a task in an environment. This can be compared with the MPT-model, where the successful matching of person and technology is seen as an interaction between person, device and environment. The combination of ValMO and MPT can be described as a person performing a task in an environment with, or without, the employment of an assistive device. When the three dimensions of occupational value in ValMO are combined with MPT, the outcome can be the concrete, symbolic and self-reward value of employing a device in an occupation (understood as operation, action and/or occupation), thus allowing a detailed understanding of contextual useworthiness of a specific device.

ValMO can be seen as the contextualisation of occupations in everyday life, where activities can be performed or desisted from on any level of aggregation from lifespan to a split second (i.e. macro, meso and micro). Thus, ValMO can be a tool when understanding the field (as understood by Bourdieu) of everyday life where meaning/value is created and recreated, activities are performed or desisted from and assistive devices used or not.

A specific assistive device may in ValMO be seen as oriented towards a meso- or a macro- level, whereas another device is fulfilling its meant action on a micro-level or single operation level. A highly specialised device, for example an adapted grip on a tap, can be perceived as useworthy in a specific operational context, but worthless when no tap is present. A more meso- or macro-oriented device, for instance a prosthesis or a wheelchair, can be perceived as useworthy in a greater number of contexts, hence a higher level. Nevertheless, without the micro-oriented device, meso- and macro-level perspectives may be rendered impossible; much in the same way that the absence of a macro-oriented device renders micro- or meso-level perspectives impossible. For instance, without a wheelchair utilised to get close to the tap with the adapted grip, the tap is irrelevant, and so on. However, a meso- or macro-

oriented device may lower the occupational value on a micro-level if it renders an operation or action more difficult to perform. Nevertheless, in all, ValMO can supply a possible meta-perspective of assistive devices utilisation in everyday life occupations.

Within the ValMO, any given assistive device may also be oriented towards one, or more, of the work, maintenance, play, and recreation occupational categories. Taken all together, the complex of a specific assistive device utilised in a particular context by a specific person, is thereby possible to describe and understand from both a level and a category perspective. This allows the understanding of a certain device's breadth concerning level of optimal function and performance for a person. The further application of ValMO and useworthiness together provides the possibility to describe and understand the contextual aspects of useworthiness of an assistive device. Thus, useworthiness can be described as the application of occupational meaning concerning the utilisation of a specific device in a specific context and occupation by a specific person.

However, the ValMO definitions of occupational value emphasise the value while performing, or having performed, an occupation (i.e. *post hoc*); rather than emphasising human motivation before engaging in an occupation. Nevertheless, the focus of ValMO is the human being coming into existence by means of occupations, in part explained by ValMO being a model allowing for analysis of human occupations *per se*; not the basis on whereupon motivated before performed (or desisted from). Pre-action motivation may instead be understood from a perspective of Maslow's hierarchy of needs.

**Figure 5: Maslow's hierarchy of needs**



Human motivation may be understood as different levels of needs emanating from the purpose of the occupation, where needs are understood as according to von Wright, i.e. as something "bad for the person to be without". Maslow's hierarchy of

needs consists of five levels, where a lower level has to be fulfilled in order to experience needs pertaining to a higher level. For instance, a person may not perceive belongingness and love needs as bad to be without when severely dehydrated alone in a desert.<sup>494</sup>

<sup>494</sup> Maslow (1943a, b); Wahba & Bridwell(1976); Burrell & Morgan (1988); Rowan (1999); Koltko-Rivera (2006)



So, how are the concrete, symbolic and self-reward occupational values of ValMO related to motivations understood in accordance with Maslow's hierarchy of needs? Assuming the post-hoc nature of ValMO, occupational value can be understood as the result of an attempt to fulfil a need. Hence, what has motivated a specific occupation describes the intention of that occupation, and the occupational value is related to the process or the result of the occupation. This process of 'doing' and/or its result may have an influence on motivation before another occupation, and so on; a form of repetitive process of human occupations. However, occupations are not isolated from the context in which they occur. Therefore, motivation (in Maslow's terms) is also affected by contextual factors before an occupation, in turn resulting in occupational value. The position of assistive devices in this recurring process may be both as means and needs, as a person may need an assistive device as a means of fulfilling another need.<sup>495</sup> In short, an assistive device may grant the possibility to meet a need, but without an appropriate assistive device, the primary need is a device enabling the possibility to fulfil the next need.

