# LIVES OF PHYSICALLY DISABLED

Stigmatization as a problem of social
interaction for the physically disabled persons

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| Title | |
| LIVES OF PHYSICALLY DISABLED: Stigmatization as a problem of social interaction for the physically disabled persons | |
| Academic subject | Type of thesis |
| **Sociology** | master thesis |
| Date | Pages |
| May 2014 | 68 pages + 2 attachments |

Abstract

In my work I will investigate the challenges that stigmatization brings to the lives and social interactions of the physically disabled. My work contains eight Finnish thematic interviews, which I collected at the end of 2012. The interviews set between the timespan of childhood and adulthood. I compose a viewpoint, which adheres the inputs from the thematic interviews but also joins forces with other sociological theories. The purpose of this work is to create an overall picture explaining stigmatization faced by those physically disabled people who have been impaired since their birth or very early childhood.

As the stigmatized position of having a disability remains a problem it does create some challenges and difficulties when it comes to the creation and maintenance of social relationships. Stigmatization also brings up prejudices, which unjustly label the impaired ones as incompetent or unskilled individuals. The negative effects of stigmatization show up in multiple arenas of life from school to work. Disability remains rather personal experience and different individuals do attribute different meanings to it. To overcome the apparent negativity of stigmatization a phenomenologically oriented viewpoint towards disabilities will be presented.

| Keywords | |
|---|---|
| disability, social, interaction, stigmatization, phenomenology | |
| Archive location | University of Eastern Finland Library |
| Other information | |

**Itä-Suomen yliopisto**

| Tiedekunta **Yhteiskuntatieteiden ja kauppatieteiden** | Laitos Yhteiskuntatieteiden laitos |
|---|---|
| Tekijä Jyrki Posti | |
| Työn nimi LIVES OF PHYSICALLY DISABLED: Stigmatization as a problem of social interaction for the physically disabled persons | |
| Oppiaine **Sosiologia** | Työn laji pro gradu |
| Aika toukokuu 2014 | Sivumäärä 68 sivua + 2 liitettä |

Tiivistelmä

Tarkastelen työssäni sitä, millaisia vaikutuksia stigmatisoinnilla on liikuntarajoitteisten ihmisten elämään ja sosiaaliseen vuorovaikutukseen. Työni aineistoon kuuluu kahdeksan vuoden 2012 lopulla keräämääni teemahaastattelua suomalaisilta liikuntarajoitteisilta ihmisiltä. Haastattelut pohjautuvat ajanjaksoihin lapsuudesta aikuisuuteen. Yhdistän työssäni haastatteluista keräämiäni tietoja stigmatisaatioon ja sosiaaliseen vuorovaikutukseen liittyviin teorioihin ja sosiologisiin näkökantoihin.

Työn tavoitteena on pyrkiä luomaan kokonaiskuvaa siitä, millaisena stigmatisaatio näyttäytyy syntymästään tai hyvin varhaisesta iästään asti liikuntarajoitteisten ihmisten elämässä nykypäivänä. Liikuntarajoitteisuuden stigmatisoitu asema luo haasteita sosiaaliseen vuorovaikutukseen ja voi johtaa vaikeuksiin sosiaalisten suhteiden muodostamisessa ja ylläpitämisessä. Vammaisuuden stigmatisoituun asemaan liittyy lisäksi ennakkoluuloja, jotka leimaavat liikuntarajoitteisia perusteettomasti epäkompetenteiksi ja taitamattomiksi yksilöiksi.

Stigmatisoinnista johtuvien ennakkoluulojen vaikutukset näkyvät negatiivisesti usealla elämän osa-alueella aina koulun aloittamisesta työelämään siirtymiseen asti. Stigmatisoinnin tasoon näyttää vaikuttavan paitsi vamman laatu myös vamman taso − vuorovaikutuksessa sosiaalisen elinympäristön kanssa. Vaikka stigmatisaatioon liittyykin sosiaalisia kokemuksia, jotka yhdistävät liikuntarajoitteisia, vammaisuus on kokemuksena kuitenkin ytimeltään hyvin yksilöllinen. Vammaisuuden kokemukseen vaikuttavat vamman ja ympäristön lisäksi myös henkilön omat tulkinnat tilastaan ja sen merkityksestä. Vaihtoehtona stigmatisoivalle vammaisuuskäsitykselle tämä työ esittää fenomenologisesti orientoituneen näkemyksen liikuntavammaisuuteen.

| Asiasanat liikuntavammaisuus, sosiaalisuus, vuorovaikutus, stigmatisointi, fenomenologia | |
|---|---|
| Säilytyspaikka | Itä-Suomen yliopiston kirjasto |
| Muita tietoja | |

# Table of Contents

# 1. INTRODUCTION

In 1963 Goffman exemplified that as a person learns to live with his stigma, he usually becomes painfully aware that his position as a stigmatized is somehow less than that of normal. Goffman suggests that the physically impaired is educated by the society that he is not what is regarded as a standard individual. (Goffman 1963, 45–46.) It has been a while since Goffman published his results but the problem of stigmatizing physical disabilities still exists as a structural deviation within our society[1].

At the end of 2012 this study began to grow from my personal aspirations to understand what did it actually mean to be physically disabled in the world of today. I found the question of physical disability particularly interesting because I have myself lived a life with one. I remember wondering actively how other persons with disability conditions experience their situations. As I needed to admit myself that the stigmas of disability do exist even today, the following question appeared: What had society actually taught me about being physically disabled and possibly stigmatized? In the end, I could not come up with anything solid that would have came even close to being an educational memory from the topic.

The starting point of this research was a pure curiosity to explore the topic of disability, which had remained quite unknown to me – even when I shared a personal link to it. When things moved forward I decided to base my research to the realization that followed me since the early days of this paper. What I initially realized was simply that stigmatization of disability seemed to be an important phenomenon happening in our society – and for some reason it was not always addressed very well. As I concluded that the two topics of stigma and disability might still not be very well understood, the initial realization matured to

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1 Disability is a stigma-mark by itself and stigmatization is the actualized result of it (Goffman 1963).

become the very center of this research. The spark to research stigmatization of physical disability became even more real when I started thinking that if I would not have years of disability movement activity behind me, I would not know practically anything about the phenomenon of disability itself[2]. I also became somewhat puzzled thinking about those people who had never been in much contact with disabilities – since their informational scope might compose other limitations that could be even more severe than the ones I had. For the previous reasons, I was very motivated to address the issues of stigmatization and physical disability in the hopes that I could create some new understanding along the way. Similarly, when it came to the academic sphere, for me as a sociologist to navigate the discussion of physical disability to actually touch more the real world phenomena of lived experiences came to serve as a big motivator for devising this particular study.

