We are not hiding behind the geraniums
An Anthropological Exploration of Wheelchair Users in the Netherlands

Masters Thesis in
Medical Anthropology

Submitted by: Kamaljit Parhar
Thesis Advisor: Diana Gibson, Ph.D.

University of Amsterdam (AMMA)
Faculty of Social & Behavioral Sciences
August 15, 2003

(Thesis Copy 1)
"We are not hiding behind the geraniums"

An Anthropological Exploration into the Lives of Wheelchair Users in the Netherlands

University of Amsterdam
Faculty of Social and Behavioural Sciences

Amsterdam Masters in Medical Anthropology (AMMA)
Supervisor: Dr. Diana Gibson

Student: Kamaljit Parhar
Masters Thesis - August 2003
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preface</td>
<td>1</td>
</tr>
<tr>
<td>Executive Summary:</td>
<td>1</td>
</tr>
<tr>
<td>Using Wheelchairs and Being ‘Normal’ in the Netherlands</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>8</td>
</tr>
<tr>
<td>Methodology</td>
<td>11</td>
</tr>
<tr>
<td>Chart One: Informant Profile (Female)</td>
<td>11</td>
</tr>
<tr>
<td>Chart Two: Informant Profile (Male)</td>
<td>12</td>
</tr>
<tr>
<td>Chart Three: Contact Methods and Sources</td>
<td>12</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>12</td>
</tr>
<tr>
<td>Presentation of Data:</td>
<td>16</td>
</tr>
<tr>
<td>Normal Life, Meaningful Existence</td>
<td></td>
</tr>
<tr>
<td>Chapter 1: ‘Normal’ Defined</td>
<td>17</td>
</tr>
<tr>
<td>Chapter 2: Realization and Acceptance</td>
<td>20</td>
</tr>
<tr>
<td>Chapter 3: Social Relationships</td>
<td>23</td>
</tr>
<tr>
<td>Chapter 4: Roles of Independence/Dependence</td>
<td>26</td>
</tr>
<tr>
<td>Chapter 5: Social Aspects of Disability</td>
<td>27</td>
</tr>
<tr>
<td>Chapter 6: Asking and Accepting Help</td>
<td>28</td>
</tr>
<tr>
<td>Chapter 7: Stigmas and Stereotypes</td>
<td>30</td>
</tr>
<tr>
<td>Chapter 8: Gender Relations</td>
<td>34</td>
</tr>
<tr>
<td>Chapter 9: Perceptions of Wheelchairs and Understanding Limitations</td>
<td>35</td>
</tr>
<tr>
<td>Chapter 10: Encounters and Encumbrances</td>
<td>38</td>
</tr>
<tr>
<td>Case Study 1: Noah</td>
<td>40</td>
</tr>
<tr>
<td>Case Study 2: Els</td>
<td>44</td>
</tr>
<tr>
<td>Photographic Elicitation Research</td>
<td>47</td>
</tr>
<tr>
<td>Informant Set 1: Noah</td>
<td>47</td>
</tr>
<tr>
<td>Informant Set 2: Els</td>
<td>53</td>
</tr>
<tr>
<td>Informant Set 3: Joreon</td>
<td>56</td>
</tr>
<tr>
<td>Participant Observation of Using a Wheelchair:</td>
<td>60</td>
</tr>
<tr>
<td>Experiencing the Self/Becoming the Other</td>
<td></td>
</tr>
<tr>
<td>Conclusion</td>
<td>65</td>
</tr>
<tr>
<td>Figure 1: Initial Problem Analysis Diagram</td>
<td>7</td>
</tr>
<tr>
<td>Figure 2: Meanings of ‘Normal’</td>
<td>20</td>
</tr>
<tr>
<td>Figure 3: The Importance of Role Models</td>
<td>33</td>
</tr>
<tr>
<td>Figure 4: Participant Observation Chart</td>
<td>64</td>
</tr>
<tr>
<td>Figure 5: Problem Analysis: Wheelchair Users’ Perceptions</td>
<td>71</td>
</tr>
<tr>
<td>References</td>
<td>73</td>
</tr>
<tr>
<td>Appendix 1A – Interview Guide (English)</td>
<td>75</td>
</tr>
<tr>
<td>Appendix 1B – Richtlijnen Voor Het Diepte Interview in Het Nederlands</td>
<td>77</td>
</tr>
<tr>
<td>Appendix 2 – Photo Elicitation Guide</td>
<td>79</td>
</tr>
<tr>
<td>Appendix 3 – Participant Observation Guidelines</td>
<td>80</td>
</tr>
</tbody>
</table>
PREFACE

Beginning this research, all the questions seemed straightforward, and I thought I already knew their answers. Very quickly, I learned that things could not possibly, and were not realistically so clear-cut. Life is not simple to understand, and neither are people.

The most difficult part of the research was also the most rewarding part. Asking people to talk about how they became wheelchair users was the hardest thing to do. It was not like asking someone to tell you his/her favourite colour. Disability is a sensitive topic for people in wheelchairs who used to be able to walk. Thankfully, I was able to contain myself during interviews and not break down into tears listening to informants’ stories.

The frustration came not during the research, nor during the writing of this thesis. While researching and writing, it was personally fulfilling to see all the ideas coming together. In addition, it was an amazing feeling to realize how much I learned about disability in only six weeks.

I felt frustrated when directors from a rehabilitation clinic I visited refused my proposal for researching in their facilities. They said that I could not have access to their patients. These people do not belong to them, and are not sick in a hospital, so why are they their patients? One female social worker asked me, “What can you do for me?” In true wheeling and dealing fashion, she expected me to pay her to gain access into the rehabilitation. I am tempted to deliver a copy of this thesis to that Amsterdam facility, to say “thanks for nothing”, but more importantly so they may learn about what wheelchair users.

I have learned a great deal about myself and about others from of this year abroad. It has shown me that life requires equal doses of patience and persistence. These are the two keys to perseverance. Above all, I have learned to make the most of my time, because at any moment, life can change.

My study in the Netherlands would not have been possible without the guidance and support of my mother and father. Thank you for broadening my horizons, academically, and for opening my eyes to realize how much you love me. I appreciate the trust and the faith you put in me, and I will always remember how much you have done for me.

I am grateful to the Dekker and van Eijck families, wonderful people who showed me how wonderful gezelligheid really is. I express my gratitude especially to Tiny, Ton, Renger and Amber Dekker, who opened up their home to me during this time so far away from my own home. I could not have wished for a better Dutch family, just as I could not have wished
for anyone better for me to love than Renger. Thank you for always being there for me. You have made my time here happy and memorable.

Thanks to Remco Houtkamp for formatting my work. Certain individuals were instrumental to my progress during the research stages, Rosemarij van Eijck and Jan-Peter Muhren. Without your support, I would have been lost.

Dr. Gibson was kind enough to review numerous drafts of both the proposal and the thesis for this research. She did so with care and efficiency, and I appreciate that.

Peter Mesker and Trudy Kanis, thanks for taking care all those last-minute details I came to you for. Whenever I needed help, I could come to you. As an international student, I have to tell you that support made all the difference in the world.

The power of the mind and body can make life so meaningful and fulfilling. For this, I have my informants to thank. You have made me think twice about life and the possibilities within it waiting for those who make the effort. You have all shown me how important it is to appreciate the good things in life more than obsessing over the bad things, and for that, thanks is not enough.

I dedicate my work to the people who believed in, listened to, and cared for me during this past year.

I give my respect and praise to those anthropological scholars who hunger for new understandings of humanity. You dare to tread uncharted anthropological ground in search of knowledge. Times are constantly changing, so we must always seek new knowledge.
EXECUTIVE SUMMARY

*Using Wheelchairs and Being ‘Normal’ in the Netherlands*

People who use wheelchairs *are* normal people, and they *are not* normal people. Visually, compared to walking people, wheelchair users are distinct from the rest because they do not occupy the same dimensions of space, and use the same forms of mobility as people who can use their bodies to fullest possibility. People who use wheelchairs do not conform to the ‘normal’, most common movement: walking. This is what makes them not ‘normal’.

However, if one can see past the exterior, and look into the lives of wheelchair users, one sees that they are in fact very ‘normal’ people. Walking people and those who cannot walk both have the ability to arrive at the same place. The only difference is that walking people use their legs, while non-walkers use their wheelchairs.

The point is that one cannot reduce things to say “This is normal, but that is not”, because everyone has their own sense of ‘normal’. To say so would be as preposterous as saying that all sports fans enjoy the same sport or that every Dutch music lover worships Frans Bauer. Just as these examples exist, ever present is the fact that not all wheelchair users have a shared definition of what is ‘normal’, but regardless, perceive themselves as ‘normal’ people. Wheelchair users experience life in such a way that for them, ‘normal’, is living as best as one can, given life’s circumstances.

This thesis discusses the life experience of becoming a wheelchair user. The concepts contained within its pages are those which were repeatedly alluded to by informants during fieldwork data collection. There may appear to be consensus on certain topics discussed in this research, but that does not mean that everyone who uses a wheelchair agrees or disagrees with how concepts are presented in this thesis. The anthropologist’s job is to study and present humans as they are, not to misconstrue and misreport findings in the name of finding hidden patterns of human behavior.

Bearing this in mind, I try to show what life is like for people who use wheelchairs, and what things matter the most to them. Exploration of ‘normal’ occurs not as a central theme in discussion, but rather as one of many which are a means to living a productive life, as perceived by informants. This report is intended to provide a window into the lives of wheelchair users, as told in their words. It is entirely not my intent to ascribe meanings to what informants have said. This thesis is the medium
with which I convey their message (Chomsky, 1975). Part of living a meaningful life is, “to do what you want”, and thinking of everyone as ‘normal’, just arriving to a point in different ways.

The mind and body together have the power to give life meaning and fulfillment in the aftermath of life-altering circumstances. For people who have gone through a transition from walking to wheelchair, this strength is as much mental as it is physical. They realize this is what is needed to overcome the difficulties with learning to live in another way. If a person who suddenly becomes a wheelchair user cannot cope with the drastic change, he/she may never learn to live a ‘normal’ life. A person has to think of him/herself as a ‘normal’ individual; someone who believes him/herself to be abnormal will never be able to live the fullest of his/her potential. Self-destructive feelings and the inability to accept being in a wheelchair has dire circumstances – depression, antisocial behaviors, and even suicide and death. Those who do not accept disability morally justify it, saying that people who become wheelchair users during their lifetimes “deserve it”. That is, of course not true; to prove it one only has look at people who have strokes, have spinal damage from medical malpractice, or are struck by a drunk driver and become paralyzed. To say that disability is punishment to immoral people is just an excuse people use to denigrate wheelchair users, and the disabled community at large. We need to understand what life is like for those who experience the change from the ‘normal’ walking life, to another ‘normal’ life of being a wheelchair user.

“We are not hiding behind the geraniums”, is an exploratory study. It is meant to shed light on what wheelchair users want from others, as well as provide insight into how people who use wheelchairs in the Netherlands feel about themselves. It is important to consider the issues that face wheelchair users, and to listen to what wheelchair users say would be solutions. Anyone can become disabled, so at least an open mind should approach the proceeding pages, because one day, the reader could be in the same circumstances as the informants are now.

Understanding how wheelchair users continue to live in meaningful and ‘normal’ ways after a changed lifestyle has additional benefits. This information is beneficial to policy makers and healthcare workers who arrange rehabilitation activities for newly disabled persons. For families of people who are wheelchair users, subjects that perhaps are too sensitive to talk about are open to learn. For this
same reason, this work has merit to the interested reader, who perhaps wants to know more about one group of disabled people in the Netherlands.

This study employs theoretical perspectives centered on Anthropology of the Body. This includes seeing the mind and the body together as the forces that shape wheelchair users’ thoughts and actions.

With respect to wheelchair user, the individual cannot be seen as having Cartesian Dualism. This line of reasoning implies that there is a power differential between the mind and body, specifically, that the mind has more value than the body. This cannot be assumed because, without bodily designation, the disabled person is not disabled. Furthermore, without a mind, the disabled person cannot imagine a life with changed mobility.

Thomas Csordas posits an “embodiment” approach, meant to how a person’s perceptions are embedded in his/her mind as a reflection of what is identified, or “inscribed”, on the physical body (e.g. a disability requiring the use of a wheelchair).

Nancy Scheper-Hughes and Margaret Lock have also explored body forms of Anthropology. The pair put forward a “Mindful Body” concept, describing how the body is present as individual, as a social body, and as a body politic. For this study, theirs is a position which allows for exploring the different ways that wheelchair users are perceived by others, in positive and negative ways by society.

These perspectives are fused with in-depth interview techniques, case studies and photographic research to understand wheelchair users. It provides adequate description about how wheelchair users are ‘normal’ people who are sitting in wheelchairs. The meaningful parts of their lives are explored in this study to gain insight into how these ‘normal’ parts of life are not only recognized by the wider society, but also by wheelchair users. The congruity of these perceptions of ‘normal’ lead one to realize that the word connotes different meanings, but ultimately means to be able to do the things that one wishes to do. These perceptions make wheelchair users ‘normal’.
INTRODUCTION
Before one can understand the present status of disability, it is necessary, and recommended to take a glance at the past. Historically, efforts were made to get change words that people used to refer to the disabled. Beginning in the 1920s, western countries including the Netherlands attempted to replace negative terms like cripple, or spastic with disabled.

Soon after this attempt, the Eugenics movement came on the scene. Eugenics was the name given to the practice of purifying, and ideally for its followers, strengthening the human race by getting rid of “social undesireables”. These people were considered outsiders to what was socially defined as the productive body. The most obvious example of this taking place in history was during WWII. Homosexuals, non-white minorities, Jews, gypsies and the disabled were examples of people who were affected by Eugenics.

Disability at that time, constituted the backward part of a human machine that wanted to move forward, but could not, so long as that backward section remained. In other words, disability constituted the reverse side of ‘normal’. It was considered a form of physical deviancy.¹

Bringing history back closer to the present, the following decades featured the rise of biomedicine, what Michel Foucault called, “The Birth of the Clinic” (1976). Classification of healthy bodies and unhealthy bodies was controlled by biomedical definitions. On biomedicine, Foucault stated the following:

It claimed to ensure the physical vigor and the moral cleanliness of the social body; it promised to eliminate defective individuals, degenerate and bastardized populations. In the name of biological and historical urgency, it justified the racisms of the state[...] It grounded then in “truth” (1976: 54).

Within the last twenty years, disability has gained considerable attention from international organizations such as the United Nations (UN). The UN nominated 1981 as the official year for the disabled. Following that, the UN declared 1982-1992 “The Decade of Disabled Persons”. The 1980s marked the start of the ‘normalization’ scheme of rehabilitating people to become functional again. Normalization drew varied responses from health workers and the public domain. While some saw this scheme as a true innovation towards allowing disabled people regain their

¹ 'Deviant', or 'deviance' are derivatives of the word 'deviate', to be different. Often the lay public attaches criminal behavior to these words, giving it a negative meaning.
independence, others felt that the normalization scheme was oppressive (Sutherland, 1981). An example this comes from Sally French, a partially blind woman who wrote about her experiences. In the library she frequented, there had been a new installation of research computers and special catalogues to search for items. Before this, French had relied on the librarian to help her find things manually, in the older card catalogue. When the new system was put in place, the librarian was happy for French because now she could find her own things and be more independent. However, things became more difficult for French because she had to ask the librarian to help her, because the letters on the computer keyboard were too difficult to read. The title of French's essay that she wrote about this is called, "What's so great about being independent?" (1991). Things that are intended to help disabled people to become more independent of others, are not so helpful sometimes, according to French.

People do nothing because they feel doubly limited; primarily because of disability, and secondly from a system they could once manage in, but now have no idea how to use. French notes that this debate of "What disabled people want", is ongoing between disability advocacy groups and academics of disability studies. This is an example of the difference between what a person who is disabled wants, and what those who are not disabled think the disabled want. French's article is a reminder of what happens when the disabled community is not consulted before changes are made to make things easier for them.