Pre-action motivation may also be understood in terms of agency and empowerment as means of meeting needs. This can include, but is not limited to, a person's (in Bourdieu's terms) habitus and agency on the field of everyday life, where everyday activities are performed or desisted from. Habitus can be understood as a person's collected experiences and internalised patterns of behaviour and ways of understanding the world and her/his place therein. Empowerment may be understood as occurrences and/or conditions supporting the agent in obtaining a sought-after (explicit or subconscious) pattern of behaviour or way of understanding occurrences, i.e. affects habitus. Occupational value, as described within ValMO, can be understood as occupation outcomes that have an effect on a person's habitus, thus affecting human motivation before possible other actions are undertaken, or not undertaken. Therefore, it can be proposed that the 'do-worthiness' of a potential occupation is directly influenced by habitus, which is in turn influenced by occupational value emanating from earlier experiences. A similar way of understanding was formed in study III, where a grounded theory emerged concerning stigma-handling strategies in everyday life among women with dysmelia. Strategies were understood as "comprehensive patterns of action based on both contextual demands and (habitual) expectations of interactional response, i.e. as means to achieve higher order goals", where earlier experiences were formed within, and as a result of, everyday life, i.e. habitus. As such, a strategy may allow for an understanding of habitual reproduction, as well as the perceived situational 'do-worthiness' of a specific occupation, i.e. on a tactical level.

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<sup>495</sup> Under the specific condition of the assistive device being a prerequisite for the occupation.

## Understanding assistive devices utilization

In the following, a structure<sup>496</sup> linking key issues of assistive devices is proposed for one way of understanding issues pertaining to assistive devices, tools, disabilities, occupational value and useworthiness.

A tool can be an object utilised to more effectively alter the form, position or condition of another object or the user her/himself. An assistive device, on the other hand, can from a medical model point of view<sup>497</sup> be an object compensating for functional impairment. Nothing in these descriptions contradicts a tool being used as an assistive device. However, an assistive device not utilised in order to compensate a functional impairment is by definition a tool. It can still be used, but not in its role as an assistive device. Hence, it can be argued that a tool extends an existing capacity, whereas an assistive device translates an existing capacity, for instance in order to use a tool or engage in an activity. To use a tool may require the simultaneous use of an assistive device, but assistive devices utilisation cannot require the simultaneous use of a tool.

One perspective on activity is given by Wilson (1998), who concludes that every person has a unique gait, and therefore, the walking speed when chosen freely may vary. A person's 'comfortable gait' is a function of speed and energy expenditure, and is the speed at which energy expenditure is perceived as most economical. If an occupation is performed in a manner slower than preferred, the result can be frustration and increased energy expenditure.<sup>498</sup> If an occupation is performed with a higher speed, energy expenditure increases. This can be compared to the fact that most people prefer to walk when they move from one location to another even though, in theory, time-effectiveness would be higher if people were constantly running between locations. However, to run as a form of ambulation in everyday life would seriously increase energy expenditure. Another example, however not emanating from Wilson (1998), is the use of crutches compared to wheelchair for persons with ambulatory impairments. Even though it may be possible for some wheelchair users to use crutches, energy expenditure would be too high and speed of ambulation very slow. Thus, a wheelchair can be chosen as a more effective means of ambulation. This has been described by, for instance Cooper & Cooper (2003), as a function of developments in wheelchair construction resulting in better and lighter wheelchairs more attractive also for individuals with lower levels of impairment.

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<sup>496</sup> The structure involves an increased theoretical abstraction of key components demonstrating the underlying syllogisms. However, it is stressed that variables may be dynamic, individual and contextual. Therefore, the aim is to illustrate, not to reduce the phenomena they represent.

<sup>497</sup> ISO 9999:2007

<sup>498</sup> Compare, for instance, using a bicycle stuck in the first of several gears (the user has to increase rpm and energy consumption to maintain speed), with using the preferred gear (thus decreasing rpm and energy expenditure).

An assumption following from the example of gait as a human occupation is that every human activity has a level of comfortable performance based on energy expenditure and speed of performance. Based on this, it is assumed that every activity can be described in terms of energy expenditure and speed, given the widening of ‘energy expenditure’ to include intellectual factors. As ‘speed’ is a description of way travelled per time unit, and also can be unpractical for describing some activities, ‘time’ is used instead of ‘speed’ in the following discussion. This is shown in figure 6 below.