I chose my viewpoint to become that of phenomenology since I felt that it was needed because it enabled me as a researcher to ask real questions from real people. Asking phenomenologically oriented questions made possible that the problems in understanding the physical disabilities could be pointed out more fully. As many debates around the ways by which physical disabilities should be addressed did exist among ordinary people and scholars alike, the field of disability originally appeared to me as a grand stage of confusion when I started my work. Phenomenology as a whole provided some much needed clarity to the confusion.

Presenting physical disabilities has proven to be a sore spot for the sociology and it seems that the confusion has reigned quite a long time. Sociology has aptly noted that there are many half-baked introductory books containing descriptions about how physically disabled as a minority group are stereotyped and stigmatized. On many of those books the realistic points of view towards the disabled people as individuals with their abilities and gifts beyond stigmas remain mostly absent. (Taub & Fanflik 2000, 17–19.) Vehmas (2009, 113–

2 Disability movement is used as a broad term referring to mixed association work.

5

114) has also pointed out that the language used to describe disabilities has been somewhat ambiguous – and because of it many confusions have emerged.

Reasons for the ambiguous language and narrow discussions seem to relate to the issue that physical disability belongs elementary to the deviation sociology but at the same time it is becoming socially incorrect to speak loudly about the deviation of disability[3]. Adler and Adler (2006, 133) have however noted that deviancy is – and has always been – an important part on understanding how and why some ideals and groups strive and others do not. Since physical disability has never been in the blaze of societal glory, there remains all the more reason to study the lives of physically impaired people to see how things are now. It should be noted that the current focus of sociology has on many occasions drifted away from the realms of bodily deviations. The topics of stigma and physical impairment have thus remained among the less studied linkages in recent times.

The viewpoint chosen by this research is one, which adopts stigma-related concepts and theories but also describes the actual persons and their lives as they go along. While the topics relating to stigmas are elaborated throughout this study, the goal is to produce an interpretative view, which showcases the challenges that those persons who have physical disabilities face in current day. In general terms, physical disability is seen as a phenomenon that an individual can have but not as something that necessarily underlines every aspect of his or her living with negativity – even when having an impairment might mean the same as denial of access to certain positions and activities.

This research contains the voices of eight Finnish informants, four women and four men, who have been disabled all their lives or since very early childhood[4]. The overall

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3 See chapter 4.4.
4 When I refer to the participants of my study I will use words such as an informant or informants.

presentation is divided into six sections. The first section has this introductory part. The second section concentrates on elaborating the sociological roots of stigmatization and disability – while addressing the problems of those roots. The section also presents tools to understand why phenomenology could be a way to create new disability information that is free of stigmatization. Third section highlights the methodological choices, which I took to compose this research. The section starts by enlisting the research questions of this study. The questions are followed by a chapter, which introduces the informants. After the informant introductions come the segments, which elaborate how the actual study was done and how the informants were initially chosen. The ethics of the study will be discussed shortly in the end of section three. The main key question that this study asks is: How does having a disability stigma influence the lives of physically impaired people?

The fourth section – being the analysis part – of this study combines the recorded words of the informants with the written information of other researches on the topics of physical disability and stigmatization. Section five draws together the conclusions and summarizes them so that the way could be paved for the discussion on the section six. The sixth – and the final – part will be reserved for discussion, which  elaborates the downsides of stigma-related understanding and aims to show that there are possibilities in sociological phenomenology to redefine physical disability differently.

## 2. STATUS TRAPS AND COERCIVE SOCIAL FACTS: PHYSICAL DISABILITY MEETS THEORY

This section will present the theoretical background of this study. The section paves the way for understanding physical disability as an outer and social experience but also as an inner and personal experience that a human with an impairment can have.

### 2.1 Disability and social status: A risky pairing with a possibility towards weaker social positioning

What is disability? A simple answer to the question would be that disability is a meaningful impairment, which inhibits or makes the living of an individual somehow harder in the surrounding society. A more complex definition of disability, which goes beyond the physical body comes from the social model of disability. The social model of disability states that while the actual impairment of the body exists it is not just the bodily definition of it that counts. According to the model, disability is also a social position. The social aspects of the impairment are actually the ones that give the bodily experience its practical de facto meaning. In other words, disability appears as a social construction and it gets many of its meanings from the social world and not outside of it. (Swain, Griffiths & Heyman 2003, 138.)

When the study at hand discusses disability it uses phrases like physical disability, physical impairment or a deviant body. While the phrases literally describe different aspects – and some of them literally relate to different theories as well – the viewpoint that this research takes is aligned towards that of Koca-Atabey (2013) manifesting that there is actually no such thing that would go under socially meaningless disability. The adoption of the social model of disability thus came to be a logical choice – since no such thing that would go

under the name of unsocial disability experience was to be found. The viewpoint of my study is that social interaction tags the disability experience into the impairment and makes the impaired individual socially less preferably positioned. Relating to social preferability of disability, Lampinen (2007, 200–203) has noted – alongside the study that Invalidiliitto did in 2006 – that the common viewpoints towards physical disabilities are still dominated by fear and pitiful approaches that lead to various socially stigmatizing disadvantages when enacted.

Disability can mean the same as a socially constructed status trap that blocks the opportunities to become seen as a competent and skillful person[5]. However, when it comes down to being physically impaired it seems that there is actually no such thing as a unified experience that everyone would share[6]. Being physically disabled actually appears to be anything but a universal conception since even a small portion of impaired individuals attributes notably different meanings to it[7]. Perceptions and meanings given to disabilities are of course quite tied to the social surroundings. Social surroundings seem to modify the overall ways of how disability is experienced and perceived as a personal and as a social status – and these modifications are sometimes quite considerable. (Koca-Atabey 2013, 1028–1030.)