With this kind of uncertainty, it is no wonder that disability is an unstable social category. Disability, as a term, is often confused with handicap. Handicap comes from historical allusions of having 'a cap in hand', or begging for charity, as in some places, disabled people were forced to do in the past (and still must beg in some places today). Impairment is also used in this way, but it is avoided by disability groups because they feel that to say someone is impaired, implies a decreased social status. Medically, these three words - impairment, handicap and disability - mean different conditions. Impairment is the loss of part or all of a limb, or any defect of an organ or a mechanism of the body. Handicap refers to what activities the individual affected can not do, resulting from the impairment (Parhar: 2003:1). Disability is the "lack of function which resulted directly from the impairment" (Topliss, 1982:3).

Many believe that the disabled body is the landing base after the fall from 'normal'. The presence of the body in its state of 'normalcy' accounts for the meanings and frames of understanding attached by those who perceive it. Disability
is found everywhere, in every country, every social category, and in every kind of person. ‘Able-bodied’ people often find it difficult to deal with disability. They might avert their eyes, cross the street, or walk the other way. Conversely, in an attempt to appear comfortable with disability, they might overtly engage in “over­
hearty acceptance”, expressing the utmost levels of acceptance and understanding, covertly realizing it is a fabricated behavior manufactured to prevent being called ignorant (Goffman, 1963).

The reality is that disability challenges peoples’ fantasies of wholeness, and completeness, associated with ‘normal’ bodies. These ideas are threatened when the ‘able’ person confronts the body that is symbolically constructed as fragmented, broken, or incomplete. Thus, the disabled body evokes a sense of the uncanny, the uncertain, and the undefined, which makes some people squirm (Murphy, 1989).

Disability may be viewed as a form of social deviance from the norm. To elaborate, the disabled body is different from what the ‘normal’ body is. Social boundaries and medical definitions dictate what is ‘normal’ and what is not. This also defines the ethical and legal rules of society; what is permissible and impermissible within a social context. People who are confronted with a disabled person in front of them decide that is not a ‘normal’ body. People who are disabled may feel differently, and say that theirs is a ‘normal’ body in a different lifestyle. One thing is for sure, however. Disability makes non-disabled people awkward, but it is not clear why. When they are making fun of the disabled, they are shaking their heads in discouragement of this behavior, but also laughing, encouraging the jokester to continue. People know it is not right, yet they find it funny to make jokes about disabled people.

In the literature written about disabled people, very are many books about the deaf and blind people. Missing from the literature is substantial work done about people who use wheelchairs. In fact, although research has been done on people with physical disability (Lupton and Seymour, 2000), to research so many types of physical disability and then write one general overview about it seems too general. For example, someone with facial disfigurement is classified as physically disabled, but so is someone who is quadriplegic. That is like interviewing a blind person and a deaf person and then combining them in a study about disabilities of the senses. Things have to be more refined than that. One specific group that deserves more attention are the people who use wheelchairs.
Figure 1: Initial Problem Analysis Diagram on Wheelchair Users in the Netherlands (Before Study)

**The Self's Perception of Social Disability:**
Roles played by other disabled and non-disabled in relation to the wheelchair-disabled person's feelings about normalcy.

**Definitions of Disability:**
Those held by individuals in wheelchairs compared to biomedical and social definitions.

**Self-Perception of Disability:**
- What does it mean to be disabled?
- What is a normal body?
- What is an abnormal body?

**Perception of Normal**
Among Dutch wheelchair users who became disabled during their lifetime.

**Negotiation (or non-negotiation) of personal normalcy**
through the process of becoming disabled.

**Suggestions** of wheelchair-disabled persons:
- How health services can help sustain (or create) normalcy for the
METHODOLOGY

As a qualitative study, data was collected using several methods, via sources located through personal contacts of the researcher. In total, there were seventeen participants in this study. Noah, one informant who participated in this study, was born disabled. Grace and Remy were two participant observers who are not disabled. Seven women and seven men participated as informants who had become wheelchair users, but were not born disabled. Of this group, six men and six women were interviewed. Els, a woman from this group of six was chosen as a case study. The remaining two people (Ana and Raymond) corresponded with the researcher online. Informants were found through family members, and by the snowball method, as well as online postings for wheelchair users. This is complied in the contact sources chart.

Employing the methodological triangulation method, three approaches were initially followed to collect data. The researcher conducted in-depth interviews with all informants; Els and Noah were chosen as case studies. Three individuals (Noah, Els, Joreon), participated in photo elicitation about their lives and what it meant to be ‘normal’. As the research was underway, a fourth approach, Participant Observation, providing “additional, more accurate information on people’s behaviour than interviews or questionnaires” (Hardon et al, 2001: 208).

The aim of the research was to gain insight into the lives of wheelchair-using persons in the Netherlands. All of the data collection was completed within the Netherlands, within the provinces of North Holland, South Holland, Friesland, Gelderland, and Flevoland. The researcher chose these locations based on three reasons. First, the researcher sought a sample representative of as many parts of the Netherlands as possible. Second, from the home base of the researcher, Amsterdam, it was financially feasible to travel to all locations with a reasonable timeframe to conduct research. Third, because the majority of informants were personal contacts of friends or family members, the researcher already had a certain level of rapport and trust established before physically meeting the informants.

This study was conducted by the researcher, with the aid of a research assistant who served as a Dutch/English interpreter for interviews in Dutch, and as a translator during the transcription process. The research assistant is a university student also currently working on a thesis for another field within The University of Amsterdam (UVA).
Research took place for a six-week period between May and July 2003. The writing of the thesis was also completed within a six-week period directly following the research phase, from July to August 2003. The three-month period of twelve weeks for research and reporting are allotted by the Amsterdam Masters in Medical Anthropology program, as required for fulfillment of a Masters degree within one year.

The in-depth interviews were conducted with five open-ended questions, originally intended to lead the conversation from start to finish. However, this intent was re-evaluated as the researcher conducted more interviews. The researcher ultimately chose not to adhere to the strict format of a structured interview, as more quality information was gained from conversation, which was not pre-empted. Consequently, the researcher adopted, and was consistent with, an open format of interviewing, where the questions were used to begin the conversation. The prepared questions were also used as replacements for questions that were difficult for informants to answer. Informants were shown, and in some cases sent via email or postal service, the questions. This gave them some time to consider the questions, as well as to prepare their answer to these questions beforehand.

In accordance with ethical conduct, the researcher recognized and understood "the importance of informed consent and ways in which it can be dealt with in anthropological research" (Hardon et al, 2001: 280). All participants of the study – researcher, informants, and translator – read and signed a consent form before commencing the interview. Verbal consent was used with participant observers, who were colleagues of the researcher and verbally agreed to participate.

Twelve interviews were done in English, and three were in Dutch. The average interview lasted one hour and a half, although in some cases, interviews turned into an evening visit lasting three hours. In the planning stages for this study, the researcher had initially created an age group of 20-25 for study. However, that age group was too restrictive for finding informants. The researcher decided to forgo the age limitation altogether for the sake of being realistic. Also, as noted, one of the informants chosen as a case study and photo elicitation informant did not become disabled, but rather was born disabled. As it turned out, this was a good decision as it added much data to the overall collection. For similar reasons, two participants asked to observe their experience sitting in a wheelchair, were chosen because they are not disabled, and are not familiar to wheelchair usage.
In the end, it was better to have many informants of various ages, levels of mobility, and personal circumstances to comprise a study about life with a wheelchair, than to have no informants, and thus no study at all. Hence, the ages vary, as shown on the informant profile later in this section.

All the informants were contacted personally by the researcher, who was responsible for arranging an appointment with them at a time that was convenient for the informants. Interviews took place in the same week as the telephone call, or in the following week. All in-depth interview informants were interviewed one time each. The two case studies, photo elicitation informants, and participant observers were in constant contact with the researcher, mostly in follow-up meetings. Eleven interviewees invited the researcher to their homes, while two met the researcher in a city where they could easily find one another, as it was easier for both parties. Participant observers met with the researchers in their chosen social settings.

A conversational format of interviewing was used because the researcher found it a respectful and effective method to approach the topic of disability. One important reason for following a conversational format for interviewing is that by doing so, the anthropologist does not control the situation too much, so exchange of information can occur at a normal pace. The researcher was partial to this method because of the implied equality between the persons engaged in conversation. It is easier to converse with people, if it is felt that they are one’s equals. The researcher wanted as much as possible to avoid an interrogative interview format for an emic and etic perspective about disability.

To elaborate on the desired emic and etic aspects for research, the emic perspective is when theoretical concepts are applied to a group from the outside. The etic perspective is taking the ideas of one’s own culture, and applying these to the outside group. In disability, assuming an emic perspective would be, for example, if a group of university students labeled all physically disabled persons as being less mentally intelligent (Parhar, 2003). An emic perspective could be someone who sat in a wheelchair who thought that all non-disabled individuals were ignorant towards the disabled community’s needs. For a further discussion on etic/emic perspectives, a useful source is van der Geest (1987:24).
### Informant Profile: Chart 1 - Female Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Wheelchair Use</th>
<th>Details of Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ana</td>
<td>46</td>
<td>Married</td>
<td>Full-time</td>
<td>Spina Bifida</td>
</tr>
<tr>
<td>Alli</td>
<td>50</td>
<td>Married</td>
<td>Full-time, 8 years</td>
<td>Multiple Sclerosis (Progressive Type)</td>
</tr>
<tr>
<td>Deborah</td>
<td>43</td>
<td>Married</td>
<td>Full-time, 16 years</td>
<td>Surgical Malpractice</td>
</tr>
<tr>
<td>Els</td>
<td>30</td>
<td>Single</td>
<td>Full-time, 10 years</td>
<td>Diving into shallow water</td>
</tr>
<tr>
<td>Gertje</td>
<td>86</td>
<td>Widowed</td>
<td>Part-time, 5 years</td>
<td>Weak Heart</td>
</tr>
<tr>
<td>Klara</td>
<td>83</td>
<td>Widowed</td>
<td>30 years</td>
<td>Deterioration of knees</td>
</tr>
<tr>
<td>Solange</td>
<td>20</td>
<td>Single</td>
<td>Full-time, 6 years</td>
<td>Connective Tissue Disease</td>
</tr>
<tr>
<td>Grace</td>
<td>24</td>
<td>Single</td>
<td>Not a Wheelchair User (Participant Observer)</td>
<td>Car Accident (What she told people)</td>
</tr>
</tbody>
</table>

### Informant Profile: Chart 2 - Male Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Wheelchair Use</th>
<th>Details of Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noah</td>
<td>24</td>
<td>Single</td>
<td>Full-time (since birth)</td>
<td>Born without two low parts of spinal column</td>
</tr>
<tr>
<td>Hans</td>
<td>29</td>
<td>Single</td>
<td>Full-time, 7 years</td>
<td>Skiing; struck a tree, damage to spinal cord</td>
</tr>
<tr>
<td>Karl</td>
<td>45</td>
<td>Married</td>
<td>Full-time, 30 years</td>
<td>Struck by a moped while biking home</td>
</tr>
<tr>
<td>Patrick</td>
<td>45</td>
<td>Married</td>
<td>Full-time,</td>
<td>Diving into shallow water</td>
</tr>
<tr>
<td>Raymond</td>
<td>34</td>
<td>Single</td>
<td>Full-time, 6 years</td>
<td>Hit by drunk driver, is now a paraplegic</td>
</tr>
<tr>
<td>Joreon</td>
<td>45</td>
<td>Married</td>
<td>Full-time, 3 years</td>
<td>Stroke, affected left side of his body</td>
</tr>
<tr>
<td>Fred</td>
<td>45</td>
<td>Married</td>
<td>Part-time</td>
<td>Regained partial use of his leg after amputation following a car accident</td>
</tr>
<tr>
<td>Hugo</td>
<td>61</td>
<td>Married</td>
<td>Full-time, 6 years</td>
<td>Collapse of thoracic vertabrae</td>
</tr>
<tr>
<td>Remy</td>
<td>27</td>
<td>Single</td>
<td>Not a Wheelchair User (Participant Observer)</td>
<td>Motorcycle Accident (What he told people)</td>
</tr>
</tbody>
</table>
Informant Profile: Chart 3 - Contacting Informants/Sources

<table>
<thead>
<tr>
<th>Internet Posting (# of informants)</th>
<th>Personal Contacts (# of informants)</th>
<th>Snowball Reference (# of informants)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total: Male Informants</th>
<th>Total: Female Informants</th>
<th>Total Informants</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>8</td>
<td>17</td>
</tr>
</tbody>
</table>

(1 Case Study Male)  
(2 Photo Elicitation)  
(1 Participant Observer)  
(1 Case Study Female)  
(1 Photo Solicitation)  
(1 Participant Observer)

THEORETICAL FRAMEWORK

This study is about the perceptions of wheelchair users in the Netherlands. Through these perceptions, its aim is to glean from informants, what they believe to be ‘normal’ for them. This is examined in those who have experienced coming to terms with the transition from being non-disabled to becoming disabled.

The main theory chosen to provide a framework for discussion of findings is Anthropology of the Body. This is a relatively new theory in Medical Anthropology, mainly coming into popularity in the 1980s to the present. However, this theory is not one blueprint with only one main idea. Development of disability studies also gained popularity during the 1980s, particularly following the World Health Organization’s delegation of 1981 as the year of the disabled.

The Anthropology of the Body consists of many different perspectives which are about the body, and from the body (Csordas, 1991). For the purposes of this study, three main theoretical orientations within Anthropology of the Body have been selected.

First, Maurice Merleau-Ponty’s assertions about the mind and body have been borrowed from philosophy, to understand wheelchair users’ perceptions of their own bodies and minds. This is contrasted sharply with Cartesian dualism, because this research is based on mind and body as together, involved in constant interplay.

Merleau-Ponty’s work on the body is instrumental to this study. What began as a counter argument to Cartesian thought, has now become a foundation for anthropology of the body. Rene Descartes (1596-1650) was the man who said, cogito ergo sum, “I think, therefore I am”. Essentially, Descartes believed that the body was
palpable, while the mind was intangible. According to Cartesians, there is an absolute separation of the soul/mind, from the body, so the soul is without any physical extension. Descartes believed that there was only a “hypothetical union of body and soul”, and nothing more (Langer, 1989:30). In an essay called Passions of the Soul, Descartes likened the mind/body relationship to a horse (body) being directed by an invisible rider (mind, the pineal gland).

Merleau-Ponty sought to break away from using language and dualism to explain humanity. He leaned towards bringing personal experience back to the forefront. He ascertained that perception came from either an increase, or a decrease in some form of ambiguity, and that it always depended on the social matrix (Strathern, 1986: 37). The central core of Merleau-Ponty’s argument was “that the perceiver is not a pure thinker, but a body-subject” (Langer). Spatiality was “the primary condition of all living perception”, which was comprised of three factors: field, perspective, and horizon. According to Langer’s exegesis of Merleau-Ponty’s 1960s work, “body spatiality...is the very condition for coming into being of a meaningful world” (Langer: 47). Mental operations are constrained by bodily characteristics. Strathern also has written about body positioning, citing for example kneeling, and how this position means “submitting to the other by assuming a posture from which one cannot be threatening or combative” (1989:31). This line of thought also relates to how a wheelchair user is usually two or three feet below other people during daily life.

A second theoretical approach is, “The Mindful Body”, an anthropological perspective put forth by Nancy Scheper-Hughes and Margaret Lock. Like Merleau-Ponty, Scheper-Hughes and Lock argue against Cartesian Dualism, calling it “a rather artificial separation of mind and body” (Van der Geest and Rienks, 1998: 349). Scheper-Hughes and Lock (1987) wrote an article called, “The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology”. They based their work on the “assumption of the body as simultaneously, a physical and symbolic artifact, as both naturally and culturally produced” (1998: 347). According to Scheper-Hughes and Lock, “the body in health offers a model of organic wholeness [...] the body in disharmony offers a model of sickness, conflict and disintegration” (1998: 348). Regarding bodily goals sought by western society, they wrote the following:

In our own increasingly ‘healthist’ and body-conscious culture, the politically correct body for both sexes is the lean, strong, androgenous, and physically
‘fit’ form through which the core cultural values of autonomy, toughness, competitiveness, youth and self-control are readily manifest” (Ibid. 364).

From this starting point, Scheper-Hughes and Lock consider the body on three levels. The first level, “The Individual Body”, is where a person places him/herself, within the surroundings, “including internal and external perceptions, memories, affects, cognition and actions” (1998:356). The ‘sixth sense’ or proprioception is part of the individual, as his/her natural intuitive process. This concept of proprioception was also cited by Merleau-Ponty. In this study, the individual body of the wheelchair user is considered by looking at self-perceptions of wheelchair users of themselves, and of their surroundings.