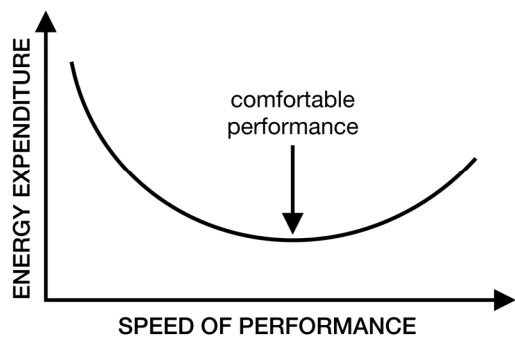
The two dimensions of time and energy expenditure can be understood from a perspective of effectiveness, i.e. components of the degree at which a specific activity is perceived by the individual as worth doing or not (‘do-worthy’).

Efring (1999) defines effectiveness as achieving a wanted result, and the wanted result as defined by the individual. Thus, effectiveness can be rational on an individual level, i.e. the person performing an activity defines the importance of that particular activity by performing, or perceiving a need to perform, the activity in question. Incorporating the ValMO model concerning value in occupations, the ‘do-worthiness’ of a particular occupation, can be described from a perspective of concrete, symbolic and self-reward values. From this follows the assumption that an individual is always striving to accomplish an occupation, or part thereof, as effectively as possible from a value perspective of human occupations, i.e. a form of ‘value-maximisation’. This assumption can partly be traced back to ValMO, as the value of human occupations can be described in similar terms, e.g. “all occupations are meaningful if they are integrated parts of a person’s occupational continuity”.<sup>499</sup>

**Table 5: Scheme of occupational performance in terms of can/cannot do, compared with wants to do/does not want to do.** *The figure is adapted from Sirkka & Brännholm (2003).*

	Can do	Cannot do
Wants to do	A	B
Does not want to do	C	D

**Figure 6: Comfortable performance described as a function of time and energy expenditure.** *The figure is adapted from Wilson (1998, p. 20), insofar as “performance” has replaced “gait”, and “speed of performance” has replaced “speed of walking”.*



A specific occupation can be perceived as do-worthy or not by the individual, but when the configuration of that specific occupation excludes the individual because she or he has an impairment, the result can be described in terms of what a person can

<sup>499</sup> Persson et al. (2001)

do and cannot do, respectively, under present conditions. This is illustrated in table 5.

Given that a specific occupation (process and/or outcome) is desirable for a person; environmental exclusion can be overcome by an assistive device aiming at rendering occupations easier to perform. However, usability of the assistive device can differ between persons.<sup>500</sup> This possible gap between the aim of a device and the degree of usability can be illustrated in terms of performing, or not performing, an occupation with, or without, an assistive device (AD).

An occupation is unaffected by the existence of an impairment

**Table 6: Scheme of occupational performance in terms of can/cannot do with/without an assistive device**

	Can do with AD, i.e. $Y_{wAD}$	Cannot do with AD, i.e. $N_{wAD}$
Can do without AD, i.e. $Y_{nAD}$	A	B
Cannot do without AD, i.e. $N_{nAD}$	C	D

when possible to perform both with ( $Y_{wAD}$ ) and without ( $Y_{nAD}$ ) the application of a specific assistive device (AD), i.e. the assistive device is redundant. However, when an occupation is possible to perform without an AD ( $Y_{nAD}$ ), but impossible with an AD ( $N_{wAD}$ ), the AD can simply not be defined as an AD. When an occupation is impossible to perform regardless of use of a specific AD ( $N_{wAD}$ ) or not ( $N_{nAD}$ ), the AD cannot be defined as usable (Us). Only when an occupation is impossible to perform without an assistive device ( $N_{nAD}$ ) and made possible by an assistive device ( $Y_{wAD}$ ), the assistive device is actually Us.<sup>501</sup> Using condensed expressions to demonstrate the underlying syllogisms, the utilisation of an assistive device in an occupation can be described as:

$$\text{if}_{\text{occupation}} = (Y_{wAD} \ \& \ Y_{nAD}) \ \text{OR} \ (Y_{nAD} \ \& \ N_{wAD}) \ \text{OR} \ (N_{wAD} \ \& \ N_{nAD}) \ \text{then AD not AD}$$

$$\text{if}_{\text{occupation}} = (Y_{wAD} \ \& \ N_{nAD}) \ \text{then AD} = \text{AD}$$

Thus, an assistive device is only usable in an occupation impossible to perform without the assistive device. The purpose of an assistive device from a usability point of view is therefore possible to describe in terms of increasing a person's zone of achievable occupations. This can be described in terms of an assistive device providing a longer lever, or changing the gear ratio, of a particular activity; time and energy are thereby exchanged. The zone of occupations can be understood as a function of energy effectiveness and time effectiveness; the zone of occupations possible to perform without assistive devices ( $Y_{nAD}$ ) is expanded by the use of a usable assistive device ( $Y_{wAD}$ ). Effectiveness should in this case be understood as the degree of correla-

<sup>500</sup> This can be due to, for instance, personal preferences, environmental demands, occupational demands, etc.