The conclusion drawn from the above is that even when the actual disabilities would remain the same the social meanings and opportunities are usually different depending on the environments. In other words, environments do create different social realities and personal disability experiences. Regardless of the environments, it seems that the ongoing universal problem of impairments is that the social attributions they receive are still in many ways mostly negative. Physical disabilities are even today pointing notoriously

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5    See section four.
6    Some people experience problems of social status more severely than others.
7    Take a look at section four's informant entries.

towards the case that impairments are the same as somehow weakened social statuses. The problems of disability and status have also been theoretically connected – and in many ways still are – to the edgy offspring of a group of influential ideas developed during the past decades, which came to be known as the medical model of disability.

The medical model presented that the misfortune of the physically disabled person was coming solely from the fact that he was physically impaired – since the disability is a medical fact that usually has some negative impacts on living. Medical model of disability did however overlook the social implications of the impairment, which led it to ignore the fact that human-life gets many meanings and purposes from the world around it. The focus on disability studies has fortunately changed a bit and the social model has become more prominent. In contrast to the medical model, the social model states that disability is never a fact that comes entirely from the individual's body. The model further specifies that social oppression and discrimination of the impaired body are the reasons, which actually create the disability experience as the unfair disposition that causes misery for the person. It follows from the previous that the impaired body by itself is just a body with an injury until it gets socially defined as something that is disadvantaged and deviated. (Swain et al. 2003, 138–140.)

It seems that the problem of disability is not about actually having the disability – as it is more about the ways of understanding the phenomenon itself. Failure to understand disabilities appears to be mainly a problem of constructs, which inhibit the ordinary people to understand the minority experience of a physically impaired as something else than a personal tragedy of missing out on things (Bickenbach, Chatterji, Badley & Ustun 1999, 1173–1174). The tragedy of disability is not the actual problem of having an impaired body nor is it necessarily even the personal experience of having a disability. What remains as the key tragic component is that the physical impairment is still commonly taken to be a larger issue than it actually is.

The failures to understand impairments are just misinformed perceptions at first but they certainly have some well documented histories on becoming actualized social truths as well. What remains tricky about beliefs that turn into social truths is that they tend to rank the disability almost automatically to mean practically the same as less happy and socially denoted. The problem of physical impairment is that the deviancy is usually there for all to see and the ordinary people might force attributions to it, which are completely alien to the disabled individual. In any case, the physical deviancy usually becomes all but a prestige symbol signaling high status. (Goffman 1963, 62–63.)

From the society's perspective physical disability can also become a very problematic concept. On the other hand it is a state of the body, which has no apparent logical reason or fixed need to influence social relationships in any way but yet it does – and usually degenerates the person's value while doing so. According to Roulstone and Williams (2014, 18–19) the physical deviancy is like a glass ceiling when it starts contributing negatively to the possibilities via structural discrimination – because being discriminated inhibits possibilities.

Discrimination is prone to happen since on many arenas of life the existing stereotypes are still prominent to support the stale ideas that having an impairment would be the same as the profound lack of competence and skills (Lampinen 2007, 200–203). Also, the fact that people with physical impairments might need some sort of help from the society or from their families – so that the physical deviancy would not decrease the quality of life – does not vote well when it comes down to creating positive and more considering disability conceptions within the social stratum (Swenson & Lakin 2014, 185–186).

In terms of social status disability can mean that physically impaired persons can be

unfortunate enough to get branded as the ones who are always dependable from the society and the good will of their fellow citizens. Today it is apparent that many physically impaired do live a life that is very independent and as such it remains puzzling that there are still strong opinions labeling their disabilities as undesired social problems. In the end one might ask: Why is disability still such a problem even in the eyes of today's citizen? Sociology provides an answer to the previous by introducing the concept of stigma and its practical application: stigmatization.

## 2.2 Hardly trouble-free: Stigmatization of physical disability as a problematic social fact

Stigmatization happens when a person gets denied of access – and thus discriminated – from certain positions because of his characteristics. In the case of physical disabilities the generalized prejudice presuming that the impaired individuals are somehow less relevant – and less fit – for the societal tasks can be considered one of the driving ideas of stigmatization. Stigmatization appears as a result of stereotypical beliefs, which get realized as negative branding of impaired individuals[8]. (Phelan, Link & Dovidio 2008.)

According to Goffman (1963) being disabled is a stigma symbol by itself, which means that the end result of stigmatization is never a positive one – since there is no such thing as a positive stigma. Stigma travels frequently with negative stereotypes and those two negatives relate to each other closely as they are what actually hampers the performance and the coping expectations of the impaired body. Goffman (1963, 152) elaborated that the problem of stigma is that it interrupts the illusion of a commonly shared reality as it introduces a deviation that manifests against social uniformity. One question on the topic does however remain: What kind of social processes actually make stigmatization happen

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8 When terms like physically disabled, deviant body, physically impaired etc. are used they are rhetoric tricks, which seek to make the presentation more readable. As such they do not seek to pass any moral evaluations.

in the first place?

It turns out that there are actually multiple ways how stigmatization can become a lived oppression for the impaired. Firstly, stigmatization does easily create a power position over someone, which means that in most cases becoming stigmatized is practically a synonym for having somewhat unequal social opportunities. Secondly, stigmatization spawns tendencies towards ratifying some of the already existing stagnant stereotypical social values, which work against disabilities[9]. The third way to understand stigmatization is by realizing that some people just do not want to be around individuals who appear somehow sick or impaired. For the individuals who feel unbearable uneasiness around the disabled ones, the whole social experience might form a scary reminder of their own mortality and weakness. Stigmatization hence occurs as a reaction to the discomfort since the fear of the unknown deviant is – metaphorically speaking – pretty much the same for these people as waving a big anxious sign in front of their faces saying: Look this can happen to you too. (Phelan et al. 2008, 362–363.)

There are probably various other options to explain why an individual with a physical deviation becomes stigmatized. Similarly, by no doubt there exists countless individualistic reasons to explain why stigmatization becomes a problematic social fact for the ones who experience it. Generally, when stigmatization happens it can mean in many arenas the same as access denied. While things have improved – during the last decades – physical disability does still create a formidable risk for social exclusion[10]. Having a deviancy can also create false incompetence expectations, which do create some really troublesome social realities for those who happen to have physical impairments[11]. At worst stigmatization of disability can become like a faulty lie-detector, which inhibits the

9 Disabilities have a long and well recorded history of being perceived negatively by the ordinary people. Goffman's Stigma book from 1963 provides some good examples on the topic.
10 Social exclusion is further addressed in section four.
11 See more from chapters 4.5 and 4.6.

individual from telling to others what he is really about and as a result they label him or her as an unfit from the start.