The second level described by Scheper-Hughes and Lock is the “Social Body”, which refers to the state of an individual body applied to the entire society. This level is about how bodies relate to social aspects, for example, how healthy bodies reflect a healthy society. In the context of this thesis, the social body is the wheelchair user’s body, which is a symbol for disability. One difference between Scheper-Hughes and Lock’s article and of this thesis is that they place great value on Douglas’s work to understand thy symbolic, social body. The contrary is true for this thesis. It is argued that Douglas’s work is not particularly useful to gain understanding about disability and wheelchair users. The reason is that Douglas’s concepts (e.g. pollution behavior and ‘dirt as matter out of place”) create a binary, with disabled people on the ‘bad’ side, and non-disabled people would occupy the ‘good’ side. In addition, vocabulary such as “the ‘disembodied self’, the ‘selfless body’, and the ‘divided body’, are inappropriate for disability studies.

“The Body Politic”, is the third level presented by Scheper-Hughes and Lock. This level involves “the regulation of physical bodies by political and social forces” (1987: 7). Medicalization of social behaviors considered out of character (e.g. PMS to explain women who have uncontrollable rage or ADHD for a child who is bored at school). Scheper-Hughes and Lock say that these disorders do not exist outside of the western world. The medicalization of “negative social sentiments’ (1998:365) is used to understand how wheelchair users in the Netherlands are called invalides, and arguably, they are blamed for their disabilities. In other countries, specifically Canada, person with special needs relinquishes the individual from any personal blame. This will be investigated as part of the research.
The last theoretical position incorporated into this thesis is the “embodiment” approach, introduced by Thomas Csordas (1991). Embodiment, as a term, has been defined and re-defined numerous times. Thomas Csordas (1994) has done anthropological inquiry into the embodiment approach. Embodiment is a way of showing how a person’s perceptions are embedded in his/her mind as a reflection of what is identified, or “inscribed”, on the physical body (e.g. a disability requiring the use of a wheelchair). Embodiment then, “requires that the body as a methodological figure, must itself be non-dualistic i.e. Not distinct from or in interaction with an opposed principle of mind” (Csordas, 1990:8). Furthermore, Csordas states that embodiment is “a methodological standpoint in which bodily experience is understood to be the existential ground of culture and self, and therefore a valuable starting point for their analysis” (1994:269). This method is a concrete, right-here/right-now relation of people to one another, as well as considering the senses and feelings they use to communicate back and forth. Within the boundaries of this disability study, an attempt is made to find an approach that is suited to reflect the embodied perspectives of wheelchair users in the Netherlands, showing how the mind and the body are involved.

These theoretical frameworks are used to study wheelchair users’ perceptions, and to understand how they have meaningful lives. Their minds are embodied and their bodies become mindful. To elaborate this last comment, some sociological work and medical literature about disability is useful to consider.

Research by sociologists is indispensable for its ability to generate embodies notions of disability by removing disability from the medical realm and looking at it just as a social construction (Goffman, 1963). Medical literature, particularly by Helman (2001) discusses the cultural binaries of ‘able’ versus ‘disabled’ bodies, followed by discussion about social labeling and stereotyping. Oliver Sacks (1984, 1986) has contributed greatly to understanding disability because he shifts the focus from the individual sufferer to the social pathology responsible for the treatment of the disabled, citing notions of ‘socially-handicapped’, and society’s aversion to the disabled.
PRESENTATION OF DATA
Normal Life, Meaningful Existence

These research findings were based on data collected during the six-week research period allotted from May to July 2003, in accordance with AMMA (Amsterdam Masters in Medical Anthropology) course requirements. The presentation of the findings has been divided into three sections:

The first section features the findings from in-depth interviews with male and female informants, 15 people in total. The section has also been supplemented by data received from two online contacts, both living in the Amsterdam area. These contacts (one male, one female), were not available for interviews, but responded to the research question with their comments via email.

Findings are reported in the first part of this thesis. The findings are divided into nine chapters:

Chapter 1: ‘Normal’ Defined
Chapter 2: Realization and Acceptance
Chapter 3: Social Relationships
Chapter 4: Roles of Independence/Dependence
Chapter 5: Social Aspects of Disability
Chapter 6: Asking and Accepting Help
Chapter 7: Stigmas and Stereotypes
Chapter 8: Gender Relations
Chapter 9: Perceptions of Wheelchairs and Understanding Limitations
Chapter 10: Encounters and Encumbrances

The second section of the presentation of data features two case studies. Noah is a man who was born disabled. This informant was included in research because he did not become a wheelchair user in his life, but began life that way. This man’s story and experiences offer another point of view to learn about wheelchair users. The second case study is about Els, a 30-year old woman, who became a wheelchair user at age 20, and is now paralyzed waist-down.

The third section features photographs taken by three informants and by the researcher. This visual data was provided by two males, and one female informant. Of the men, this includes the case study informant Noah, as well as photographs by Joreon, whose wheelchair use began at age 42. Els provided photographs she took for this research, as well as photographs she wanted to include from her personal photograph collection.

Findings take into account that each individual is unique. At the researcher and her informants’ insistence, it is urged to maintain that every person is different.
Not all disabled people are the same, and certainly not all wheelchair users share the same characteristics. In some cases, the only thing that one wheelchair user may have in common with another, is that they both use a wheelchair and live in the Netherlands. In agreement with Bernard Helander, “There is no set of attitudes or actions reserved for the disabled” (1995:73).

This research was intended as an exploration into what Zola referred to as, “the ordinary lives of people with disability” (1982). Many of the themes discussed in the following section were also findings in a study of physically disabled people in Australia by Lupton and Seymour (2000). The two researchers noticed attributes similarly present in this research, such as communication, mobility, and participation in a wider community (1855).

I. ‘Normal’ Defined

“Either you try to cope with it, or you get in a very deep depression...I tried to restart my life.” (Hugo)

According to what informants said, from interviews and photographs, there appear to be two ways of defining ‘normal’. The first is looking at it on a societal level, and the second way is viewing it from a personal standpoint.

Informants commonly used examples of bright hair colors, body piercing, and strange clothing to illustrate that the nature of what constitutes ‘normal’ is itself shrouded in ambiguity. Normal is not necessarily negative either. It can be very positive, as Noah described, “The people who are famous are famous because they are different. What is normal? I think normal is disappearing.” However, after some reflection, Noah commented, “I think everybody considers himself or herself to be the most normal person in the world. In the eyes of many people, I am not normal, because they cannot relate to me. People who aren’t used to persons like me.”

Nevertheless, some did attempt to provide their definitions of what is ‘normal’, beginning with the society. The social context of ‘normal’ in the Netherlands has shifted (from what was said by informants) greatly since the 1960s and 70s until now. What has been learned from wheelchair users is that there has occurred a movement towards accepting disability as a normal event in life. This has been furthered by implementation of normalization processes, and by better rehabilitation centers for people to learn how to live the best way that they can with disability.
The wheelchair makes its user stand out from others in a crowd. If looked at as a tool, or as equipment, the wheelchair is no different than say, a prosthetic limb. However, although they are the same because they are both meant to improve the lives of their users, it is in two different ways. The wheelchair is meant to improve mobility, and is not really to do with how a person looks. That is the difference between someone who is in a wheelchair and someone who has a prosthetic leg. The prosthetic leg is to make the person look more ‘normal’, as in looking like everyone else. Perhaps the prosthetic limb serves a purpose in this case to avoid being a wheelchair user and in doing so, also bypassing stigmatization. But even prosthetics are limiting in their own way:

We are subjected to continual pressure to conform a ‘normal’ image. This is one of the major reasons for the manufacture of elaborate prosthetic limbs and hands, which are often poor substitutes for the purely functional devices, such as wooden legs or metal hooks, which they replace.

Sutherland (1981) wrote these words in his book Disabled We Stand, a book he wrote from the perspective of a disabled man living in the United States. In his work, Sutherland struggled with the concept of ‘normalcy’, and tried to determine what place being ‘normal’ had in the lives of disabled people. As seen by his comments above, Sutherland felt that prosthetic limb replacements were not functionally useful to those who were fitted with them. He felt that the main reason for the move away from metal hooks and wooden legs was to make people appear more ‘normal’ by having limbs that physically looked like the limbs of those who are not disabled. On the one hand, wheelchairs improve functionality, but they are visually stigmatizing. On the other hand, prosthetics are not so visually stigmatizing, but may not help functionality.

The comparison between what was visually appeasing versus that which was effective in its use forms part of the disabled/non-disabled dichotomy Dartington (1981) wrote about in the same year as Sutherland. Dartington looked at how society viewed a disabled person as “a less-than-whole person”, who was not ‘normal’, when compared to the “really normal” non-disabled people in society. Society as a whole not only separate disabled people from the mainstream by emphasizing their differences, but by doing so depreciate the disabled individual’s sense of personhood, thus robbing that individual of a portion of his/her human dignity.
Wheelchair users know these things, and they are the first to say that being in a wheelchair, is not a ‘normal’ way of living. They also add that though this is true, a wheelchair is not considered abnormal anymore, either:

Normal is changing, because normal is...we as a society make what is normal. As a child, normal is walking. I think it is the same as wearing strange clothes, or having different hair. The normal now, is different than the normal then. There was a more social binding of people to each other, and there was more ethical way about how people should act in a society (20-30 years ago). I think that it is now more, acceptable that people are having...things like that.

“Normal is walking”. When someone has an accident, or something happens in their body to cause them to need a wheelchair, the first things that came to the mind of many people was to learn to walk again. Karl, now 46 years old became a wheelchair user at the age of 15 in an accident with a motor vehicle. He experienced these feelings of wanting to walk again, especially when he was admitted to a rehabilitation center. “At the rehabilitation center I met, for the first time, people in a wheelchair. Karl was not told right away by his family and doctors that he would not walk again. He believed he could make himself walk again at the time, because that was ‘normal’ for him. “And, if I do, very hard, my best, I will go walking out again.”

“In the beginning I was trying to walk because that was your ideal...that was normal. It was normal that you were walking. So, I was trying to reach that ideal.”

After Karl realized that walking was no longer an option, he said, “Okay, so I will stay in a wheelchair.” Speaking to Karl now, he says, “Now, I think I am normal. But when I am talking about then, I’m not feeling normal because I can see it on the faces on people.”

After finding such varied responses to the question of, “What is ‘normal’?” informants’ descriptions of ‘normal’, were put together into a pictorial representation, appearing on the following page. It examines what wheelchair users say is a ‘normal’, meaningful life for them, and how they explain this:

---

2 All names used in this study are pseudonyms to protect informants’ privacy.
Wheelchair users maintain that although they may not appear physically 'normal' when compared to walking people, they are fully capable and do lead very 'normal' lives. The arrows show a cycle of normality, with each section important to the meaning of 'normal'. Informants were positive and encouraging, and said that to be able to live with disability, this was impossible without an optimistic state of mind. The phrases that appear in the arrows are the actual comments of some informants, made during interviews and through correspondence.

Chapter 2: Realization and Acceptance

Let me say, from the moment that you have this disaster, and then you are condemned to a wheelchair, you have to accept it as normal, because otherwise you have no reason to live anymore.

From the point of view of wheelchair users such as the comments above, shifting normality and internalizing the concept of disability occurs in two stages.
First, is realizing what “Life is never normal again”, when a person realizes that walking has become “too heavy” to do anymore, and that sitting in a wheelchair is the new option. “When it’s happened, you think everything is gone. My work was gone, everything was gone. Then you think, I’ll never find anyone, no life, goodbye! You can be depressed about it.”

In conjunction with a loss of the ability to blend-in with the crowd, arrives the realization that one is no longer anonymous. “The body of the physically disabled person is seen as marked by disability. The missing limb, blind gaze, use of sign language, wheelchair, or prosthesis is seen. Disability is a specular moment” (Davis, 1995:12). Karl described this process:

There’s a change in you. You are suddenly aware that people are looking at you. You will see it immediately. They know me because I am sitting in a wheelchair. You are not normal anymore.

The second stage arrives with realizing that life does not have to end because a person is in a wheelchair. This comes with the acceptance that life is changed, and what was ‘normal’ before for that individual may not be normal anymore. There is a new definition for the individual of what is ‘normal’ in his/her life. Perhaps some things can still be normal, but in a different way. “You have, more or less, to accept that you should not think in terms of, Hey! By the way, what should they think of my problem? Try to be normal.”

For example, those who learn to drive a car again are doing something that is largely considered a ‘normal’ activity in the Netherlands. However, it is now accomplished not by using foot pedals, but by controlling the gas and brakes with a hand-operated lever beside the driver’s seat.

According to wheelchair users, it is difficult, yet crucial to arrive at this point of accepting disability, and realizing that life is going to be different, if one is to enjoy their life from that moment onwards. Moving forward for some cannot be possible, of course. There are those who at first recalled fighting against the world because of their own frustration and anger towards their bodies:

When I was 15, 16, 17 years old, I was trying to convince them that I was just a normal person. I didn’t want his ice cream, I didn’t want his ten guilders...trying to convince them that there’s nothing wrong with you. Then you realize it’s too many people...you’re not able to convince 100 people everyday that you’re ‘normal’, it’s too much.
There are the people whose depression consumes them. Depression, however, is not the next step after acceptance of disability, according to data. It is going on with life and thinking about what one wants and how that can come about. Murphy also emphasized getting through this phase, “The handicapped individual must fight all his own impulses to flee back inside himself, to wrap himself inside the mantle of his own impairment” (Murphy, 1990: 158). Karl described his way of thinking about disability:

You are not ill, you just have a handicap. The one thing you must try to do is be happy, because you must live with it. Handicap...you can see it as a tree, with all kinds of leaves, there is something broken off and then something is growing new again. Okay, you are not able to use your hand again, but you are able to do other things. You must find it.

Another informant described what he did after he became disabled:

From the very first moment, I was calculating...I made, already new plans for the future. The fact that I was always making planning, helping me to make my life normal. You must have plans for the future, otherwise life is very difficult.

Normal is being able to do what you want to do, when you want to do it” Then you realize that you are as normal as everyone else, just sitting in a wheelchair, and you are starting to live your own life. Normal is a very wide understanding.

Informants feel they do not fit into the common definitions of being normal. This definition, as used in the English language, means to conform to the masses, or not to deviate or be different from everyone else. Wheelchair users know that they appear different, and that they have a different lifestyle after their disability, then they had before it.

Informants did not suggest stress as something to overcome, or contend with. One may divide the concept of stress into two parts, mental and physical stress. The former was not made point of by informants for this research. The latter, in contrast, relates to how individuals understand their physical limitations once they become disabled. This matter will be discussed later in “Chapter 8: Perceptions of Wheelchairs and Understanding Limitations.”
Chapter 3: Social Relationships

The social network a person has before and after disability occurs is crucial to impact on how he/she copes with an altered lifestyle. Three relationships are important to how a person will react to disability. These are spousal and familial relationships, clinical interactions, and strong friendships.

Married couples interviewed said that their significant other was one of the most important people in their lives, in terms with coming to terms with accepting and living with disability. One couple in particular, Jasper and Alli were interviewed together. Alli is a 50-year old woman living Muscular Dystrophy (MS). The onset occurred in her early forties and because of the progressive type of MS, Alli has been a full-time wheelchair user for eight years. Progressive MS is a gradual deterioration of muscle tissue that always gets more serious as time goes on.

For this couple, ‘normal’ means that they both live with MS together as a unit. Ali said that she was the positive one and her husband Jasper, was the negative one. Together they balanced their dispositions to be steady and able to cope with new adjustments they inevitably had had to make, and would continue to make. Jasper mentioned that before he and his wife knew the diagnosis of MS, there was uncertainty in the air and it was an unsettling time for them until they had a diagnosis. It was then that they knew what it was, and because they knew what was happening, they were better able to deal with it and try to live as they best could with MS. For Alli and Jasper, one of the most important aspects for mature adults in a wheelchair is the presence of a strong marital bond. In their case, Jasper has become Ali’s lifeline to the outside world, and the life they now lead is one where she is very dependent on him.