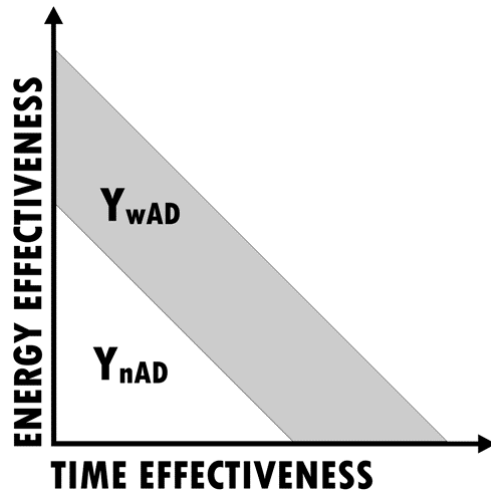
<sup>501</sup> AD=assistive device; Y=yes, possible; N=no, impossible; <sub>w</sub>=with; <sub>n</sub>=without; Us=usable

tion between the user's investments and the perceived gain of the occupation. A person with an impairment may perceive the utilisation (or not) of an assistive device as an effective means of achieving a preferred outcome of an occupation on any level of the ValMO. Thus, effectiveness is increased both concerning energy and time. In the case of energy or time expenditure not being the goal of a specific occupation,<sup>502</sup> expenditure is lower with a higher degree of effectiveness.<sup>503</sup> This is shown in figure 7, where the origin represents the point at which energy and time expenditure are perceived as not worth investing.

Any particular assistive device may be understood both in terms of usability and useworthiness, i.e. not only perceived as functional but also as being worth using on the basis of user's high priority needs, in an occupation worth performing ('do-worthy') or not. The degree of usability can be described in terms of applicability, i.e. if it has the possibility of lowering energy and/or time expenditure to a level perceived as possible for the user to maintain for a desired amount of time, thus creating an achievable and comfortable performance.

Applicability of a specific device can also be affected by the proficiency of the user utilising the device. Even the best device can be rendered close to useless if the user does not know how to use the device in a manner perceived as effective. However, a device perceived as ineffective can still be of continued use if use is perceived as more effective than non-use. Thus, use, or non-use, of an assistive device in a specific context is possible to describe as correlating with the active (proficient) or passive (less proficient) deployment of the device, all affecting the perceived usability and useworthiness of the device. This is shown in table 7.

**Figure 7: Zone of possible occupations with and without use of an assistive device, described as a function of energy effectiveness and time effectiveness**



<sup>502</sup> Energy expenditure can be a specific goal in, e.g. sports activities, whereas time expenditure can be a specific goal when waiting for a train or a bus being late.

<sup>503</sup> Increased expenditure leads to decreased effectiveness, and vice versa.

**Table 7: Active/passive use/non-use of a particular device in a particular context performing a particular occupation**

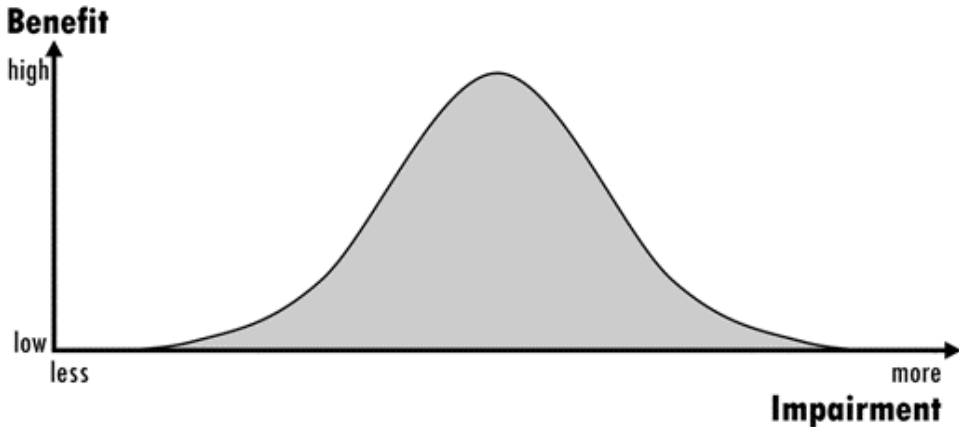
	<b>Active</b>	<b>Passive</b>
<b>Use</b>	Proficient and experienced in the use of his/her technical aid, and feels at ease with the usage.	Does not use the full capacity, neither in themselves nor the technical aid.
<b>Not use</b>	Has chosen not to use any technical aid, but has good knowledge of their existence as well as their function.	Does not know of any technical aid that could facilitate the performance of an activity.