Furthermore, when stigmatization occurs it also has moral implications. Casting a stigma can be understood as a moral and value-based reaction to the perceived deviancy, which means that the actions that do stigmatize other individuals are not just empty statements without any meanings. The moral aspect can be taken as a one way to answer to the question of what is acceptable and what is not. In practice, moral aspects do mean that stigmatization of physical disability develops a capacity to become deeply invested with judgments since people might attribute all kinds of prejudices to the deviant body – and those attributions hardly ever remain neutral. (Yang et al. 2007, 1528.)

The grand problem of physical disability is that even though it is not by itself in any way wrong the society produces values, which do label it as a secondary and subordinate to normality. One result from the values, which subordinate disability are the situations where the one who is impaired becomes discredited. Goffman (1963, 27–28) described the experience of being discredited by stigma to be similar to the invasion of privacy: A rampage of the ordinary people to the area where they think they know all the answers – even when they are lacking the basics.

It seems that when it comes down to actually changing the attitudes that stigmatize, the troublesome reality hardly ends. The previous is also because the media of today is a very powerful tool when it comes to shaping and creating opinions. As such the presentations portraying impairments in a positive manner seem to remain small. The publicity given is usually something that has a negative tone in it. The specific problem of negativity is that – while it might increase program ratings – it does make things even more difficult for the people with physical disabilities and might actually even enhance the danger of becoming

stigmatized[12].

While there is nothing wrong with publishing negative things from physical disabilities – if they are based on the facts – the problem of negativity is that it usually remains colored and as such boosts the already existing and stigmatizing errors of thought. If one were to look for more drastic and clearer examples that create stigmatization and negative stereotyping then movies would serve well. According to Rieser (2011, 71–73) what could be found there would be some very simplistic and stigmatizing ways of presenting disabilities as either a quality of evils or as an obstacle to be defeated by superheros.

All in all, when stigmatization is looked as a social fact that actually happens it surely seems negative enough. Given that the stigmatization is such a negative thing it comes to mind that perhaps it would be better if a person with a stigma would try to hide or minimize the visibility of it – even if the stigmatizing feature would be hard to hide as it is a physical one. The proposition to hide the stigma sounds like a solution but it turns out that hiding has some social costs as well. When it comes to physical deviancy the reality is that it can hardly be hidden during a direct social interaction. However, today's world is quickly becoming a world of Internet and it is not uncommon that people meet online and discuss their matters there. The problem of these new ways of communication is that they actually make it easier to hide the existence of a physical stigma all the way to the point that revealing it could become a social burden all by itself.

The glitch of the physical disability – which is general knowledge for those who have it – is also that during the normal social communication there is always something that gets left out from the picture even when the impairment is a very visible one. The things that can be left out quite easily are the feelings and viewpoints clarifying how a person who has a

12 From the dangers of media see as an example: Briant, E., 2013. Disability & Society 28:6, 874-889.

physical stigma actually experiences it all. The reasons for leaving out information seem to have some negative impacts on experiencing belonging. For example, the social self-image might take a hit since physical disability could include some limitations that are not so obvious for other people. Hiding something elementary about the physical experience could thus transfer to become a series of social actions that ordinary people find bizarre or even so weird that they could actually start avoiding the person with the physical disability – simply because they lack the information to know any better. (Newheiser & Barreto 2014, 59–60.)

The actual reasons for leaving out information remain multiple but the most common case could be that it is generally really hard to explain to a person how does having something that he does not have feels. The danger of disability stigma – and one of the reasons it remains a  problem – is that the attributions and the results it can have are all but based on solid and well explained facts. What remains interesting is that already Goffman (1963) saw impairments practically and socially the same as having a downgraded citizenship. World has advanced much since Goffman's writings but still in 2014, more that fifty years after his entries, the stigmatizing attitudes do exist and they remain essentially the same as they used to be all those decades ago[13].

It hardly is surprising that stigmatization is still a problem that occurs. To overcome it there needs to be new ways to understand the impairments more fully than before. Currently the situation is that the dominant public opinions towards impairments seem to be almost solely linked to the negative prejudices, which do not really capture what it means to be a physically disabled person. Since the need for a fresh way to conceptualize impairments remains urgent, there is one possible route to create a vision that could contribute to the understanding of disabilities – and that is the gaze that rises from the sociological

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13 Similarly to Goffman, Markku Lehto's Vammaiset suojatyössä from 1973 provides a good example from the area of employment showing that while things have changed there still exists similarities to current date.

phenomenology.


## 2.3 Thinking outside of the box: Understanding physical disability through phenomenology


The problem of disability stigma is that it is full of beliefs and viewpoints that are negative and not quite descriptive to begin with. The most obvious sense of non-descriptiveness is that the actual disability phenomenon and the ways by which it is experienced by those who have it usually gets overlooked. In fact, stigmatization creates labels that come from the outside rather than from the inside and those labels only capture the ways that tell "how others see it" and ignore the ways by which "they actually experience it". Losing the experience component can create quite serious errors in understanding and that is exactly the reason why applying phenomenology to physical disability is important. What phenomenology does is that it enables the possibility to explore what the persons actually think about their disabilities and – more importantly – how they have lived with them. (Kleiman 2004, 8–10.)


Forming a viewpoint that describes the mindsets of those who are in danger of becoming stigmatized can also open up new possibilities to conceptualize the impairments as something more than disadvantages. As the phenomenological viewpoint gets applied to the disability what will appear is a conscious approach, which takes into account the experiences that a person actually has while having an impairment (Finlay 2013, 124). In contrast, the problem of stigmas – and also that of the more radical formations of the medical model of disability – remains to be that they do not see much added value in the actual experiences of those who are disabled. In fact stigmas do quite the opposite and load great value to somewhat outdated prejudices and stereotypes.

17

Some possible social results of the prejudices are those that were described on the chapter 2.2. What does remain quite concerning is that in addition there also exists theoretical problems in the general patterns of disability discussion if it is to remain without the phenomenological input. The specific theoretical problem that emerges from lacking the phenomenology would be that the conceptualizations of disability might fall all the way back to become fully dominated by the medical model of disability. The general problem of medical model is that it sees the body as a vessel of deviant misfortune. Medical model as such is hardly something that could be adopted as a base if the goal is to create some solid and socially meaningful interpretations about physical disabilities. (Swain et al. 2003, 138– 139.) What phenomenology gives instead are some new and valuable opportunities to address the inner experiences and the outer experiences of living. The great attribution that phenomenology could give to discussion can hence become understood as a tool that both combines but also separates the inner and the outer experiences of disability from each other – and by doing so creates a more complete picture. (Paterson & Hughes 1999, 601– 602.)