In some cases, disability after marriage serves to strengthen mutual understanding and married people become closer. Hugo, aged 61, says, “It is not only me that has it; in fact she has it as well. That is the key to success if you are able to accept this with your wife and family, and build up a new life. My goal was that I wanted to experience new experiences, in fact.”

Friends are also important sources of support. Karl balanced having a supportive wife with having a best friend whom had also experienced the transition to becoming a wheelchair user. Karl’s friend Patrick, 46, was also interviewed as part of this study. Both men emphasized the importance of a social tie with another person
like a spouse or friend helps the disabled individual accept what has happened to him/her. When Patrick recalled his time in a rehabilitation center, following his swimming accident, he was in a room with seven other people. It was at that time that Patrick met Karl and the two befriended each other. Patrick said that it was important as a determinant of his future, because “everybody was fighting”, and that they derived strength from each other. When asked to think about his life now in retrospect to then, Karl said:

The people who are around me, they are not saying about what is normal/not normal, that’s just me. If I am going right or left, there’s nothing about what is normal and what is not normal, not in the sense of being handicapped. More about who you are, mostly about how you are going in your own direction.

If I was telling them what was normal/not normal, and I think about it, what was different with the people in the rehabilitation unit...about their way of entering, I think they were not telling me about what was normal. They want you to be happy with yourself.

Another reason why friends who have shared experiences are important is the establishment of a joking relationship among friends. Solange and her friend Noah make jokes about being in wheelchairs, and often tease each other to “hurry-up”. The comments they make back and forth are not meant to hurt each other. Actually, by joking about their disabilities, Solange and Noah say that “it makes it easier to talk about it”, because the topic is no longer taboo, but is brought lightheartedly into the open.

Deborah, 43, said that sometimes when asking an employee in a shop to show her something, the employee may say “Sure, walk this way”, then realize what they said and feel embarrassed. Though for Deborah, this is not a problem, as she understands that the person does not say it maliciously, but rather says it because it is a part of speech. Her husband Fred commented on this matter. He said, “They don’t have to think about it every minute of the day. But realize they are there.” Deborah added, “There are people there. Most of the people in a wheelchair are using the wheelchair as if they are walking, ‘walk with me’, or ‘walk this way’, and then they realize, Oh my god, she’s in a wheelchair. It’s a normal saying here, and the wheelchair is my legs. For me it’s no difference. Yes, I’m a little bit lower, but it’s no difference.”
Another informant named Patrick, 46, emphasized the importance of having a self-help or support group to help cope with disability, following an accident. He became a wheelchair user as a teenager because of a swimming accident. Patrick said that it is more important than talking to a psychologist, who may be called for patients who are suspected of being in denial. Patrick said that self-help or support groups are important because they are formed by people who are all going through similar circumstances. When asked to clarify that he meant that it is not the same as telling these things to a professional, who does not really understand, Patrick said, “Precise”. Patrick’s comments would disagree with findings in a study done by Fitzpatrick (1987), reported on by Bury (1991:458):

Younger patients [...] were looking for a more ‘instrumental’ style of intervention, and information about tests and treatments. Older [...] patients were more concerned to communicate with the doctor about their personal and family circumstances, and the wider impact of their condition.

Comparing Fitzgerald’s findings with the current one about wheelchair users in the Netherlands is not possible. To begin with, many informants were younger when they became disabled. There is no consensus among them that is representative of Fitzpatrick’s findings. They were concerned about their families, about themselves, and about learning to live with disability. They could have cared less about whether their treatment was ‘instrumental’ or not; once they had realized they would not walk again many of them were trying to focus on accepting this. Moreover, several of the informants emphasized the importance they attached with communicating with medical staff. Informants asked to see medical records as Deborah had. Els wanted to know exactly which part of the spinal column was damaged. Hugo had thought about saving money in case an operation could correct his “injury”.

Within a clinical setting, not only are the fellow patients influencing factors to how someone learns to live with disability, but clinical workers are also significant contributors to this process. When informants were asked to recall their time in rehabilitation centers, many noted the differences between those centers that had pleasant atmospheres, and those that usually evoked a shudder from informants, such as the “Het Dorp” project (Zola: 1982). Deborah provided an example of how she felt the rehabilitation center in North Holland where she stayed was excellent, on two points. First, the hospital teaches patients how to live well with disability, showing
them that there are many possibilities for them. Second, there are people from the clinic who take it upon themselves to make arrangements for an individual’s home situation (wheelchair accessibility suggestions, care giving schedules, calling local authorities for notification, etc.) while the person is still in the hospital. The transition to using a wheelchair is made easier by the medical professionals who show their patients that it is not the end of the world, and make sure that they are taken care of after leaving the rehabilitation clinic.

Chapter 4: Roles of Independence and Dependence

When formulating research questions, the relationship between independence and normality was assumed to exist. However, this association did not hold true as expressed by informants. One point that was described and clarified by informants was the importance of asking for help if needed, and doing things themselves which they could do. This latter point came in reference to the sometime-awkwardness of non-disabled persons, who often do not know if they should ask someone who is disabled, if he/she needs help. Sally French (1991) wrote about her own experience with partial blindness and asking for help, “Disabilities tend to make us slow, they are inconvenient enough without making matters worse in a futile attempt to be independent.” French meant that by not asking for help when needed, disabled persons who insist on doing things themselves inevitably only oppress themselves, and that this individualizes disability because it removes it from a social context into a personal struggle. To add to this comment, French wrote,

Disabled people have been conditioned to ‘manage’ and ‘overcome’ their disability, to be ‘normal’ and the play the ‘disabled’ role (....) Striving for independence and normality can lead to frustration and low self esteem (1991:47).

Field research showed that wheelchair users themselves did not link their perception of ‘normal’ with that of their independence or dependence upon others. Rather, they saw these as exclusive of each other. “Very ‘normal’ people can also be very dependent, and people who are very independent are often not normal”, said one informant. Meaningful parts of life as a wheelchair user were captured

Those individuals, who had driven a car before the onset of their disability, expressed their desire to regain that independence which they derived from being able to drive themselves and not having to rely on others to drive them places. This
opinion was also expressed by younger people who did not have their driver’s license yet, as well as those who had become disabled in their teens. "Oh, I will never be able to ride a moped...that was my first thought, and I was not thinking about what it was like to be sitting in a wheelchair..."

How important driving a car is for one’s sense of independence may never occur to someone who is non-disabled and a driver. There are wheelchair-adapted vehicles which wheelchair users can buy, or adaptations which can be fitted to one’s car, truck or van. For wheelchair users, however, this is a crucial necessity, being able to drive a car. This is a way someone who uses a wheelchair can have some control over going where he/she goes. Irving Zola’s "anatomy being destiny" (65), does not stop people who use wheelchairs to try their best not to let their disability prevent them from driving.

Chapter 5: Social aspects of disability

As seen through the wheelchair user’s eyes, there are concerns that they feel should be made open to the public’s awareness. The first is in reference to governmental policies and accessibility to subsidies. Second, there is difficulty often associated with receiving subsidies governmental offices to make necessary wheelchair adaptations to one’s home. According to some informants, it depends on whom a person is in their community, as well as whom he/she knows in their community, and that dictates how fast their requests are fulfilled.

All informants have at some point or another experienced the waiting period often endured by wheelchair users. This can be for many reasons, such as waiting for a part to come in for repairing a wheelchair, having to have tests done to prove one’s facility, or insufficient funding for a new apparatus. Karl wanted to make adaptations to his new home, and applied for government subsidy, which is available for disabled people. About the time it takes from applying to receiving any financial support, Karl said, “you’ll be dead by the time the money comes”. Hugo discussed how the status he had secured before his disability occurred, has helped him learn to live with it. “Frankly speaking, I never met people who made me aware that I was not normal. That could depend on the certain status that I have.” A successful businessman, Hugo is convinced that “My profession, my wealth that I have, my experience, enabled me to be as I am.” For him, the status he had obtained
before the disability and the economic and social advantages that came with that success allowed him to go on with his life.

Another point made by wheelchair users is the need for disabled people to seek out benefits and resources to help them. Raymond, a 34-year-old paraplegic, felt that other disabled persons ought to search for themselves and become aware that there is help available to them if they are pursuant of it. An example of this is that, for some disabled individuals, there is a subsidy for sporting. If he/she wants to join a sports club, money is available to put towards a six-month membership. Another example of support is that if a disabled person needs to move, he/she can receive partial funding to defray the costs of hiring moving professionals.

When wheelchair users need specific services for themselves, such as repairs to their wheelchairs, or needing questions answered, it depends on who one knows. Those who were asked about this said that it depends on how prominent a person is in the community in which he/she lives. If a disabled person knows influential people in his community, the speed at which required services are rendered is quicker than if a person is not well known. Hugo, age 61, mentioned that this phenomenon differs, from large cities to smaller ones, because a person is more likely to make a greater presence on a smaller audience, such as those who dwell in a small city.

Chapter 6: Asking and Accepting Help

“Do you ask for help and take help from others?” Wheelchair users asked about this matter said that it is a most difficult growing experience to learn to ask for help. Ana, a 46-year old mother of two said, “The most hard thing to learn is ask for help, the most lovely thing to discover is all the alternative ways you will find if you are looking in a creative way.”

Hugo also said in his interview that when he asked for help, people were helpful. “So far, I’ve never met people who said, Hey! My God, this guy is in a wheelchair. They all were very helpful. That’s one of my experiences.” In addition, it is important to do things that can be done independently of others, but if there is a task that is too much to handle, it is important to ask someone to help. Informants gave examples of times when they did not ask others for help when they should have. This resulted in aggravated injuries, worsened health conditions, and being put at risks that could have been avoided if they had asked someone for their help. There are
disabled people who try to do everything by themselves, and act invincible.
Informants feel that sort of behavior is "abnormal", because it is 'normal' to ask for help. Some people don't want to burden others by asking them for help. Others want to do it themselves, because it is part of who they were before the disability. Sadly, those who do not ask for help in fact dis-able themselves even more. In a discussion on the matter with Deborah and Fred, they had the following to say to the researcher about asking and taking help from others:
K: Is the most difficult thing to ask for help?
Both: Yes.
Fred: When I go out, and I want to go into a store, I ask somebody, “Can you help me into the store?” You can’t go the ‘normal’ way everybody else can.
Deborah: That’s what they teach you. To learn to...you have to ask. Because if you’re not asking something, you can’t go anywhere. Then you’re sitting at home.
Fred: Then you are sitting behind the plants.
Deborah: That’s what they say here in Holland, then you are sitting behind the geraniums.
Fred: They don’t want to ask somebody to get them out of the house.
K: Is that because they are scared?
Deborah: Nee, they just don’t want to ask.

When Solange was asked if she accepts help from others who offer it, she replied, “I’m not too happy about it, but, when I put my wheelchair in my car, they always say, ‘Can I help you?’. No, I can do it myself. Of course I can do it; I have to do it three, four times a day. The only problem is if I say ‘NO’, and they are doing it anyway.” Her 24-year old friend Noah added, “It’s good intentions, I know. But, when you say “no thank-you”, and they still do it; that’s very annoying, I don’t get that.” This opinion was not limited only to younger informants.

Older informants were also asked about asking for help. When asked about his perspective on independence and dependence, Jorcon (age 45) said,

You are very often depending on people, and the disability that most people have is, that they don’t dare to ask for help. In some cases, that is a bigger disability than the wheelchair. With help, I think you should ask for it. People want to look independent.

Asking for help was not something limited to the regular wheelchair users. Remy, 27, was asked to do participant observation (discussed in more detail later). When his assistant left him stranded, Remy asked someone passing him to help him across the busy street.
Chapter 7: Stigmas and Stereotypes

Erving Goffman defined stigma as, “the situation of the individual who is disqualified from full social acceptance” (1963:9). He emphasized that social identity is established at first sight, and is denigrated by “undesired differentness” (Ibid: 15). Some informants also engaged in “Impression Management”, or trying to behave the same way, and do the same activities as a person did before they became disabled (Goffman, Csordas).

Informants were asked during interviews to discuss three topics. The first was to provide examples of situations of when they felt mistreated. Second, informants were given an opportunity to express their frustration about why mental disability was associated with physical disability. Thirdly, informants also emphasized a need for media to portray disabled people better, and offered solutions to this problem.

For example, when informants went shopping with non-disabled friends or family, they would ask the shop clerk a question, and the clerk’s answer would be directed towards the non-disabled person who accompanied the informant.

A link described by certain informants was the connection made by non-disabled persons of mental deficiency with physical disability. The emphasis was also noted by the researcher in previous observations (Parhar, 2003). While there are many possible reasons for this mental-physical link, it was necessary to ask the wheelchair users, why they thought this happened.

When asked why this occurred, one informant replied, “I only saw it on t.v., and I thought that everyone was mentally disabled.” He also recalled his youth, when the only wheelchair user he met was a man on the bus:

Before the accident, that was the only man I knew with a wheelchair, and what he did, when he was going by a bus, cause he could walk a little bit...and he always made cat noises...so I thought everyone sitting in a wheelchair were lunatics.

There is no such thing as wheelchair users having a silent acknowledgement, or gravitation towards other wheelchair users, or wheelchair organizations. When one person riding in his scootmobile passes another on the street, there is no obligatory acknowledgement, perhaps, unless he/she wants to know something about the wheelchair the other person using. People who use wheelchairs do not go out of their way to greet each other in a special tone. In fact, some wheelchair users avoid other wheelchair users altogether, saying, “It is not my world”. These people abhor
disability organizations and publications. Although they create bonds among disabled persons, they also are felt to separate them from the wider society. They say that special organizations make disabled people much too "out there", than need be. This is why Noah, aged 24 denounced a practice taking place in the Netherlands currently, involving celebrities who make a disabled fan's dreams come true by spending the day with them. According to him, this made disabled people look "pathetic".

Younger informants stressed the importance of the media portraying disabled persons in a favorable light. In Lupton and Seymour's study on physically disabled people in Australia, a 30-year-old paraplegic woman called Jenny, said:

All those soppy [women's magazine] articles that have these brave profiles - 'They told me I'd never walk again and I walked out of that hospital'. Yeah right! You could've been doing something useful, get yourself a decent wheelchair, go and learn how to use it and then go and do something useful! (2000:1858)

Solange felt that there needed to be more disabled people on television in the Netherlands. This would help non-disabled people learn more about disability. Also, she added that this would offer positive role models for other young people who were disabled, and would help them cope with disability better by seeing someone successful who was also disabled featured on television. "The media...they have to make programs about what people can do, not what they can't do. That is the biggest problem." If one can recall, this concept was visited in the Introduction, with discussing how people who are not disabled sometimes assume that they know what disabled people want. This need not be such a problem, however, especially based on what informants said about other people deciding for them. The simple solution to avoid the frustration and waste of time and money when the wrong implementations are made is to ask the disabled community what they need. It is so simple to ask someone to list things that would make their life easier. If this were done before a television program was made about disabled people, for example, it would save the bad fan mail the program would surely get later.

An informant spoke about a television show that was made in the Netherlands, in which a "stupid" reporter wanted to 'help' a disabled man with his sex life. The reporter arranged for a prostitute to entertain and perform coitus with the disabled man. Now, maybe this was what the man wanted, and maybe it was just what the reporter needed to boost his ratings, one never knows. In any event, it did not show
the disabled community in a good light. It does not bode well for the image of other disabled people in the Netherlands, because it portrays them as lonely, sex-starved beings that need others to help them get their fix. If disabled people were asked if they wanted such a program to air, they would have said, “No”. It only served to reinforce the wrong-minded stereotypes that many people believe about disabled people, like the one about them not having sex and sitting in the window looking out all day long.

The example cited above is not limited to reporters. Russell Shuttleworth (2001) wrote an article entitled, “From Experience to Theory in Anthropology’s Engagement”. Engagement is what Shuttleworth did for one informant of a study he was doing who was disabled. Shuttleworth arranged sexual partners for Josh (the informant). Then, he placed his actions in the realm of positive ethnographic involvement. Shuttleworth first created an ethical disaster and then wrote an article about his multiple roles as a disability ethnographer and a disability scholar! He portrayed himself as a savior for young disabled people and made it seem like they cannot find sexual partners on their own.