Useworthiness can be described as a function of the personal motivation of the (presumptive) user to utilise a particular device in a particular context, where motivation and the following actions are possible to describe as an externalisation of habitus, i.e. agency. Thus, the (presumptive) user has to benefit from the use of the device, not only concerning the type of device, but also the adaptation of the device to the particular demands of the user, as well as the degree of proficiency in its use.

The usability of an assistive device (UsAD) and the useworthiness of an assistive device (UwAD) can together be described as the perceived benefit or effectiveness of a particular assistive device for a particular user in a particular context (i.e. action, operation or occupation).

In order to perceive a high degree of benefit from the utilisation of a device, the device must be optimised for the user. A person with a minor impairment may not need to use a device, whereas a person with a major impairment may need assistance in order to gain control over the assistive device, for instance concerning placing objects within reach, transfers to and from wheelchairs, or donning/doffing prostheses. But, there is also the question of whether the relative benefit is valued in comparison with a device more optimised for the user, or with the absence of a device. In other terms, the absence of a device can be a form of null-hypothesis of benefit, i.e. the benefit of a device is equal to not using a device at all (i.e. the assistive device is not an assistive device). This can be the far end of the tails in figure 8 (below), whereas the high centre of the curve describes a situation where the device is optimised for the user, thus gaining a high degree of benefit from device utilisation.

**Figure 8: Relation between perceived benefit and degree of impairment for a particular assistive device in an activity**



However, it may be noted that the perceived benefit (or: PBAD, Perceived Benefit of Assistive Device) is not only related to the degree of impairment. The PBAD may also be understood as a function of the application of a specific device in a particular context, possible to describe as a function of an occupation on a single level (thus also the underlying levels) of the ValMO hierarchy, i.e. operation, action, single occupation and occupation. This can be exemplified as enabling multiple occupations (a normal day at work), enabling a single occupation (having lunch with a colleague at a restaurant), enabling an action (eating a bowl of soup), and enabling an operation (to grip a spoon). In sum, the PBAD is the sum of useworthiness and usability of a particular device in a particular occupation being larger than non-use of an assistive device in an activity. Using a condensed expression, this is described as:

$$PBAD = \sum (UsAD \& UwAD)_{\text{occupation}} > nAD_{\text{occupation}}$$

Any given assistive device exists and is constructed to assist a given user in activities in everyday life. Thus, the *raison d'être* of an AD is to enable the user to perform an occupation without obstructing any of its lower order activities, as defined in ValMO; for instance, the accomplishment of an occupation within daily living without obstructing any of the actions or operations involved. This can be seen as forming the basis of effectiveness of any given assistive device, i.e. its ability to support a user in an occupation without obstructing components of that particular occupation. (However, the definitions of “ability to support” and “obstructing components” are always defined by the user her/himself.) Hence follows the possibility to discuss types of assistive devices from their primary level of utilisation in ValMO, and the occupational value combined with this utilisation and the occupation of which utilisation is a part. For instance, some types of assistive devices can be seen as oriented towards a more general level of occupations, e.g. prostheses and wheel-

chairs, whereas others can be more operation- and/or action-specific, for instance an adapted grip on a spoon.

In sum, the only person able to decide on matters concerning the useworthiness and usability of a device in an occupation is the user her/himself. This was found among both wheelchair users (concerning the form and function of active wheelchairs) and persons with dysmelia (concerning use or non-use, and type of hand prostheses). Assistive devices may be more or less well prescribed, constructed and/or adapted for the specific user in terms of social and functional demands, but when utilisation is discussed, the (presumptive) user decides on whether or not a specific assistive device enhances the occupational value of a task or activity, in turn affecting the habitus of the (presumptive) user.