To showcase the differences of the inner and the outer experiences here is a simple example. A person who has been living with a physical disability for a long time is hardly the one who sees himself or herself as the most unluckiest person that has ever existed. The ordinary people might however visualize this person as someone who is always in a constant and never ending misery because of his or her visible impairment. In the example there are two different layers of experiences: The inner and the outer one. Stigmatized understanding only sees the outer experience and is prone to attribute it as a misery and practical devaluation – and at the same time the inner experience is what becomes sorely missed. Phenomenology can be seen as a gateway to a better understanding since it includes the inner aspects as well when asking: What does having a physical disability actually mean for the person who lives the experience? The difference between phenomenological and the stigmatized understanding becomes quite obvious if compared.

What stigmatization does is that it tells a person how he should feel about his disability – since it is perceived as a misfortune happening in front of ordinary eyes and of course the ordinary gaze is always right. In contrast, what phenomenology does is that it gives a voice for the person who experiences the outer and the inner aspects of his disability. The danger of stigma is thus that it concentrates to the outer and forgets the inner experience completely. The dispute is also that when the negative prejudices and beliefs transfer to become social practices then a situation develops where the outer meanings of disability overpower the inner meanings given to it. In goffmanian vein the scenario could be expressed by saying that when stigmatization happens it can alter the balance between the actually visible outer meanings of disability and the more virtual and personal inner meanings attributed to it. (Goffman 1963, 57.)

The downfall of disability is that it is not a norm of society but instead it is commonly apprehended as a deviation from it. If the stigmatized norms that target disability are accepted by the impaired ones, the payoff ought to be everything but pleasant since it would practically mean the same as becoming unequal and accepting it. (Goffman 1963, 46–47.) For all these reasons it is clear that phenomenological views of disability need to come forth. The possibilities of phenomenology to create new and stigma free understanding towards physical disabilities will be discussed more on the section six.

# 3. FROM IDEA TO QUALITATIVE CONTENT ANALYSIS – REVIEWING METHODOLOGICAL CHOICES

This section sheds light on the methodology and gives insights to the ways by which this study was done. The section begins by enlisting the research questions, which formed the frame of this study. An introduction of the persons who became the informants of this study will be presented after the research questions. Informant introductions will be followed by entries describing the processes of doing the study itself. Next, a body of information will be given highlighting the logic that led to the choosing of the informants. Finally, ethical considerations will conclude the reviewing of methodological choices.

## 3.1 Asking it out loud: The research questions

As my research is phenomenologically oriented it was influenced by Alfred Schütz's work. Schütz's idea stating that reasons behind social interactions can be found when studying the meanings, which individuals give to the events, came to be very central to my research. (Eberle 2012, 281–282.) When I started my phenomenologically oriented quest the purpose was to find an answer to the following main question: How does having a disability stigma influence the lives of physically impaired people?

Once my study progressed it became quite clear that while people do share similarities in their interpretations of physical disabilities there are still many things that usually differ quite drastically. The drastically differing elements of disability were the ones that touched the personal decodes of it. The multitude of personal meanings made me consider the main research question more profoundly and in the end the conclusion was clear: I needed to split the question to additional sub-questions so that I could actually provide some satisfying answers.

When I created the sub-questions I attached them to the categories of deviant body, social interaction and stigmatization – and thus linked them inherently to my analysis and the sections that appear in it. The first sub-question came to be: How does a deviant – disabled – body influence on social interaction? With this question the intention was to find out what kind of reception did the impaired body get when entering social interaction and did the bodily deviance bring any difficulties to the picture. I found this question to be quite mandatory since living is usually, one way or another, tied to being social – and if disability was about to make its negative mark to it then all the more reason to investigate.

My second sub-question came to be: How does the physical disability influence on the perceived social opportunities of an individual? The second sub-question, being an extension to the first one, was something that I though of as a possibility to create a more tangible vision to the phenomenon of physical impairment. I also wanted to point out more strongly with the question that the viewpoints towards physical disabilities are not even remotely universal. Thomas (2004, 573–576) also highlighted the existence of disagreements when she wrote about the different meanings that disability can get both theoretically and practically.

The third and the final sub-question was: What sort of problems does having a physical impairment create when entering to labour market? The orientation of this sub-question was designed to provide more practical examples about the problems faced when having a physical impairment. According to Goffman (1963) disability generally votes bad for appearing competent and skillful and it is also known that having an impairment does make getting a job more difficult than it is for the ordinary people. For example: Linnakangas, Suikkanen, Savtschenko and Virta (2006, 43–46) provide some statistics on the topic of employment, which highlight the apparent difficulties. With the questions outlined above,

the purpose is to widen the understanding towards the stigma-related challenges that those who are physically impaired have to face in their lives.

## 3.2 The ones who answered: Introducing the informants

This study at hand contained eight people, four women and four men, who became the actual informants to be cited[14]. When it came to the level of education, majority of the informants had attended to upper secondary school and finished it. Every informant who had been an adult longer than nine years had also some sort of professional education. Having a professional education was more apparent among those few people who had discontinued upper secondary school and moved to obtain vocational training instead – with a direct aim to a certain profession. In general, half of the informants did also have plans to obtain or complete an ongoing university/university of applied sciences education. Hopes of obtaining more education were appearing mostly among the ones who were in the early segments of their twenties[15].

Among the eight informants there were three persons who moved only with a wheelchair while four of the informants used multiple supports from wheelchairs to walking sticks and walkers. There was only one informant who moved without any supports during the time of the interview. The ages of the informants varied from nineteen to thirty-seven. Half of the informants were in their middle or late twenties while two informants remained closer to their early twenties. There were also two informants who formed a segment, which was aged over thirty years.

All but one of the interviews were done face to face. The one that was done technically via

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14  See citations on section four.
15  This was also because the ones who were older already had the level of education they felt they needed.

Windows Live Messenger's text chat was the very first interview – the pilot interview of this study. The reasons for doing the first interview technically related to distance but also to the logging capabilities of the used technology, which provided better chances to audit the research questions – so that any needed changes could be made. In the end the changes remained only cosmetic and because of that the pilot interview was also included to become a part of this study – with the approval of the person who was an informant in it.