Media portrayal of Dutch musicians who are disabled is not favorable. The researcher, while at a social event during the course of this research, was shocked, and amazed at a rendition of “Ik verscheurde je foto”, done by a non-disabled man. Originally, for those who do not know this song, it was sung by Koos Alberts. During his singing career, Alberts was in a car accident, consequently his back was broken, and he is now in a wheelchair. Watching a non-disabled man act out his perception of what he thought the disabled man looked like when singing was abominable. Scanning the faces of the crowd, however, revealed people who were laughing while shaking their heads. Equally appalling were the comments of one guest who defended the singing act, saying, “he had to make it funny”. Another guest said, “I know I mustn’t laugh at them, but it was funny...and the guy who sings it is like that. The researcher did not take issue with the guests because she had not yet seen what Alberts looked like. One day when an image of Alberts was shown to her, the researcher felt there was no real likeness to the gigolo who impersonated him at the party. The entire scene was a mockery of wheelchair users. At the end, the man pretended to stand, and then fell back into his wheelchair. That particular moment showed someone who thought that wheelchair users all want to stand up, out of their wheelchairs, but cannot do it, and will inevitable fall down and back into their seats.
A room full of people saw that performance, and the researcher was told that the same performance has been done several times. A photograph of Koos Alberts appears below:

As much as some people discredit the disabled people in the Netherlands, it does not have a traumatizing effect on strong minded people like Hugo. Role models are positive influences that are encouraging to people who must cope with a life altering disability. Hugo, aged 61, drew a pictorial representation of his own coping with disability, which was made easier by finding role models. A similar drawing to the one made by Hugo is shown below:

**Figure 3: The Importance of Role Models**

**Before Injury**

- Examples: Political figures, sports athletes

**After Injury**

- Role models
Hugo described two lives that he led. There was the life he had before the ‘injury’, and the life he has now, living with the result of the ‘injury’. Because of his gravitation towards finding role models, Hugo put depression behind him. Emily Martin also uses this description as “the end of one kind of body and the beginning of another kind of body” (1992:121).

Chapter 8: Gender Relations

Solange was asked about her opinions on dating. For her, a single woman of 20 years, dating was a regular activity, contrary to what she said most non-wheelchair users might believe. The process of finding someone takes longer for people in wheelchairs, but to Solange, it is worth it because, “when you are going out with people who are thinking more about the world than standard, you are serious.”

Contrary to popular opinion is the assumption that disabled people prefer to date other disabled people. Of all the couples interviewed, only one pair included both husband and wife were disabled. When Solange said she was out with Noah, she said that people always assumed that they were together, as a couple. Solange prefers to date people who are not in wheelchairs, because it is “easier”. This opinion is shared by Raymond, who at 34 years old is seeking a committed relationship “with someone walking”, because he feels that mobility and intimate relations “are better if both of you aren’t disabled. Then it gets too tricky and you can both get hurt trying to do things.” Raymond says, “We can have sex, too”.

When two friends of the same sex have a similar disability, it can happen that one friend considers him/herself to be tougher, than the other does. Noah described one of his biggest pet peeves as the “pathetic” disabled person, who thrives from others’ pity. During an interview with Alli, she retold a story about a female friend of hers. She was talking about a telephone conversation the woman (who also has MS, but in a much less severe form). The friend is still able to walk and use the washroom facilities by herself and requires only minimal assistance in her daily tasks of living. According to Ali, her friend is always complaining about having the disease to Ali. Ali laughed as she noted how she herself never complained about the pain, yet her female friend always complained, and that friend didn’t have nearly as much difficulties as Ali had. Ali said that she wanted to say to her friend, “Just be normal!” and deal with it instead of wanting others to glom over her and make a fuss.
Chapter 9: Perceptions of Wheelchairs and Understanding Limitations

This section explores two main ideas. The first part is about how physical limitations bring about considerable stress in people who suddenly become disabled. It is an elaboration of a theme mentioned at the end of the first chapter. The second part reports on how wheelchairs perceive themselves, and where the wheelchair fits into their definitions of self.

It is stressful when a person recognizes that his/her body is vulnerable. Although the actual manifestation of stresses can be mental and physical, physical stress seems more prevalent among wheelchair users. Stress about the body is compounded by feelings of frustration and defeat because the individual can no longer do what he/she used to do.

Often, wheelchair users push themselves hard at the things they can do. Unfortunately, this attempt at finding something they can do well can backfire and hurt them when it is taken too far. Hans competes in many athletic events for people with wheelchairs. He is an avid sailor, races a handbike, and plays wheelchair tennis. During the interview, Hans talked about how he pressures himself to compete in exhausting sporting events because it makes him feel ‘normal’. When he has just finished a race, or won a tennis match, he has something to brag about to the friends who he “partied hard with” before he became disabled. Sporting is one of the only things Hans feels that he has in common with his old friends. Part of the interview is transcribed below:

K: Wow, sailing, biking and tennis, too? You sure are an active guy. How do you do it all?
H: I make myself do it because I feel normal when I’m out there doing the regular guy-stuff that other guys my age are doing.
K: How does sporting make you feel ‘normal’?
H: Well, it’s like...the more I do it, the more I can feel good about the situation, you know?
K: So you do so much so you feel better about being in a wheelchair?
H: Yeah, I guess that is part of it. I push myself because...what else can I do now?
K: What was it like before?
H: We were so crazy back then; we pushed ourselves to take risks for the thrill. Yeah, they’re still so crazy; they jump off cliffs, just because they want the thrill. How can I compete with that?
H: I do my sports because then when they call me or come and visit me, I have something to talk about. Otherwise, you’re sitting having a beer with friends, and there is nothing to say.
K: So you have something to talk about?
H: Yeah, because they’re out having the time of their life and you’re stuck in a wheelchair. It gives me something to talk about, to still look like I am one of the crazy guys.
K: What will you do if you hurt yourself doing too much?
H: It doesn’t matter because I’m already sitting in a wheelchair now. Then that’s it.

Unlike Hans, when people hurt themselves for most it comes as a wake-up call to slow down. Karl recalled a time when he was redoing his driveway, on his hands and knees for hours a day. He pushed himself to get the job done, but ended up causing him pain. He damaged one of his hands doing too much. It taught him a lesson about personal limits.

Through making these kinds of mistakes in judgements, wheelchair users become very aware of their bodies and of their limitations. “I know where my problems are”, said one woman. She referred to her physical restraints and parts of her social life that had become limited since she became disabled. Travel, for example is a part life that becomes limited when disability occurs:

You have to understand that there are many limitations. Going out for holidays, for me [...] we never go on holidays anymore. Is there a huge room? Is there a huge bed? Can I get into the washroom?

Many wheelchair users prefer to stay home, or have their own car if they need to travel. They say that other European countries are not as accessible for them, and that they can come and go as they please with their own transportation. They are glad “to be disabled in Holland”, because they consider the Netherlands among the best countries for disabled people to live in.

The second section of this chapter is focused on how the wheelchair becomes part of the self, or rejected as part of the self. The way an individual feels about his/her limitations relates to how he/she feels about having a wheelchair. There were many responses to the question of whether or not informants felt that their wheelchair was a part of their person.

Individuals expressed distaste towards other disabled persons’ designating their wheelchairs of crutches as part of who they were. When asked if she would reply in such a manner to a question of whether she felt her wheelchair was a part of her, Solange retorted, “No, no. It’s a part of me? That’s not a part of me.” Hugo similarly answered, “I don’t see my wheels. My wheels are all the time behind me. That’s how, from the very first moment, how I accepted it.”
However, there were mixed responses to this question. Deborah said of her wheelchair, “My wheels are my legs”. Merleau-Ponty compared this to adjusting to a new car, “To be a good driver, one must engage in a sense of incorporating the car into one’s body, and this process is necessary” (Langer: 47). For Deborah, the wheelchair is what keeps her mobile, to be able to move from one place to another, and without that, she is bed-ridden.

When I am sitting in a wheelchair, the wheelchair is part of me. It is bringing me where I want to be, so it’s part of me. That is what you have to learn, and sometimes it is difficult to accept, and sometimes I said, “I don’t want to see it, get the wheelchair away from me, for a day, two, three, four or five, but we can’t do without it. It’s part of your life, and you can better enjoy it.

Wheelchair users are aware of what their bodies can do, and what they cannot do. Often, the feelings that are associated with new limitations on one’s body are difficult to endure, and cause stress and frustration.

In the transcribed section which follows, Joreon, age 45, described his experience to the researcher:

J: There is a lot of frustration, but you have to overcome that.
K: How do you overcome that?
J: It depends on the situation. Sometimes you have to give in, just have to accept it and say, “Okay, that is something I can’t do.” In other cases, you have to fight it hard enough to do it yourself in another way, or ask for help.
K: Has disability made you stronger, mentally?
J: Absolutely. If you’re not strong, then you don’t survive.

Body awareness was shown by Hugo, who is 61 years old. When Hugo was 55 years old, there was a collapse of a blood vein in his back, and it ruined the spinal cord entirely. He has no feeling beyond his thoracic number seven and is a wheelchair user. Every 24 hours, Hugo experiences phantom pain in his lower body, what has been written about by Oliver Sacks in his knowledge of amputees and paralyzed patients (The Man Who Mistook His Wife for a Hat, 1986). Hugo knows when his pain will occur, and because of this, he must schedule his appointments on days when he knows he will be pain-free. Hugo experiences phantom pain sensations every 24 hours, without fail. “It is felt on the upper part of the skin, and normally you should not feel the pain, but I do. [...] The pain is always the same. It is part of normal.” He must plan his life according to which days are not a “pain day”.

Merleau-Ponty recognized the phantom pain phenomenon in which people have lost a
limb or use of certain body extremities. The memory of a body function is still in the mind; therefore, sensations still occur in the body, triggered by the mind. “This is an example of how perceptions are conditioned by their personal, bodily memories” (Strathern, 1996:37).

Chapter 10: Encounters and Encumbrances

“There are so many stupid rules for people who are disabled.” (Hugo)

A question was raised during interviews, about under which circumstances wheelchair users feel they are marginalized, and made to feel not ‘normal’. Informants were asked to give examples of times in their lives when they felt mistreated, and to tell how they dealt with those attitudes of indifference.

Staring is something everybody does, but nobody is comfortable with being stared at. For people who must use a wheelchair, going to a Queen’s Day festival in Amsterdam can be a harrowing experience. This is not only because of the careful navigation which must be done to weave in and out of crowds with a wheelchair. This discomfort arises when one realizes that “someone is gawking at them”. This may be something obvious for wheelchair users who have become accustomed to people looking at them, but for people who haven’t been in a wheelchair for long it is a different experience. Solange, the young woman mentioned in previous sections, said,

It only happens when I go to the Supermarket, by my parents’ house, and there are very stupid people. When you go to an event in Holland, like Queen’s Day, that’s the reaction you always get, “What are you doing here?

Solangne had pursued an academic interest in the medical field. She was not able to finish it because others covertly and overtly rejected her. In addition, she felt that they treated her as a specimen for analysis. “Someone said to be, ‘It’s a study about disabled, not for disabled.” Solange continued:

Sometimes when I visit an information desk for new schools or universities. I went in a medical course once, because I liked it. But you feel the eyes on your back.

But sometimes, I think that is not the only problem. They are like, 17, 18 years old, they’ve never seen a wheelchair before, “Ah, a girl in a wheelchair”, so everyone is watching and you’re thinking I can’t do anything stupid. When I
go to school with blue hair, everyone recognizes me, when I fall down, everyone sees that. You are a show.

In contrast, some people who use wheelchairs believe that looking at someone intently may also be a way of trying to understand them. This is displayed often by young children who may look at someone in a wheelchair with a curious face. They want to ask the person sitting in the wheelchair questions, because they want to know what happened. That is natural and ‘normal’ for children to look, or ask questions, when someone looks interesting to them. According to Deborah, the part that makes it a negative scene happens when parents pull children away and chide them or apologize profusely for their children’s ‘rudeness’. If they are told not to look, or not to ask questions, they will learn to be awkward around people who are disabled. Hans, age 29, says “I don’t like it when people act strange around me. They don’t need to be like that.”

Deborah says that children are on the same level as someone sitting in a wheelchair, and perhaps because of this, children are more apt to question. A portion of an interview with Deborah and her husband Fred follows:

D: People who are standing are looking on the level they are standing. That’s why children ask people in a wheelchair, ‘What’s wrong with you? Why can’t you walk?’, because you’re on the same level. When they’re standing, they look over you. It’s not that they’re not interested in you, but they don’t see you. Children always go to a person in a wheelchair and ask, ‘Why are you not walking?’

F: And then you give the answer and they go away.

D: Parents you see taking their kids and they say, “Don’t ask”. Let them ask, because then they know and realize that there are people who are not going to walk and are sitting in a wheelchair.

Noah brought up another important point to consider. He said, “You don’t always know why people stare, it could be your trousers, it could be your wheelchair; there could be multiple reasons.” Perhaps people are not staring at the wheelchair. After all, someone in a wheelchair might notice the type of wheelchair someone else is using, and inquire about it. “Sometimes if you are interested in somebody, or the wheelchair they are using, you get into a conversation.” Just because someone stares does not necessarily always mean that they are staring at the wheelchair. “Maybe your zipper is open and everyone wants to see what you’ve got, you never know”, jokes Hans.
CASE STUDIES

Case Study Informant: Noah
Interview 1: Saturday, June 14, 2003
Interview 2: Thursday, June 19, 2003

The researcher was contacted by Noah as the outcome of a posting that was placed online www.handicap.nl, a consultation website for disabled people living in the Netherlands.

Noah is 24 years old. Unlike the other participants of the study, Noah did not become disabled at some point in his life. Rather, he was born without the lower two portions of his spinal column. Noah comes from a Moroccan family background, but he identifies himself as being Dutch, which made him eligible for the Dutch sample of this research. Noah spent most of his life within medical centers. Therefore, he was more in contact with other Dutch people than with Moroccan people. That is one of the reasons he identifies himself to belong more to a Dutch cultural origin. Growing-up, Noah only saw his family on weekends, perhaps once a month. He and his father had a strained relationship, and his father died two years ago. His parents had other children, and decided that Noah would be best taken care of by facilities of the Dutch healthcare system. However, Noah does not have resentment towards his parents, as he feels that he was better off being raised in the clinical setting than being raised at home.

Noah has an excellent command of English. For this reason, the interviews were easily done conversationally, with Noah being able to convey to the researcher what he wanted to express. Photographs taken by Noah appear in the photo elicitation portion of the findings.

On the topic of normality, Noah felt that there were many ways to define ‘normal’. For instance, ‘normal’ can be the way one feels about him/herself at a given point in time. In addition, Noah alluded to the common definition of normal as belonging to the group, fitting in, or conforming to a recognized norm:

Normal is very personal...it depends, it's also a cultural thing. In the Western world, it is the situation that the majority is in. When you lead a life exactly like most of us, studying being healthy, walking, being happy, marrying when you are 25, you know, or 26. I think that is normal.
When asked if the above description applied to his life, Noah was uncertain if that was the case. He felt that his life and his experiences set him apart from most people, primarily because most people had not spent as much time as he did living in different hospitals and medical centers. After some reflection on the question on his own perceptions, Noah answered, “Considering my background, and the things I have gone through. It is a gray mass.” He situated what he was saying by probing into the notion of normality. “Everyday, less people want to be normal. There is a change in the Western world. Many people don’t want to be normal anymore.” Noah considers himself different from others, because of his upbringing, “When you are not part of that gray mass, you are special. Everybody wants to be special.”

Noah clarified what he meant by “special” by giving an example of how celebrities earned fame and sought fame through being different from everyone else. “The people who are famous are famous because they are different.” Then, stepping back from the example, Noah thoughtfully added, “What is normal? I think normal is disappearing.”

Noah was asked to return to his own perception of his own normal-ness. “I think everybody considers himself or herself to be the most normal person in the world. In the eyes of many people I am not normal, because they cannot relate to me.”

Noah is adamant of his detestation of other disabled people in wheelchairs that play the role of the “pathetic” person. “I hate people with attitudes like the pathetic person [...] don’t call me pathetic or awkward. I’d be insulted.” For Noah, there is no need for people who are disabled to be so weak and futile, because of the many opportunities and help available. In the same breath, Noah also feels that as much as disabled people need to come out of their shells, so do those who are not disabled. “Both sides have to be flexible [...] I go to school, I sing. To lead a life as normal as possible, it should work both ways – the government, citizens and the disabled themselves.”