# Summary in Swedish

## Svensk sammanfattning

Avhandlingen innehåller tre delstudier och behandlar frågan om funktionshinder och hjälpmedel i vardagslivet, närmare bestämt hos personer med funktionshinder definierade utifrån kroppens funktion i termer av mobilitet (t ex rullstolsanvändare) eller kroppens utformning (t ex dysmeli i form av transversell reduktionsmissbildning av övre extremitet). Då funktionen och/eller utformningen av kroppen ses som avvikande utifrån en kontextuell normalitet kan detta leda till stigmatisering. Funktionen och/eller utformningen av kroppen konstituerar inte själva funktionshindret, då detta uppstår först då miljön (fysisk och/eller social) exkluderar personen baserat på dennes kroppsliga utformning och/eller funktion. För att motverka dessa funktionshindereffekter hos den sociala och/eller fysiska miljön kan individen välja att använda, eller inte använda, ett hjälpmedel.

Hjälpmedel ses i avhandlingen som såväl inkluderande (möjliggörande av deltagande och kan fungera självförverkligande) som exkluderande (hindrande av deltagande, begränsande av självförverkligande och stigmatiserande). De hjälpmedel som inkluderas i studien är aktivrullstolar och handproteser. Ett skäl till val av dessa hjälpmedel som exempel är att de skiljer sig åt på flera plan, vilket gör att de sammantaget kan utgöra en bredare bakgrund och därmed öka antalet perspektiv. Ett fysiskt plan kan representeras av att en person med mobilitetsbaserat (t ex pga spinalskada) funktionshinder blir mer eller mindre strandsatt utan en välfungerande rullstol, medan en person med kroppsutformning (t ex dysmeli, dvs i detta fall medfödd avsaknad av t ex en hand) som s.k. funktionshinder genomför i princip samtliga önskade aktiviteter. Ett socialt plan kan representeras av att en person med mobilitetsbaserat funktionshinder och som därmed använder rullstol, omedelbart kan uppfattas som funktionshindrad (och därmed tillskrivas vissa attribut), medan en person med kroppsutformning som jämförelsemässig avvikelse kan uppfattas som såväl en av 'de egna' (dvs inkluderad) så länge avvikelsen förblir oupptäckt, och som en av 'de andra', dvs utdefinierad och exkluderad såsom stigmatiserad efter att avvikelsen upptäckts och distinktioner upprättats/externaliserats. Ett hjälpmedelsbaserat plan kan inkludera matchande av person och hjälpmedel utifrån såväl individens fysiska förutsättningar som dennes övriga preferenser.

Perspektiv på hjälpmedel och personer med funktionshinder definierade utifrån kroppens funktion och/eller utformning inkluderar t ex stigmatisering, kroppsupp-

fattning ("body image"), coping, egenmakt (agens), empowerment och aktiviteter i vardagslivet. Användande av hjälpmedel i vardagslivet diskuteras utifrån ValMO-modellen ("Value and Meaning in Human Occupations"). Diskussionen kring hjälpmedel behandlar också frågan om ett hjälpmedels användbarhet och användbarhet, samt avseende samhälleligt tillhandahållande utifrån t ex lagstiftning och reglementen. Hjälpmedel ses således inte enbart som uppgifts- och arbetsassisterande i termer av effektivitet (Newton), utan också från ett självbildsperspektiv utifrån habitus och agens (Bourdieu). En persons användande (eller icke-användande) av hjälpmedel kan baseras på å ena sidan externa krav som t ex miljömässiga, lagmässiga och praktiska, och å andra sidan på korrelationen mellan hjälpmedlet och användarens habitus.

ValMO definierar en aktivitet ("occupation") som en person som utför en uppgift i en miljö. Värdet av en aktivitet ("occupational value") är en förutsättning för upplevelsen av mening och kan ses utifrån de separata men sammankopplade nivåerna av makro, meso och mikro. Aktiviteter kan indelas i fyra kategorier: underhåll, arbete, lek och återhämtning. En femte kategori är sömn, vilken dock inte inkluderas pga sin avsaknad av faktisk aktivitet. Ett makroperspektiv kan ses som ett livsforloppsperspektiv av aktiviteter, ett mesoperspektiv innefattar aktiviteter under en dag, medan ett mikroperspektiv består av komponenterna inom en aktivitet.