Since I had crafted my research in such a way that it was influenced by phenomenological orientation, it meant that the method of analysis came to be that of qualitative content analysis. Content analysis as a method was required because of the initial phenomenological orientation, which was all about finding out how people with physical disabilities experienced their impairments in their daily lives. Furthermore, as the interview questions had already been constructed with the spesific topics in mind, it became rational to do a content analysis. I also adopted a viewpoint that while phenomenology by itself can be about analysing the words of the infomants – in order to obtain deeper meanings – things quite innately will point towards qualitative content analysis when phenomenology meets real and tangible orientation stemming from the science sociology.

## 3.3 From an inner monologue to a wider dialogue: How the study was done

When I set out to do this qualitative study, the goal was to find out how does stigmatization influence the lives of those who have physical impairments. The research itself became connected to phenomenology as it was after all describing two phenomena – physical disability and stigmatization – and the ways by which they were experienced in the real life. The specific goal of my presentation was that I could provide what Creswell and Miller (2000, 128–129) called thick and rich descriptions since I considered phenomenology without deeper elaborations as something that could hardly be seen as a form of sociology.

Since my study was oriented towards sociological phenomenology, it practically meant that the design of it followed the idea, which took the bodily state of the impairment and social situations as things, which would only get their meanings from the individual's interpretations of reality (Paterson & Hughes 1999, 601–602). Doing phenomenology also meant that my inputs as a researcher needed to be thoughtful and considered – so that the informants would feel related to the topic in a comfortable way. In this study everything began with a careful planning of the interview structure. Much time was invested on forming the interview questions in hopes that they would be able to meet the needs to gather information from the informants who later became part of this endeavor.

When things progressed and I was finalizing the questions I did consciously try to control my own biases and opinionated experiences about having a disability. As I was not about to study my own life the realization of my own biases took some hard and conscious thinking, which actually never stopped and kept going until the end of this study. Conscious thinking was also needed since it occurred to me that disability and stigmatization can be experienced in more complex ways than I had ever imagined. Following the realization of complexity I decided to divide my interview questions into three section. As I was doing a phenomenological study, the interviews themselves were thematic in nature concerning the themes of stigma and physical disability. The finalized design idea for the interview frame was also notably inspired by the considerations that were present in the traditional books about disability and stigma, which stated bluntly that physical disability as a phenomenon would be something that influences all the stages of human-life with negativity[16].

The interview frame was developed in such a way that it adhered the commonly used practices of semi-structured in-depth interviews. Using semi-structured interviews gave

16 See for example Goffman 1963.

valuable support to my phenomenological cause since according to DiCicco-Bloom and Crabtree (2006, 315) the semi-structure allows interviews to go deep into subjects under focus, which was the exact goal of my orientation as well. The interview frame itself was divided to contain the periods of childhood, youth and adulthood[17]. The study also included some questions about future aspirations, which were placed after the period of adulthood[18]. All the questions became styled as open-ended favoring narrative free speech within the general frames of the sections. The reasons for choosing a more open-ended approach were that of fostering some additional control over biases but also that of increasing the possibilities of actually getting to the phenomenological roots of disability and stigmatization experiences. (Finlay 2013, 124.) Just after I had completed the interview frame, I set out to do my eight interviews. The time that elapsed on the newly arrived interview stage was about two months. The first interviews begun around September of 2012.

When I was doing the interviews it meant that every single one of those occasions began with some general questions, which helped me to get the basic knowledge about the informants. After the opening ceremonies had ended, the attention moved towards asking more specific questions about friendships, social relationships, possible stigmatization experiences and other disability experiences alike. Depending on the informant some sections did collect more than others. When the person was older the information I received from adulthood section was notably larger than from any other. Overall, things did remain well balanced between the sections. The average time spent on each of the sections was ranging from ten to fifteen minutes[19]. The most shortest part was almost always the part following adulthood, which included few questions about the future aspirations.

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17 Childhood contained years from six to twelve. Youth contained years from thirteen to seventeen. Adulthood contained years eighteen and onwards.
18 For further details see the interview questions in Finnish found from Attachment 2.
19 Each of the interviews lasted approximately from fifty minutes to an hour.

Future-related questions were originally designed to be nice ways to end the interviews and also to counter the strain of earlier – and sometimes rather demanding – questions. Telling about personal matters was not easy for some of the informants and because of that few question were also skipped as too difficult. Following from the previous, it seemed only right that the interviews were to end with some nice and positive tones rather than negative ones coming from the stigma. I noticed after-wards that future aspirations did also serve as valuable inputs in describing the phenomena of physical disability and stigmatization[20].

Once I had completed all the interviews it was time to start analyzing the words I had recorded[21]. As I had designed my study to become phenomenologically oriented it meant that the recorded words were wrapped and tied around the core research question, which was: How does having a disability stigma influence the lives of physically impaired people? When I was analyzing the recorded words and relating them to theoretical considerations, the leading idea was that disability has a dual nature. Adapting the presentation of Kleiman (2004, 10): Disability in my study became a theoretical concept, which could raise multiple theoretical questions[22] but it was also a part of a more empirically visible reality that could be experienced.

In order to understand how the phenomena of physical disability and stigmatization work and actually impact the physically disabled people I needed to start with a very careful reading and auditing of all the materials, which I had collected. Along with the recorded words, the materials included many research articles and some relevant books relating to the phenomena of physical disability and stigma. A careful reading was also quite mandatory step to take as I conducted my interviews in Finnish and was about to write my work in English. The important part was that of making sure that I could translate

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20  See more from section four.
21  For recording purposes I used a digital recorder.
22  Navigate to chapter 2.1 and compare the basics of medical model and the social model of disability.

everything needed from one language to another without losing any information[23].


The next step on my research agenda was to label the information. For labeling I chose the categories of deviant body, social interaction and stigmatization. The categorical choices came to be because of the inputs, which pointed strongly towards the case that the impaired body gets its meanings during the social interaction and the results are often stigmatizing (Yang et al. 2007, 1525; Phelan et al. 2008, 362–363). While I analyzed the informant entries it was also quite evident that the categories of deviant body, social interaction and stigmatization did form a triad in which all the parts were much needed to understand the whole phenomena of disability and stigmatization.