On opportunities, Noah feels that people should take it upon themselves to seek out ways that can make their lives easier and more enjoyable. “People in a wheelchair should know that there are more opportunities than they’re aware of.” There are wheelchair users who do not make the most of their time, and spend the time that they do have complaining about what they do not have, yet do nothing to acquire things for themselves.
Because Noah spent much time outside of a home life with his family, he felt differently about his own personal experiences compared to someone who grew-up with his/her family around.

Noah said that for him, death was not a huge deal because all around him growing-up, people died, so he became desensitized to the process of dying and mourning. “I’ve seen so many people die that I think to die is very normal.” When his own father passed away, he recalled having little emotion. “Dying is normal, everybody dies. Why should you mourn so much when they die?”

Noah says that he was at an advantage because he was able to do many things on his own. “It was an advantage, because I learned to be very independent. I did many things myself.”

However, after some thought, Noah countered his statement by admitting that for him, perhaps a negative part of growing-up in hospitals and rehabilitation centers was that he did not really have a home. “The disadvantage is that I never had the comfort of a home. I always moved. I wasn’t in the same room longer than half a year, so I never had a firm base.” Despite this, Noah maintained a reticent disposition about the situation and does not have resentment towards his parents. When asked if he did, Noah said, “No. I know my father, I know my mother. I understand the situation too well. I think it was the best solution, and in a way I’m glad.”

Noah says that growing-up, he never knew what being homesick meant, and that he could not understand sometimes when on trips with kids his age, and some would start crying saying that they missed their pets or their mother. For Noah, this was a foreign thing, homesickness, because he was almost never at home with his parents.

Remembering times when he was treated indifferently, Noah recalled, “I was surprised at how backward some people were.” One example Noah gave was of being in a shop and being ignored. “For instance if you ask your question to a shop keeper, a reply not to me but to the person I was with.” One reason for this ignorance could have been that people did, and still do, associate physical disability with mental disability. Noah was asked whether he thought some people did assume this to be true. Noah said, “Yes, yeah. One of the many interpretations is, when you are in a wheelchair you are institutionalized (mentally).”

An issue that Noah faces daily is the problems with travelling. There are two ways this is a problem, transportation, and accommodation.
Last year, I went to Belgium, and that time, I really had to take care of things in advance. They really wanted to know a few days ahead, “When will you arrive at the station (because we have to take care of the bridge to put you on the train)?”

For people who use wheelchairs, specialized taxi vans are available to contact for rides. These vehicles are suited for wheelchairs. They are convenient when they pick-up and drop-off at regular times, but Noah has experienced times when he had to wait too long to arrive to a destination which should have taken much less time to reach than it did. Noah wants to get his driver’s license as soon as possible. He is taking lessons in a wheelchair-accessible car. “A huge problem would be travelling. It is important to get a driver’s license.” Transportation can be a hassle for many people who use wheelchairs, because they must always call ahead and make arrangements.

Noah has certain views about building accessibility in the Netherlands. He does not expect that every building on every street is made suitable to wheelchairs, because in some cases, it is not possible to reconstruct historical buildings.

In an ideal world, everything would be accessible for me, but it wouldn’t be realistic. It’s difficult, but you have to be realistic. That is my personal struggle... In what way, should all places in the world be accessible. I know a boy who says, “Every building in Holland should be accessible!” I think you would be crazy to think that.

On being realistic about accessibility, public places in the Netherlands should be more accessible for wheelchair users. For many students who use a wheelchair, academic choices are seriously limited by the lack of universities designated as ‘wheelchair friendly’. Noah believes that people should be flexible. He means that both disabled and non-disabled people should try to meet halfway, especially in circumstances where helping someone could avoid the problem of access:

Public places, on the other hand, should be accessible. I should have the possibility to study wherever I want to go. That should change. If I want to go to a club, and I know there are stairs, I have to make up my mind: Should I go with other people who can carry me, or should I go to another place.

Along with exploring the possibilities, enabling oneself to overcome obstacles, and being positive about life, Noah has an important message for others. Noah believes that, “As long as you are creative; as long as you are willing to work for solutions”, people can do many things in life.
**Case Study Informant: Els**

Interview 1: Saturday, May 24, 2003  
Interview 2: Thursday, July 3, 2003

The researcher first met Els on May 24 at a handbike race held in Vondelpark, sponsored by an Amsterdam revalidation clinic. During the races, both researcher and Els chatted casually about the race event. Following the race, Els agreed to go for a stroll in the park and talk about her experience in a wheelchair. The second interview took place in Utrecht, at the home of Els.

Els is 30 years old. The interviews were conducted in English, as Els is comfortable with her English. Her mother is American and her father is Dutch. Els has been using a wheelchair full-time since she was disabled in a diving accident at the age of 20. She was on vacation with her family in the United States during the summertime and they went swimming. She jumped from cliffs into the water below because, "it looked deep enough to dive into", but the water was too shallow. Her spinal cord was damaged by the accident, and since then, she has not been able to walk and has to use a wheelchair.

For Els, being 'normal' is not easily to define. Els says, "I think I'm a regular, just like everyone else, only I sit in a wheelchair. But I'm still completely a normal person." She added that she did not appreciate how people sometimes stare at her when she is trying to run errands by herself. "I think others don't... when they look at me, they think it's strange, but I am trying to live as normal as I can." Els can do many things independently of others, helped by her motorized wheelchair and scoot mobile. Because of these things, she does not have to ask people to push her around, or feel that she cannot go far from home. She can do it, but only with the aid of her wheelchair and scoot mobile.

Els has a two-sided response to whether being able is the same as normal:

If you mean to do something, to be able to do something that others can do also, yes, then it is the same. You cannot say that if I am not able, or that I am handicapped, disabled, whatever, that I am not a normal person. I don’t think that I am abnormal.”

Els feels that people who do not know what disability is about, often make “connections” which are unrealistic assumptions. Before her accident, Els had only heard stories about disabled people, “They were the ones who were...a little bit crazy, lived in sanitariums, mental hospitals, you know?” She had also made the mental/physical connection that many people make about people who use
wheelchairs. “Before it happened to me, I thought their legs didn’t work right because their heads weren’t working right.” She added that she thought that “something wasn’t working right, properly in their brain, and that’s why they could not up-stand.”

Having a good time is important to Els. She has an active social life. She enjoys watching other wheelchair athletes compete, but also competes herself in ballroom dancing. “I do what I like. I go ballroom dancing with my friend every week [...] in a wheelchair. You can still enjoy yourself.” One thing that Els regrets that she cannot go out like she used to. “You cannot do whatever you want all the time. Your life changes. It’s impossible for me to go to the disco alone. If I go, I must go as part of a group, or with someone who can help me.” All of this must be to go to a place that is wheelchair accessible, which Els says is not commonplace for nightspots in the Netherlands. “They think we just sit at home all day and do nothing, but we like to have fun, too,” says Els.

For many people who begin to use wheelchairs during their lives, they have to struggle with depression. The transition from walking to being seated in a wheelchair can be a very difficult change. Els knows how this feels. In the beginning of her wheelchair use, she had to learn to cope with anger and frustration that she felt about herself, and also control herself from projecting that self-negativity towards people who were trying to help her. When asked about these feelings Els said the following:

How do I handle bad feelings? Ja, well, it happens, so what? You go on. I get to feeling bad sometimes but it’s not lasting for very long [...] get over that and learn to live with the disability. Otherwise, then you might as well be dead - you die on the inside. That is why I try not to let what other people think bother me. But I am not dead. My life is not over [...] think positive. If you get depressed with it, then everything becomes more heavy than it needs to be.

Els experienced a big change from her life before the accident and after the accident. When asked to give examples of things in her life that were not the same now as before, the first point Els made was about dating. This is similar to what Noah and Solange said about relationships. This is part of the dialogue with Els:

K: Was there a change of ‘normal’ for you?
E: Yes, I got more boyfriends before I got the accident (laugh). Ja, now it is different because some men are not comfortable with the idea of dating someone who is sitting in a wheelchair.
K: How do you feel about that?
E: In a way, it is bad, but it is not all bad because when you finally meet someone, and things are going well, then you don't worry if he's with you for other reasons. You know that he is with you because he likes you. That's important.
K: But getting to that stage, that's the hard part?
E: Oh, it is awful trying to meet people. I chat with people on the internet, but I always have to make sure to tell them that I am in a wheelchair. That makes things difficult.
K: Do you have a boyfriend?
E: No, not now. But I will try to find one. I had a boyfriend before, but that was not good because he was also handicapped and he was sick all the time.
K: Do you prefer dating someone who is walking or in a wheelchair?
E: Walking, absolutely. It is easier that way. You can have help to get around. I know, that sounds like I am... a hypocrite. But if I fall out of my chair, who will run to get help if I am with a man who is also in a wheelchair?
K: What about intimacy?
E: You know, that's funny because people don't think that we can have sex. Well, I say to them, "Sure, we can have sex!" We can do it, if we get a chance to, and it is not that difficult if your partner is not disabled it goes easier.

K: Is that another reason why you prefer men who are not in wheelchairs?
E: A big part of it, ja (laughs).

On the topic of how she feels about the Dutch treatment of disabled persons, Els feels good about it. "It is better to be disabled here than any other country in Europe." Els feels that in the Netherlands, there are "special services from the government and good healthcare", and that is why she is happy to live here. The only problem Els has with the system of healthcare in the Netherlands is the length of time it can take to make changes. For example, she has had to repeatedly telephone and write letters to have repairs done to her wheelchair's seat. Recalling the incident, Els said, "They should realize that it takes a "normal" person much energy to call again and again, but it takes double the energy and time for us to do it. They need to be faster."

In her opinion, it depends on if people are accustomed to seeing people in wheelchairs, to gauge how they will treat them. She has her own reasons why people may stare at her, saying "Because they don't understand it, or they are afraid to ask me." Els emphasizes the importance of encouraging people to ask questions, so they learn more about disability. If she sees someone looking at her, she will usually ask them if they are curious about her, and tell them that it is alright with her if they ask questions. Of particular importance to Els is the fact that parents still discourage their children from looking or asking. "That is how they see it is 'normal' [...] it's another way of being 'normal', and then they learn that they don't need to be afraid."
PHOTOGRAPHIC ELICITATION

Photographs were used to show the 'normal' lives of people who use wheelchairs, and to show what things in their lives were meaningful to them. Using photographs as a research method preserves first impressions and orientations, especially when a researcher's time is limited to six weeks.

Three informants were asked to take photographs: Joreon, age 45, Noah, age 24, and Els, age 30. Joreon and Els became disabled at ages 42 and 20. Noah did not become disabled during his life, but has always been in a wheelchair. The photographs and comments that accompanied them reflect many themes that were also found apparent during in-depth interviews. These relate to notions of spatiality and accessibility. This section is divided into three parts. The photos taken by each informant are found together with his/her comments, in the appropriate section.

Noah's Photo-Reflections:
(Comments written by Noah about his photographs are also included in italics)

The Church
Noah: Near the town I live and my birthplace. A nice centre with a beautiful church, The Eusebius. You can go there for concerts or exhibitions. There is an elevator of
glass which can almost reach to the top. So it’s possible for me to climb this beautiful monument.

Playing the piano
Noah is enjoys music, and the performing arts. He attends lessons for performing arts. “Music is very important to me”, says Noah. He enjoys playing the piano and singing. His dream is to perform as an actor.
Taxi Transportation

Noah: It’s called ‘regiotaxi KAN’ (Knooppunt (junction) Arnhem Nijmegen) and is for disabled and elderly persons, an alternative for public transport. Not a very good alternative (as I told you before) but the taxidrivers are cool, most of the time. Inside the bus is a system for chaining the (powered) wheelchairs. It’s currently my only possibility to travel independently. But that will change soon.
Student Driver

Noah is learning to drive a car adapted for wheelchairs. One of his short-term goals is to pass his driver's examination and obtain a license. This way, he can look to buy a car for himself, and he will not have to rely on others for rides. With a car, he will save time and stress because he will be able to travel when he chooses to. The interior of this vehicle is shown in the following photograph. Note the levers intended for hand-use, as well as the grip on the steering wheel.

Noah: Soon I'll try to get my drivers licence and get my own car. But until then I have to use this red Volkswagen Golf. A nice car with the right adjustments for me; hand gas and a brake right below the steering wheel. The drivers' seat can go as low or high as I need it to be.
Noah’s Home
Noah: A temporary apartment which I’ll leave soon for my own home in the South of Arnhem. I used to train there for independent living (administration, household etc.). I have nice neighbours there. On the picture is the great Moniek. She is slightly spastic and sometimes needs crutches for walking. We both live in the last two apartments of the block and it’s really the noise/voice area, since both of us sing all the time.
This photograph shows the parking garage of the facility, where one day Noah hopes to store his own personal vehicle. First, he has to pass his driver's license. Below, Noah is standing outside the entrance to his building:
Photographs from Els:

**Vondelpark Handbike Race, May 2003**

Els is an avid fan of handbike racing. She and the researcher recently attended a Handbike race held in Vondelpark, where these photographs were taken. A friend of Els is pictured in the foreground, wearing the red jacket.

Els feels that it is important for others who are, or have attended rehabilitation centers, to show their support to others. She goes to the events, “to cheer on other people who may need some encouragement to keep on going.”
Friends: Els is close with her friends, who help her during times “when I feel depressed”. They joke around together and joking helps Els deal with “bad days”. She cautions, however, that “when I make a joke about myself I am doing it to make things less awkward.” Els says that other people may not have the same intentions when they are making jokes about disabled people, “maybe they are also trying to be funny, but sometimes you have people who are trying to hurt you.” When Els feels that someone has crossed the line she says, “Then, you have to, you must speak out and tell them not to do that. They have gone too far.”

Els goes with friends to what is known as “winter sport”, going skiing in France and Austria. Els cannot ski, but she has friends who are instructors and are disabled.
Ballroom Dancing
Every week, Els goes dancing with a friend of hers. She was given a photograph of this origami representation of two people dancing. This photo is very special for Els because "Dancing is normal, and when I look at the photo, I think That is me, I am also normal, because I also dance. Els enjoys her ballroom dancing classes very much.

**Joreon’s Photographs:**

These photographs were taken by Joreon at his June vacation, a week-long getaway hosted by the Zonnebloem organization for disabled people. On this trip, there were 51 people, some of whom are photographed in this section. While Joreon is away, his wife and two sons also go on their own vacation separately. This year marked the last year that Joreon is eligible to attend the Zonnebloem trip, because it is only for people
aged 45 and under. These photographs were taken at the farewell dinner of the vacation. Joreon appears in the first photograph of the set.
PARTICIPANT OBSERVATION

Experiencing the Self/Becoming the Other

During in-depth interviews, several informants informed the researcher that the best way to understand being a wheelchair user was to “ride in a wheelchair for a day”. At the insistence of informants such as Raymond, the researcher considered this as a way to understand how wheelchair users are treated in public settings. “Observation is a technique that involves systematically selecting, watching, and recording behaviour and characteristics of living beings, objects, or phenomena” (Hardon et al, 2001: 207). A participant-observation study was designed by the researcher. Two non-disabled acquaintances of the researcher agreed to each sit in a wheelchair for a day, and attend a public function. They were to go to an event happening in the Amsterdam area, and one was to sit in the wheelchair, while being assisted by the other, who would be walking alongside. The two participants were required to also report to the researcher following the exercise, how they felt and what their impressions were about being in a wheelchair and the treatment they received from others. The researcher was present at both occasions, as an unobtrusive observer, blending into the crowd so as not to influence the outcome.

The two participants were both Dutch students of the University of Amsterdam. They chose to be identified as Grace, a female of 24 and Remy, a male aged 27 years old. Verbal consent was obtained for this exercise, and reporting was done in English, while public interaction was in Dutch.