Delstudie I undersökte förskrivares i Sverige upplevelser av, och uppfattningar om, förskrivning av aktivrullstolar. Data samlades in med hjälp av en enkät som besvarades av 278 förskrivare i Sverige. Som tolknings- och analysram användes MPT-modellen, där MPT står för 'matchning av person och teknik' (MPT: Matching Person and Technology). MPT-modellen består av tre ömsesidigt påverkande komponenter: (1) användarens preferenser; (2) aspekter hos tekniken; och (3) den fysiska och psykosociala miljö i vilken tekniken används. Ett syfte hos MPT-modellen är att identifiera hinder för användning av tekniska hjälpmedel, samt att föreslå metoder för hur ett specifikt hjälpmedel kan anpassas för sin användare i syfte att denne/denna ska uppnå högsta möjliga grad av självständighet avseende såväl fysiska som sociala aspekter. I delstudien användes chi<sup>2</sup>-test för att analysera betydelsen av karakteristikas hos förskrivaren inflytande på dennes uppfattningar av förskrivning. Förskrivare med längre erfarenhet i yrket tenderade att uppleva både det egna inflytandet över användarens livsstil och betydelsen av ekonomiska aspekter som mer markanta än trendmässiga aspekter, t ex nyheter på rullstolsområdet, val av färg och typ av bakhjul. Längre erfarenhet tillsammans med ett förskrivningsansvar för flera brukare tenderade att vara aspekter associerade med upplevd lätthet att hålla sig informerad om nyheter på rullstolsområdet och andra sortimentsrelaterade frågor. Generellt sett underströks snygg design, snyggt utseende och övriga estetiska aspekter som centrala och viktiga hos rullstolen. Det som hindrade förskrivarna att tillgodose dessa aspekter hos användarna som önskade dem tillgodosedda var lokala (och andra) regler och handläggningsmässiga hinder. Andra hinder identifierade av förskrivarna var brist på vana pga. för få årliga förskrivningar (strax över en rullstol per förskrivare och år i genomsnitt), samt att den huvudsakliga källan till information och kunskap var information/marknadsföring från tillverkare och dessas försäljare. Sammanfattningsvis kom studien fram till att även om förskrivare verkligen vill

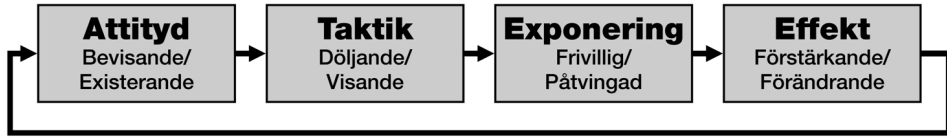
tillgodose brukarens behov av en optimal rullstol, så kan de vara förhindrade att göra det utifrån: (1) brist på erfarenhet/vana och specialiserad kunskap; och (2) lokala och övriga regler, t ex smalt sortiment. Det konstaterades att båda emanerar ur politiska beslut på huvudsakligen kommunal nivå.

Delstudie II beskrev upplevelsen av förskrivning av aktivrullstolar, och viktiga aspekter hos rullstolen, bland erfarna aktivrullstolsanvändare i Sverige. En tematisk kvalitativ innehållsanalys utfördes, baserad på intervjuer med elva erfarna användare. Resultaten av studien visade att aktivrullstolsanvändare förhandlade sina behov av en optimal aktivrullstol utifrån perspektiv och termer som fysisk funktion (lätt att köra, bra sittegenskaper, lätt att underhålla och vara hållbar) och social funktion (överensstämma med individens identitet och självbild, vara ett medel för agens, och erbjuda personlig autonomi). Aktivrullstolsanvändare upplevde att förskrivarna inte hade en tillräcklig budget, och inte heller tillräcklig kunskap eller erforderliga argument för att möta användares behov av, och krav på, en optimal aktivrullstol. Dessa brister ledde till att aktivrullstolsanvändare upplevde sig som orättvist behandlade och otrygga inom förskrivningssystemet, vilket baserades på bl a en upplevd oförutsägbarhet hos förskrivningssystemet. Det konstaterades vidare att förskrivare (och den organisation inom vilken de verkar) behöver ökade kunskaper inte enbart kring tekniska faktorer, men även den sociala betydelsen och funktionen av aktivrullstolen.