After realizing the complexity of the topic that I was researching I once more turned my attention intensively to the materials I had collected. I focused particularly on listening the recordings I had obtained to see whether they still contained a bit more than I had hoped for. As my study was designed to go along with the stages of childhood, youth and adulthood – while containing some future hopes and dreams – I soon realized that I actually had a wealthy repository of entries telling about the changing nature of stigmatization experiences[24].   Writing an analysis begun to take shape around the concept of the deviant body and its social interactions. The deviant body became a clear starting point for the writing because the informants talked a lot about how they had been socially treated during their lives because of their impairments.


When things progressed and I was conceptualizing the youth related parts of the interviews there was one particular conclusion that was quite obvious: Youth for many had been a time where they clearly felt that they were not always treated like everyone else –  because they

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23  All the informants of my study were native Finns.
24  It seemed that when the times changed so did the outlook of stigmatization experiences.

were physically disabled and had impaired bodies. For the youth section, the rational choice was to broaden the topic of social interaction and to develop it further. This time the focus was bound more to the school environment and the actual youth experiences since they were, for many, the grand arenas of social exclusion and stigmatization. When the analysis proceeded to the adulthood segments there was an unexpected rise in competence discussions. As I looked upon the adulthood, it was quite clear that the specific stigma-related issues there were the problems, which the informants had experienced when they had been trying to get a professional career or a job. Having a disability had been for many a brand marking them as unfit for work. Since competence and work-related topics provided interesting viewpoints to stigmatization they came to be included to this study as the final sections of the analysis[25].

Throughout my research I constantly checked what had been already written about stigmatization and physical disabilities. In the beginning, the downside of the approach was that there seemed to be quite many sources about disabilities but the majority of them talked only about mental rather than physical ones. The best part of a phenomenological research, which starts growing from the informant materials is that in the end those materials pointed me to multiple supportive sources, which I could utilize and actually use. The previous is also what remains beautiful in sociology for me: When the study begins it is still a mystery how it will actually end – and so it was for this one as well.

## 3.4 Staying informed: How the participants were chosen

When I was choosing the informants I used my already established contacts to scout for the possible personnel. As I had been a part of the disability movement[26] it had introduced few

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25  The chapters in question are 4.5 and 4.6.
26  As mentioned earlier: Disability movement is used as a broad term referring to mixed association work.

resources, which I could utilize. The search for the informants followed the most simple pattern of asking from my contacts if they possibly knew people who could participate into my study concerning stigmatization and physical disability. The downfall of being a member of the disability movement was however the fact that since I had been around long enough, I had at least met the majority of the people who rose to become the most prominent participants to the research itself. While the potential participants kept coming I established a criterion, which would either qualify or disqualify them as informants.

The criterion of selection followed a principle, which I formulated as follows: Was there a very close and well-established history with any given potential informant? The specific danger for me was that if I would have actually known the full life-histories of my informants – and also been an integral part on them – there would have been no chance to go and do an in-depth phenomenological interview without the feeling of mutual uneasiness. The worst possible ending that I imagined could have been that I would have only wasted my time from fifty to sixty minutes without actually getting anything but an in-depth feeling of awkwardness and that of course is not an acceptable way to do any proper phenomenological sociology.

After I had formulated the level personal well-knownness as a gatekeeper criterion I decided that I would disqualify a participant if a recent and widespread contact with him or her would exist beyond the formal disability movement circles. I was also primarily prone to choose participants from the group of people who I had met and associated during earlier times but with whom I lacked deeper and meaningful shared experiences in the near past. With the decisions that are listed above, I made sure that I could be objective enough to do a research, which would have some everyday relevance on addressing the issues of disability and stigma –  rather than having none (Alasuutari 2010, 149).

Personal histories aside, it was of course important to talk to the informants. As it happens my informants were located all around Finland – this was both a good thing and a bad thing. The good thing was that a wider scale of areas came to be represented by the informants who had their different backgrounds and communities. The bad thing about having a wide array being represented was the fact that a few very potential informants had to be disqualified simply because of the accessibility issues. The disqualifying scenario happened few times mainly because of the distance between me and the potential informant, which was at worst over five hundred kilometers. Since the distance proved to be problematic I finally chose to target areas, which were inside the approximate range of four hundred kilometers so that I would not be straining myself or the potential informant too much.

Upon making my final decisions about whom to include to my study the communication channels provided by the social media and the email did help a lot. Actually, it is more than likely that without the social media there would have been some extra difficulties to do this kind of research because young adults and adults of today seem to be quite immersed to it. Social media by itself made it very easy for me to get the final confirmations from the people about their participation and to answer their questions – if they had any. The traditional email had its place too as it also served as a communication channel established between me and the informants who were outside the social media.

One very big decision influencing to the choosing of the final informant group came to be the eagerness of the participants to actually become included to my research. As I recall it, there were some potential informants who did raise a concern of commitment in me from the start. I still remember being worried that they might withdraw because simple lack of motivation when the D-day would come. In the end I was lucky enough to find a solid group of eight adult participants, four women and four men, who demonstrated both

eagerness and interest towards my study. For myself as a researcher the previous was a reward of its own kind as I saw that I had chosen my informants well because they were all persons who wanted to be present and donate their information.

## 3.5 Remembering fair-play: The ethics of the research

Based on books and articles about ethics there certainly seems to be more than a few ways available to start building the ethical framework for a qualitative study. For me the most obvious starting point on the ethics was that no real names would be used. Some details were also edited out and omitted because they could have potentially revealed the identities of the informants – possibly causing harm to them. I also stated clearly to the informants that their inputs would be used only in this study and that their recorded words would be kept safe with me. As I discussed the usage of the recorded words, I also further clarified that not even my personal notes, which I made during the interviews, would be transferred to other parties[27]. The previous steps were taken so that the anonymity would be maximized. A very clear agreement was also made stating that the real names of the informants would never be revealed to anyone, even after time. (Shaw 2003, 15–16.)

It should be clarified that even though my initial ethical elaborations started from anonymity, the overall standpoint I took was a wider one. Ethics for me came to mean the same as the concept of fair-play. The main ethical guideline I set to myself was thus that of keeping things clean and sophisticated. Being ethical also meant thinking carefully about the steps that I would take when conducting and transferring the interviews from the recorded words to the written citations appearing on the analysis of this study.

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27 My personal notes did contain details, which could have revealed the identities of the informants.