There were no specific instructions given to Grace and Remy, however, they were cautioned to maintain their roles, and to make sure no harm was done to anyone who they communicated with. It was the researcher's responsibility to make certain that Grace and Remy were safe at all times during the two days over which the exercise lasted. It was of utmost importance to be respectful to the wheelchair community, so the idea was first discussed to make sure that it was not disrespectful to those involved as well as the people whom they portrayed. To ensure this, the researcher and the participant observation concept were introduced to a medical doctor and a disability studies researcher for approval, prior to conducting the exercise. Once verbal approval was reached, the researcher allowed Grace and Remy to choose where they wanted to be for the exercise. For the first day, Grace was seated in the wheelchair (which was borrowed from a local geriatrics facility), and Remy assisted her. For the following night, Remy sat in the wheelchair and Grace...
assisted him. The wheelchair was not powered, so one had to be pushed by the other, or rely on his/her arms for mobility.

Scenario A: The Flower Festival

Grace chose to use a wheelchair at a local flower festival. Remy had to push her around in the wheelchair. Before they began the day, Grace and Remy were in high spirits and curious to see how they would experience getting around in a wheelchair. However, at the end of the day, Remy was “irritated and tired from pushing Grace all day”, and Grace’s agitation showed clearly in her impressions of the day, which were given to the researcher. Grace’s account of the day’s activity is recounted in the following, which was in her own words:

I did this because I wanted to know what it would be like to be in a wheelchair. I thought it would be an experience I could learn from. I was right, but this turned out to be an experience which impacted me harder than I had expected. I never knew before how it would be if I lost the use of my legs. I thought that Remy would do all the work, and I could just sit and relax. Although I was to do participant observation, the idea of being pushed around all day and enjoying the ride was good. Then I began to realize that this was not going to be a friendly walk in the park after all.

Sitting in that chair when it was going around corners and curves almost made me throw-out. I had no idea that those little bumps on the pathway could be so uncomfortable. Never had I thought that every swerve and every turn could turn disastrous if he suddenly tripped and fell, or lost his grip on my handles. I felt the hairs on the back of my neck stand on end as I realized that in a very large way, my life was now in the hands of someone else.

Every time my chauffeur reached for a cigarette, I slide to the right side. Each time he decided to stop, I had no choice but to be stopped. By the end of the park trip, I was so annoyed at people behind me saying, “Oh, look at that pretty flower!”, or exclaiming, “What a cute puppy!”, that I thought I was going to scream. Could they not understand that I couldn’t turn to see? Could they not recognize why I told them to hurry-up and keep moving, when they had left me on the top of a hill without brakes, and at any moment I was about to go forward or backward? “What?” “Come again?” “Pardon me?”, they did not come to my level, so they couldn’t hear me from two feet below them.

Then he took me into a crowded gift shop, and the wheels drove over plants growing along the floor. While feeling half-sorry, half of me said “Good, you deserve it”, as the tourist in front of me swung around too fast, too close, and smashed his knee into my armrest. My frustrations were getting the best of me, but I couldn’t help it, I wouldn’t help it, because these inconsiderate ingrates around me weren’t a help to me at all! I just wanted to walk away, but then I remembered that I had to stay.

Sit in a wheelchair for a day? I never want to do that again. I thought it was going to be easy, like that expression of walking in someone else’s shoes. But, that did not apply for me because someone else was doing the walking for me. I felt trapped in the wheelchair. Then I thought about how it felt to run, jump. But I only was pretending, but some people must stay in the wheelchair. They can’t walk away.

When we were going to leave, people my age were staring, some snickered to themselves. I almost said to them, “I’m not really disabled, this is only an experiment!” I repeated my statement to the clerk at the ticket booth when she spoke only to Remy. She ignored me, and would not look at me in my eyes.

We were almost to the car when I had to go to the toilet. I was slowly pushed to the washroom, although I knew I should have run because I wasn’t going to be able to hold it much longer. I thought about it for one second, before I almost jumped out. I saw a man in a wheelchair, being pushed past me. I couldn’t jump out of the wheelchair now, how would that look? How would that make that man feel, to know I was just playing? Just a few more
meters, but then Remy saw someone he knew and began talking. I had to sit and wait for him to finish talking before I could go to the toilet.
I didn’t like being in a wheelchair. Now I understand what people who have to stay in one must feel. It is not easy.

Scenario B: Amsterdam Nightlife

Remy wanted to challenge the researcher’s prior work on wheelchair accessibility, (Parhar, 2003), so he decided to go to Rembrandtsplein on a Saturday evening. He sat in the wheelchair, and Grace went with him. As she went to the bank machine, Remy waited for a short while. Then, Grace ran into some friends of hers, and began talking with them. Remy became annoyed at this point, because he did not want to push himself over the tram tracks in the street, across from which was the bank. After almost ten minutes, Remy asked a passer-by to push him across, and then decided that he needed a drink. Remy decided to go inside a dance club.

At the entrance, he was stopped by a door man, who asked Remy what he was doing there. Remy said he wanted to go into the dance club. Later, Remy confided that at the moment he was approaching the entrance to the dance club, he forgot that he was not walking, and just thought he was Remy. When he saw the expression on the door man’s face, Remy said that it made him feel “so strange, he was looking at me like I was crazy.” The door man told Remy, “You cannot enter. This gate is not wide enough for your wheelchair”, referring to the metal detectors at the door. Remy said that he wanted to go inside, and again the door man said, “That’s not possible”, this time gesturing to the narrow hallway which came after the metal detectors. Remy insisted this time that he be let inside, and began to get angry with the door man. The door man continued to look puzzled, then went inside and told Remy to wait there.

In the meantime, Grace looked up and saw that there was a problem. She quickly crossed the street and stood beside Remy, who would hardly speak to Grace because he was mad that she had “abandoned” him. When the man returned to the door, another security member came with him. The second man, looked at Grace, and then spoke quietly to the first man. Then, they offered a solution, saying that normally, they did not do this, but Remy could enter the club from a side door. However, upon realizing that there was a speaker arranged in front of that side door, the two men again conversed among each other.

The final decision was that they would manually move the metal gates to make it wider, and then Remy could fit through the narrow hallway. It took the men one minute to drag the metal gates apart, and once inside, the hallway was not narrow;
in fact, it was almost twice the width of Remy's wheelchair. The researcher noted that once Grace and Remy were inside, the two door men exchanged a joke and laughed about the situation.

That evening, after they had left the dance club, the two participants and the researcher met and discussed what had happened. Remy felt that he had been treated badly. Not only was he angry at the door men, but he was also furious at Grace for leaving him sitting on the sidewalk. Grace began to explain that she had been distracted, but then she stopped short and said to Remy, "Now you know how I felt when I had to use the toilet!"

The three compared their observations of the two scenes. The researcher noted a change of non-verbal body language between Grace and Remy. They were angry with each other because they both felt they had been taken care of poorly when they were in the wheelchair. In the assisting role, both felt they had done reasonably well, and taken care not to place their friend in a dangerous position. However, Grace said Remy was not attentive enough, and Remy said that Grace was more interested in talking to her friends than helping him. Observations made by Grace, Remy, and the researcher during this discussion process are compared on the following page:
### Figure 4: Participant Observation Chart

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Participant:Grace</th>
<th>Participant:Remy</th>
<th>Researcher</th>
</tr>
</thead>
</table>
| #1 Flower Festival (Grace seated/Remy assisting) | - People were staring  
- No control of own movement  
- Grace felt “trapped” in the wheelchair  
- She did not like the experience “at all”  
- Bad experience with using WC facilities | - Felt like people were trying to decide if Grace was his girlfriend/sister/wife; made him nervous  
- Did not feel strange pushing someone in a wheelchair  
- Grace only a few times | - Remy kept looking around, and talked to Grace  
- Grace appeared frustrated because Remy could not hear her, then she stopped talking altogether. |
| #2 Nightclub (Remy seated/Grace assisting) | - Grace was glad to be assisting this time  
- She left Remy alone many times because she “had to do some things” (e.g. bank machine, talking to friends) | - Remy did not enjoy the experience; he felt abandoned by Grace  
- Remy felt bad that he was “hassled” by the doorman  
- Remy no longer will go to that nightclub, since he felt unfairly treated by the staff members | - Body language of doorman suggested he was uncomfortable speaking to Remy (e.g. arms crossed, not making eye contact, shifting standing positions) |
| General Impressions | - “My arms hurt from pushing myself, and my armpits, too.”  
- “I learned a lot, but I don’t want to do it again.”  
- “It was horrible!” | - “It is hard to believe that people can be so arrogant.”  
- “I was ignored by everyone, even my assistant.”  
- “I’m glad I did it.” | - Both participants disliked sitting in the wheelchair, and felt like specimens being examined by others |

64
CONCLUSION

This study set out to prove certain theoretical aspects. Its first aim was to show how wheelchair users in the Netherlands cannot put precedence on the mind more than the body. The second aim was to place Schepert-Hughes and Lock’s “Mindful Body” orientation, within the context of wheelchair use. The third aim was to look at how the embodiment approach put forth by Thomas Csordas, may be applied to this anthropological exploration of the lives of wheelchair users in the Netherlands.

First of all, the mind is not more powerful than the body, and the body cannot solely control the mind. Wheelchair users must always maintain an interaction between what their mind says to do, and what they realistically can do. Merleau-Ponty argues against Cartesian Dualism, in the realm of philosophical anthropology. Essentially, Descartes believed that the mind was the seat of all control over the body. The core of the mind was the pineal gland, where the mind drove the body, like a person drives a car, or as Descartes put it, as an invisible rider on a horse.

Wheelchair users move back and forth between what their mind wills them to do, negotiating this with what their bodies can do. The finest way to understand this interplay is to ask a wheelchair user to give an example of solving potential problems of access and/or mobility. Noah stressed the necessity for wheelchair users to be creative, flexible, and find solutions wherever possible. The example is outlined below:

1) Noah notices an obstacle in his way: He wants to go into a cafe, but there is a large step and no ramp for wheelchair access. His friends are possibly inside, but perhaps he cannot see them from outside.
2) Noah stops and thinks about his options: He can keep looking for another place, or he can find a solution. If he keeps going on, he might have overlooked his friends. Alternatively, he can try to find a cafe that is accessible for wheelchairs.
3) He feels that he should check to see if his friends are waiting inside for him. He thinks of possible ways to overcome the obstacle, according to his own capabilities.
4) He decides to ask for help, from a worker in the cafe, to aid him to get past the step.
5) Noah verbally asks an employee for help, and he is given help from that person. Using his own physical strength, and a friendly push from another, he can hoist himself up, balance on the step, shift his weight, and with that momentum, get over the step.
6) Noah is now inside the cafe, and finds his friends awaiting his arrival.
Using Noah as an example, wheelchair users must be aware of their abilities and limitations. This is as much of a mental realization, as a physical one. On the one hand, not listening to the mind’s warnings that something is too heavy or too difficult results in injury. On the other hand, not pushing oneself may result in low confidence and self-esteem, leading to mental and physical consequences.

Before the onset of disability, some informants of this study admitted, that they were demand too much of themselves, and allowing others to demand too much from them. Limits were readjusted and often forgotten altogether, until “Something just snapped”, “One day I couldn’t move”, and “I knew something went wrong”, end with “My life changed forever.”

These are a handful of expressions describing that threshold they reached when their minds and bodies were pushed too far. Moving onto the second theoretical approach, one can see this as the strife to maintain a mindful body. Scheper-Hughes and Lock’s “Mindful Body” seeks to understand people on various levels - the individual body, the social body, and the body politic. Considering wheelchair users from an individual perspective helps gain holistic understanding of their lives. The individual body of the wheelchair user is considered by looking at self-perceptions of wheelchair users about how they feel about their disability. The individual body is the experiencing body; those circumstances which led to, caused, and have affected the individual mark a transition between two different lifestyles. When informants spoke about their lives before they became wheelchairs, they are recalling individual experiences.

When informants continue, and describe the onset of their disability, what is noticed is a sense of proprioception. This “sixth sense”, evolved in these people, from the increased necessity to be aware of one’s mind, body, and personal limits. People who have experienced becoming wheelchair users must listen to this intuition, to tell them when they are pushing their bodies and minds too hard. Those who do not listen to their intuitive process may hurt themselves. This may be, for example, recalling Hans and his insistence on pushing himself hard, not to surpass his own limits but rather to stay on par with his friends who are not wheelchair users. Others may do this unknowingly, honestly believing that they can manage the task, but not realizing it is too much until they cannot move the next day.

Let us remember Hugo, the man who at the exact moment of his ‘injury’ realized that, “Life is never the same again”. He, like many disabled people,
maintains his social status and does not identify with other disabled people. There are many people who continue to fight against being identified as disabled, saying, “It’s not my world”. Scheper-Hughes and Lock’s second stage is the social body. The social body refers to the state of an individual body applied to the entire society. This level is about how bodies relate to social aspects, for example, how healthy bodies reflect a healthy society. In the context of this thesis, the social body is the wheelchair user’s body, which is a symbol for disability.

One difference between Scheper-Hughes and Lock’s article and of this thesis is that they place great value on Douglas’s work to understand thy symbolic, social body. The opposite may be argued, in terms of the lives of wheelchair users in the Netherlands. Within Mary Douglas’s notions about dirt and pollution, Lord Chesterfield’s over-used, cliché of “matter out of place”, is horribly disrespectful if it is to be used to describe disabled people. The expression implies that something is there that should not be, and if it were used in this context, it would imply that the disabled are “matter out of place”, that they do not belong. That is not true, and when authors include this example in their work to show how disabled people are treated by society, it has these implications. Lupton (1994) attempts to paraphrase these concepts in her own words, in Medicine and Culture. Lupton’s argument is that notions of the able-body ‘normality’ are juxtaposed with ideals of morality and virtuosity. This is the same implication as Douglas, except that the message here is disabled people represent the opposite ends of the binaries; they are “immoral” and/or “non-virtuous”, two things that are untrue in the wheelchair user’s perceptions. People in wheelchairs are not ‘foreign matter’, or social dirt. They belong to society, with another way of living, but they are not separate from the rest of humanity.

In addition, Douglas’s work on pollution and its principles is not applicable to this study. Douglas made a dichotomy of uncleanness versus holiness. The unclean body can be seen as the body risked to danger. An example of this could be a disabling occurrence, which causes the body to be polluted because it becomes disabled. Therefore, the body deviates from that which is considered the ‘normal’ image of a body. Accordingly then, the disabled body is relegated to the socially marginal body, denied access, and perceived as a ‘broken’ body. Disability is thus the opposite of ‘normal’, and is not only not ‘normal’, but also ‘abnormal’. This is not correct in the scope of disability because the disabled body is still a body, therefore is still classifiable within the realm of ‘normal’. Anatomically, there may be minute
differences, such as a missing limb of decreased mobility of the legs. However, the fact remains that the mind is still very well in tact, and the mind together with the body constitutes ‘normal’.

The body politic is the third way that one can use “The Mindful Body” approach experiences of wheelchair users. The way Schep-Hughes and Lock describe the body politic is that it is how the body is controlled, or regulated by society. Disability advocates claim that able-bodied members of society put obstacles in disabled persons’ ways, thus keeping them down. This is of course, sometimes inadvertently done, as in the case of French’s experience in her library. In the eyes of many informants, there are far too many restrictions and rules that disabled people must follow to be eligible for things they need. One example is of the amount of time that it takes to be heard, when there is a problem that needs addressing. Often, wheelchair users must wait long periods of time to be assessed for receiving subsidies for house renovations. If that were not a problem, informants would not have nodded in agreement when the comments of Hugo were told to them, “You are dead before you get it”. It should not take so much time, especially when people like Els have to put so much effort repeatedly calling and writing letters to be heard.

A final look at the embodiment perspective by Thomas Csordas reveals notions of the body having meanings “inscribed” or “imposed” on it. Although embodiment is a real process evident in wheelchair users, inscription or imposition of meaning is difficult one to consider within the lives of wheelchair users. Although wheelchair users do embody certain values, such as the levels of positivism, to say that they have these written all over them is incorrect. This is because this type of reasoning tends to assume that the body is a ‘blank slate’, void of any cultural meanings. Especially with reference to the people who become disabled during their lives, to say that there is no prior definition or way of looking at a body is not accurate. It does not hold true that a person who becomes disabled will still be ‘inscribed’, or encoded with the same cultural meaning that he/she held before becoming disabled. Some people go to great lengths to avoid being identified as being disabled. The participant observers, for example, did not want to be the one sitting in the wheelchair. They preferred the role of the assistant to the wheelchair user.
Looking at wheelchair users, the body is not like a receptacle, as in it does not have pre-scribed ideas which are carried forward through life and remaining static through life’s entirety. The body as a whole, including the mind, is the medium to produce meaning, to give meaning to something. The procedures of the body are what define the body, e.g. the way it works, how it moves, the traits and characteristics of that body, etc. For example, a disabled body may move differently than a non-disabled body, so that is how the first body is labeled as, “disabled”. Its movements and coordination are examined relative to what is considered part of the ‘normal’ body repertoire of ‘normal’ skills. The disabled body does not agree with that which defines a non-disabled body, most obviously by the wheelchair, less obviously by the experiences of wheelchair users compared to someone who is walking.