Delstudie III är en *grounded theory*-studie som påvisar en anpassning av stigmahanterande strategier till situationer i vardagslivet hos kvinnor mellan 20 och 30 med dysmeli, närmare bestämt transversell reduktionsmissbildning av övre extremitet ("*transversal upper limb reduction deficiency*", or TULRD), vilket också kan uttryckas som medfödd avsaknad av en hand (och eventuellt en del av underarmen). Dysmeli är en generell beteckning på medfödda sk 'avsaknader', där termen 'avsaknad' ska förstås som att det refererar till ett slags generellt upplevd normalitet, där en 'normal' kropp har två ben, två armar, tio fingrar, etc. För en person med dysmeli innebär den egna normaliteten att fortsätta vara på samma sätt som man är född, som man alltid varit; det anmärkningsvärda i att vara som man alltid varit är något som tillskrivs av andra. Personer med dysmeli kan välja att använda eller att inte använda en protes. Denna kan fungera som ett hjälpmedel för fysisk och/eller social funktion, t ex som medel för att få en helt ny greppfunktion (myoelektrisk protes) eller för att fylla ut ett internaliserat, därav upplevt, tomrum i personens kroppsuppfattning (kosmetisk protes). Det kan dock påpekas att en sk kosmetisk protes kan ha en fysisk funktion (t ex mothåll) och att en protes med grepp kan ha en kosmetisk funktion (fylla ut ett upplevt tomrum). Således är den fysiska och sociala funktionen inte enbart baserad på konstruktörens avsikt med hjälpmedlet, utan även på hjälpmedlets faktiska funktion, dvs vilket behov hjälpmedlet uppfyller.

Strategier är omfattande mönster av agerande syftande till att kontrollera förmedlandet av information om den egna statusen såsom avvikande från en i stunden gällande normalitet, vad som betecknas som en *ad hoc* normalitet. Strategier består av: (1) attityd (bevisande/existerande); (2) taktik (döljande/visande); (3) exponering (fri-villig/påtvingad); och effekt (förstärkande/förändrande). Detta visas även i figuren nedan.

### Förståelsemodell (delstudie III)



En bevisande/existerande attityd bildar bakgrund för en kontextuell anpassning som kan förstås i termer av en döljande/visande taktik, vilken syftar till att understödja eller försena en exponering för kontextuella attityder och eventuella förutfattade meningar. Om exponering fördröjs, smälter dysmelisten in i situationen. Exponering kan vara frivillig eller påtvingad, där det sistnämnda innebär att dysmelisten ofrivilligt 'avslöjas' som avvikande. Efter exponering kan den relativa betydelsen av dysmeli minska i den specifika kontexten, och på basis av erfarenheten av att exponeras kan effekten bli förstärkande eller förändrande av individens attityd.

Tidigare diskussioner kring hjälpmedel avsedda för personer med funktionshinder har i lägre utsträckning fokuserat användbarhet och användvärdhet (dvs att ett hjälpmedel inte bara ska fungera, utan även upplevas som värt att användas) utifrån ett aktivitetsperspektiv i flera nivåer, dvs från minsta uppgift till ett livslångt aktivitetsperspektiv (ValMO). Hjälpmedel ska inte bara fungera för sin fysiska uppgift utan även tillgodose krav på social funktion då de kan vara en central och omistlig del av livsföringen för personer med funktionshinder, t ex i syfte att motverka effekterna av miljömässig (eller annan) diskriminering. Samtidigt pekar resultat från avhandlingens delstudier på att delar av den offentligt anordnade förskrivningen av hjälpmedel i Sverige i hög utsträckning utgår från användbarhet och fysisk funktion, och inte tar hänsyn till användvärdhet och självbildsperspektiv hos användaren. Detta kan tolkas som att förskrivning i Sverige fokuserar på funktionsnedsättning och inte på funktionshinder utifrån en ICF-baserad ("International Classification of Functioning, Disability and Health") terminologi.

Avslutningsvis konstateras att den enda person som kan besluta i frågor kring användbarhet och användvärdhet hos ett hjälpmedel är den som använder hjälpmedlet, dvs användaren själv. Detta befanns vara fallet såväl hos användare av aktivrullstolar (avseende formen och funktionen hos den aktiva rullstolen) som personer med dysmeli (avseende användande, eller icke-användande, samt typ av handprotes). Hjälpmedel kan vara mer eller mindre anpassade, förskrivna eller konstruerade för (den presumtive) användaren, t ex i termer av social och/eller fysiska krav, men då användande diskuteras är (den presumtive) användaren den ende som kan bestämma huruvida ett specifikt hjälpmedel ökar eller minskar värdet hos en aktivitet.





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