While it is true that others may not perceive wheelchairs and the people who use them as ‘normal’ people, the wheelchair users themselves feel ‘normal’ in their lives. Society labels the body because “the body becomes the central metaphor for social, political and cultural activities and anxieties” (Turner: 1992). One would think that what a person looks like on the outside, then, would dictate how they were received by society. This is partly true, in agreement with Lupton’s view that:

A body that does not function “normally” or appear “normal”, that is confined to a wheelchair or bed, is both visually and conceptually out of (its) place, as evidenced by the lack of public facilities for people with disabilities” (1994:38).

Moving away from theoretical classification, into real, lived experience, wheelchair users remind us that there is more to living a ‘normal’ life than appearance. With the physical component, there is, what an informant named Hans calls, a “mental” way of living. “Normal is not something physical. It is more a mental thing. I feel normal because I can still do the same as before my accident.”

They are unique individuals because compared to walking people, wheelchair users who accept their changed lifestyle learn to appreciate things that others overlook. A fine example came from Karl, who compared life and sudden disability to a tree sprouting new branches. The message is that mobility may be reduced, but that opens the door to discover new things in life. For some, this is volunteering or writing for disability magazines. Others “restart” their lives, by strengthening ties with family and friends. Noah was asked about what he would say to someone who
told him he could walk again. He said, “It happened actually, in Arnhem. I’d had to believe in Christ and then I would be able to walk. I said I was Islamic!” Noah says,

No seriously, I don’t want to walk, honestly. I’ve been in a wheelchair all my life and I got used to it. Sometimes I am frustrated if I can’t climb the stairs somewhere but that feeling is temporary. It sounds strange but I would like to walk but then in another lifetime and body. (Names himself) needs to be in a wheelchair and happy what he’s achieved and will achieve.

In the informants’ perspectives, without theoretical attempts to classify them as this or that, there is refreshing meaning that wheelchair users themselves seek from their lives. Many of these people are glad they have the time to appreciate those meaningful parts of their lives that they ignored before they became wheelchair users. They are the first to admit that it was their own ignorance of “the things that matter most in life”, that placed them in vulnerable positions which caused them to become disabled. Most people learn to live in a way that makes them happy, not looking in terms of what is ‘normal’, and ‘not normal’. Noah’s outlook on his life is to live relatively. “Sometimes I would like to drown in a pool of sadness and unhappiness, the other moment I am on top of the world. I think it’s important for me to realise that everything is relative.”

One can learn many things from people who have experienced this much change in their lives, but also admire their perseverance in rebuilding their lives to include those people and things that keep them living happy lives. Their legs are not moving them, but their words and the vigor for life that ebbs from these words is so powerful, so moving.
Figure 5: PROBLEM ANALYSIS DIAGRAM
We are not hiding behind the geraniums

Realization:
Life as a different kind of normal than before

Defining 'Normal'
"Your life is not over"

Acceptance:
Life is 'normal' in creative ways, more than before

Self-Understanding of Disability

Family/Spouse

Social Relationships

Friends

Talking about Wheelchair Use

Dating/Sexuality

Gender Relations

Peers and Pity

Interactions with others

Knowing Personal Limits

Pushing limits too much to fit in with others

Asking and Taking Help

Self-harm by going beyond own limits

Travel Details
- Costs of taxi cabs
- Funding for cars

Driving a car

Waiting Periods
- Wheelchair repair
- Subsidies

Connections

Media Portrayal of Disabled People

Stigmas & Stereotypes

Finding role models

Meet staring faces with a smiling face

Social Aspects of Disability

Encourage children to ask questions
People who use wheelchairs in the Netherlands remind non-wheelchair users that disability can happen to anyone, but it does not have to end one's life. “Disability is the one minority group that anyone can join at any time [...] unless we die suddenly, we are all disabled eventually” (Wendell, 1992: 178). Those who are not in a wheelchair would benefit from learning about the experiences of people who do use them. Both healthy minds and healthy bodies may be crippled. “The fact that ‘normal’ people can get around, can see, can hear, doesn’t mean that they are seeing or hearing” (Goffman: 22).

People who use wheelchairs are not, as the Dutch expression goes, “zitten achter de geraniums”, or “sitting behind the geraniums”, staring out at the world and watching their lives pass them by. A wheelchair does not equal total doom. For people who live with disabilities which require them to use wheelchairs, there are options. Participants of this study are examples of people who are making the best of their life, because they realize that they still have a life, and are not dead, so they should live it. Individuals can choose to either take a seat behind the geraniums, but that is not ‘normal’ to them. Instead, they opt to get into their wheelchair and continue living a life that is very ‘normal’.
REFERENCES


Wendell, S. 1992, *Towards a Feminist Theory: Crossing (out) the border – Autobiography and Physical disability*,

APPENDIX 1A
DATA COLLECTION TOOLS:
IN-DEPTH INTERVIEW GUIDE (FOR INTERVIEWS IN ENGLISH)

1. Preliminaries
   a) Introduction of interviewer to interviewee(s):
      Hello (shake hands), my name is Kam Parhar. I am a student at The University of Amsterdam, in the field of Medical Anthropology. I am currently researching for my thesis, which is due to be completed as part of the course fulfillment for AMMA (Amsterdam Masters in Medical Anthropology), in August 2003.
   b) Describing the objective of the study to informant(s): To learn from Dutch male and female wheelchair users about what ‘normal’ means for them, and to learn about their lives and experience with disability.
   c) Topic of Interview: Wheelchair use, disability, and ‘normal’.
   d) Use of Data collected for this Masters Thesis:
      I would like to know from you what things are important in your life as a wheelchair user, and how these relate to your feeling of ‘normal’. This data collected from you is solely for my own purposes of this Masters thesis, and will not go any farther than myself, or is used in any circumstances for other research studies.
   e) Informant and criteria upon he/she was selected:
      I have contacted you because you are a man/woman, who has knowledge about, and experience using a wheelchair. I feel you have much to tell about what it is like for you to lead a ‘normal’ life, as you see it. Others can benefit from your comments.
   f) Duration of interview: 1 hour-1.5 hours
   g) Tape Recording: Do you mind if I record our conversation?
   h) Ethical Conduct:
      What you tell me today is completely confidential. I will not be using your real name in my reporting, only a pseudonym (false name). Only my thesis supervisor and I have access to the data collected in this period. This data is only going to be used for my AMMA thesis. If you would like, I will send you a copy of the thesis in time for me to do necessary revisions if I have not understood your comments to your satisfaction.
   i.) Questions: Do you have any questions before we begin?

2. Interview Proper
   Interview Guiding Questions:
   i. What does the word, ‘normal’ mean to you? Do you think that being ‘normal’ is the same as being ‘able’?
   ii. Was there a change in ‘normal’ for you, before and after you became a wheelchair user? How did your disability affect your independence and dependence?
   iii. How do you think that Dutch society considers wheelchair users? How do you feel about being Dutch and a wheelchair user in the Netherlands?
v. What can you tell me about your experience that you think is important for me to remember when writing that others need to understand about people who use wheelchairs in the Netherlands?

*Researcher's note: These questions were asked at each interview, although the search for 'normal' became only one of the issues which I decided to focus on learning more about, such as social relationships, community connections, and self-perception.

3. Concluding the Interview
   a) Thank the informant(s) for their time and sharing of details.
   b) Ask to contact him/her for further clarification if needed.
   c) Reaffirm that they will receive a draft of the thesis in progress to reflect upon
   d) Offer contact information should they want to add something in the meantime.
   e) End of interview.
Inleiding

a) Onderzoeker en onderzoeksassistent stellen zich voor aan de geïnterviewde:
"Hallo, mijn naam is Kam Parhar. Ik studeer medische antropologie aan de Universiteit van Amsterdam. Ik ben op dit moment bezig aan mijn eindscriptie, waarmee ik in Augustus mijn studieverplichtingen teen aanzien van het AMMA (Amsterdam Masters in Medical Anthropology) afrond."

"Hallo, mijn naam is Renger Dekker, ik ben de onderzoeksassistent en ben hier aanwezig om als tolk te fungeren."

b) Het doel van de studie wordt uitgelegd: onderzoek verrichten naar de beleveniswereld van rolstoelgebruikers in de Nederlandse maatschappij? Wat betekent "normaal" zijn voor de betrokkene en hoe gaat hij/zij om met zijn/haar handicap?

c) Onderwerpen van het interview: gebruik van een rolstoel, handicap en "normaal zijn".

d) Gebruik van de data bij het schrijven van de eindscriptie:
"Ik zou graag willen weten welke aspecten in uw leven als rolstoelgebruiker belangrijk voor u zijn en hoe deze aspecten relateren tot uw gevoel wat "normaal zijn" voor u betekend? De informatie die u mij verstrekt zal enkel en alleen gebruikt worden voor mijn eigen eindscriptie en zal niet aan derden verstrekt worden of gebruikt kunnen worden bij andere studies.

e) Reden(en) waarom de te ondervragen persoon geselecteerd is:
"Ik heb contact met u opgezocht omdat u een man/vrouw bent, en ervaring heeft met het gebruik van een rolstoel in het dagelijkse leven. Ik heb het idee dat u mij veel kunt vertellen over wat uw gevoelens zijn ten aanzien van het leiden van een zo "normaal" mogelijke leven. Uw informatie kan wellicht nuttig zijn voor andere rolstoelgebruikers."

f) Tijdsduur van het interview: 1 à 1,5 uur.

g) Gebruik van bandopname(n): "Is het goed als ik ons gesprek opneem op band?"

h) Ethische gedragscode:
"Alles wat u aan mij vertelt gebeurt op vertrouwelijke gronden. Ik zal bij het schrijven van mijn stuk uw echte naam niet gebruiken, maar gebruik maken van een pseudoniem. Slechts mijn scriptiebegeleider en ikzelf hebben toegang tot het verzamelde (geluids-)materiaal. De verkregen informatie zal alleen gebruikt worden voor mijn AMMA eindscriptie. Als u het wil, kan ik u een kopie toesturen van de eerste ruwe versie, zodat u mij wellicht kunt attenderen op enkele fouten of misvattingen. Ik heb dan nog genoeg mogelijkheden om deze te veranderen."

i) Vragen / opmerkingen: "Heeft u nog enkele vragen of opmerkingen eer het interview begint?"

Het daadwerkelijke interview
Vragen die als richtlijn dienen voor het interview.
1. Welke betekenis heeft de term “een normaal leven leiden” voor u persoonlijk? Staat “normaal zijn” voor u gelijk aan “in staat zijn”?

2. Zijn er duidelijke veranderingen aan te wijzen in uw leven voor- en nadat u in een rolstoel belandde? Welke invloed heeft uw handicap gehad ten aanzien van uw onafhankelijkheid en zelfstandigheid?

3. Welke houding, denkt u, hebben Nederlanders in het algemeen ten aanzien van mensen die gebruik maken van rolstoelen? Hoe is het voor u om als rolstoelgebruiker in Nederland te leven?

4. Wie of wat geeft u steun in uw dagelijkse leven en geeft u het gevoel “normaal” te zijn? Wie of wat heeft hier een negatieve invloed op?

5. Zijn er nog enkele essentiële zaken waar ik rekening mee moet houden bij het schrijven van mijn scriptie? Wat zouden mensen, die niet gebonden zijn aan rolstoelen, moeten weten over het leven met een dergelijke handicap?

*Opmerking van de onderzoeker: Deze vragen zijn bij elk interview gesteld, desondanks is het onderzoek ten aanzien van “normaal zijn / functioneren” slechts een van de vele aspecten van mijn studie geworden. Door de uitkomsten van mijn onderzoek ben ik mij tevens gaan richten op de sociale verhoudingen, de contacten met de samenleving en het zelfbeeld van mensen die gebonden zijn aan rolstoelen.

Afronding van het interview

a) De ondervraagde persoon bedanken voor zijn / haar tijd en verstrekken informatie.

b) Toestemming vragen of het mogelijk is verder contact met de persoon in kwestie te hebben, indien er zaken zijn die achteraf niet geheel duidelijk blijken te zijn.

c) Benadrukken dat hij of zij de eersteuitwerking van de eindscriptie toegestuurd krijgen om eventuele misvattingen te verbeteren.

d) Vermelden dat het altijd mogelijk is contact op te nemen met de onderzoeker indien er zaken zijn die de persoon tijdens het interview zelf vergeten is te vermelden, maar desondanks wel van grote waarde zijn voor het onderzoek.

_Einde van het interview._
APPENDIX 2
PHOTO ELICITATION GUIDE

1. Preliminaries

a) During interview: Introduction of photographic research as a concept to informant: Photographs are a way for me to further what I learn from you in an interview. By looking at which things you take as important for you, I can see which things are meaningful to you, as well as which of them add to living your life 'as normal as possible.'

b) Asking the informant to participate: Would you be interested in taking some pictures for me?

c) Discuss meeting again for a discussion of photographs, or other arrangements.

d) Deciding mutually on a reasonable period in which to complete the roll of film, and have it ready for the researcher to pick up and develop.

e) Questions: Is there anything I forgot to explain?

2. Follow-up

*Researcher’s note: Since meeting with informants multiple time was not always possible due to scheduling, they were encouraged to choose a method of correspondence from the following.

a) Written: Informant asked to provide an explanation of why he/she chose certain images to capture on film, at their convenience (e.g. letter form or via email).

b) Verbal: Informants were asked if they would rather prefer to talk on the telephone about the pictures. All telephone costs were to be sustained by the researcher. This also applied to purchasing the disposable camera and photo developing costs.
APPENDIX 3: PARTICIPANT OBSERVATION

Inquiring Questions:
1) What is it like to be seated in a wheelchair in the Netherlands?
2) How are wheelchair users treated by non-wheelchair users in the Netherlands?

Preliminaries:

a) This activity is meant as an exercise for persons who do not use wheelchairs to experience using a wheelchair in a social setting.
b) Recording and reporting observations serve a purpose for the participant to consider his/her experiences, as well as for the researcher to compare these to her own observations, as an unobtrusive participant.
c) Asking participants (colleagues of researcher), would you like to sit in a wheelchair for a day, to see what it is like?
d) The activity has been approved of, and suggested by in-depth interview informants spoken with for the former parts of this thesis research.
e) The wheelchair has been in circulation amongst patients of a health care facility, and has been inspected for safety and assured that all parts are working properly, prior to beginning the exercise.
f) The participants are involved entirely of their own free will; as such, verbal consent suffices for obtaining of permission from participants.
g) Participants are financially reimbursed for the expenses they incur during the exercise. However, this is not to be confused with payment for participation, as the two have agreed as a personal favor to the researcher.

Exercise Proper:

a) Participants (2) have agreed to refrain from revealing the true nature of their research intentions, as well as their actual degree of mobility (walking) to persons with whom they come into contact with for the duration of the time taken to complete the exercise.
b) Participants are to be respectful of others and of themselves. No harm should come to them, or to others who come into contact with the participants during the observations.
c) The duration of the exercise is two days, one of which is a daytime activity, and the other is an evening activity in social settings.
d) The social settings are chosen by the participants, as places where many people of different gender, age, and status are present.
e) At the end of each observation, participants are asked to provide a written notation of their experiences, both as being seated in a wheelchair, and as the assistant, to the researcher. They are asked to explain their feelings and comments to the researcher.
f) Participants are asked to comply with requests for follow-up meetings to discuss the results of the activities. However, they are not obliged to reconstruct any of the events, nor are they expected to sit in a wheelchair again for another observation.
g) The researcher has also agreed to take observatory notes during the interactions, for later comparison.
h) Upon completion of the thesis, both participants may request a copy, provided by the researcher.