Keeping things sophisticated and straight-forward was much needed since many participants were concerned about the usage of their stories. Because the informants expressed worries it meant that addressing the matters of ethics came to be very important in the process of clearing out anxieties. Quite many of the participants also told – before the recordings – that they had never been on interviews before and that gave all the more reason to address any potential worries with detail. In practice, addressing the concerns did become the very first thing I did before the actual interviews took place. Before powering up my digital recorder I once more explained to the informants how and where I would use their words. In any case, it would have been ethically shady if my informants would have not known  or remembered what I was about to do and why.


The only really difficult ethical problem – causing headaches – appeared when it came to describing the statuses of physical disabilities. I was worried that including too detailed impairment descriptions would undermine the whole ethics of my study – since I realized that many of my informants had quite specific characteristics in their disabilities. In the end I chose to describe the disabilities with general statements to overcome the ethical dilemma of revealing too much[28].


Ever since this research started, the fact that the participation was completely voluntary was clarified – first via the invitation letters[29]. Voluntarity practically meant that participation could be canceled with ease at any time if so wanted[30] (Wester 2011, 301–302). I also did highlight the point of volunteering strongly during the interviews since I noticed that some questions were really hard to answer for some of the informants. Given that particular questions proved troublesome it was only fair that we skipped those and moved forward –

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28 The general statements included lines such as, a person using multiple supports or a person in a wheelchair.
29 The invitation letter can be found on Attachment 1.
30 Some potential informants did cancel their participation and they were replaced before the interviews started.

since an ethical research is also the one where informants can refuse to answer if they do not feel like wanting to do so. By doing what has been described above, an ethical position which gives credit to the informants is hopefully achieved to its full extent.

## 4. SOCIAL INTERACTION AND THE STIGMA OF DISABILITY

This section focuses on analyzing the recorded words of the informants as they described their lives with physical disabilities. The focus of the chapters below remains on the topic of stigmatization and circles around the themes of accessibility and competence. It turns out that accessibility and competence issues come in many forms and remain socially challenging for the physically disabled people of today.

### 4.1  Just cannot hide it: Deviant body in social interaction

> *"People who tend to stigmatize others easily are the ones who are always highlighting normal situations either by telling about their own experiences with the disabled people or by asking overly personal questions. These kind of persons could also be the ones who have a disabled person in their family-tree and for that reason they tend to over-generalize the whole phenomenon because they think that one case covers all. Also it happens quite easily that a person with a physical disability gets to be labeled as a mentally handicapped as well."* –Laura a twenty-nine years old woman in a wheelchair.

What Laura states above is quite a common case happening to physically disabled people when they enter social interactions. The problem of the physical deviants is stemming mainly from the fact that they do not get to be labeled as the ordinary people – at least in the majority of cases. Researchers have also  noted  that substantial difficulties to establish actual social interactions exist. Difficulties emerge because physical deviancy might be for the ordinary people an overly undesired quality all the way to the point that it inhibits the opportunities to socialize. (Wiegerink, Roebroeck, Donkervoort, Stam & Cohen-Kettenis 2006, 1026–1028.) What having an undesired quality means in practice is that the physically impaired persons get avoided and ignored simply because they cannot hide their

impairments, which appear as overly problematic social facts for various possible reasons [31].

As it does remain clear that the actual social interaction does require some sort of bodily presence, it also becomes apparent that hiding a physical deviancy is just something that cannot be usually done very well. The specific problem of deviancy is that it can pave the way to the point where a person becomes stigmatized – unfairly labeled as an unfit composition of qualities – and that certainly raises some concerns. The tragedy of stigma is that the physically impaired gets some bonus-points when it happens. The result of the previous is that what begun as a purely physical misfortune suddenly becomes also seen as a socially disadvantageous hallmark of deviancy signaling profound and overall lack of skills and competences. (Goffman 1963, 12–13.)

Everything has to begin from somewhere and those "signals of lacking the competence" must start from somewhere as well – the problem is that usually they start from the very building blocks of our society[32]. When Rieser (2011) discussed about disability presentations on the movies he traced the roots of stigmatization to the negative stereotypes, which seem to have a wealthy repository of attitudes to tap into. The problem that is evident in disability stereotypes is that they are more than often describing physically disabled persons as non-sexual misfortuned and sad human beings who have comedy value at best. In some cases the situation can even get ridiculously inverted and a physically disabled might become seen as a some kind of super-human with something extra – because he or she can actually have a normal life with that "horrible" impairment that no common man has been able to tame. (Rieser 2011, 35–38.)

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31 See chapter 2.2.
32 See more from section two.

When it comes to disability the problem remains in the encounter of reality and the actual physical experience. What usually happens is that when reality meets impairment the treatment that physically disabled gets is already negatively tuned to begin with. As such stigmatization does remain a real threat that the deviant body faces during the social interaction. The upside of things is that stigmatization is not a threat that all physically disabled face unprepared. One prominent strategy to control the danger of the negative stigma is to control the environment where social interactions take place. Controlling the environment is something that has its impacts on social possibilities but still there are benefits to it since becoming stigmatized can be really damaging to later social interactions. Jonna, a woman aged twenty-six using supports from wheelchair to walker, told the following about the problems of being a physically disabled and having social interactions:

> "I am afraid of social situations because of my disability and it certainly limits my possibilities to move outside my home. I hang out with people who certainly accept me and see me as myself and not just as a physically impaired person."

Jonna's strategy that was about limiting her social space echoed closely the viewpoints, which presented stigmatization as a social problem on the second section of this study. What comes on top from Jonna's entry is that when disability and the danger of becoming stigmatized are joined together it sometimes does create a world of troubles that can expose limitations to social space. Everything votes strongly for the case that there is no such thing as socially meaningless disability. It also appears that there is indeed no such thing as a trouble free stigma – since even a mere danger of stigmatization can influence the possibilities and choices, which create the actual social reality.

When it came to the other informants, they did remain more open for social interactions. For many the fear of stigma had been something that they confessed of having in the earlier

days – but presently not so much. As it came to the actual experiences it was very surprising that the stigmatization did not always happen at all as expected. Roni, a thirty-two years old man in a wheelchair, had this to say about stigmatization:

> "I was afraid of being stigmatized and I did experience some prejudices from my classmates during my school days. The most common cases were related directly to my movement and participation chances. I controlled my fear of becoming stigmatized with self-irony, which was in a way an extension to the insults I received relating to me as a person. The insults and prejudices that I received came from my schoolmates who were also disabled people."

The surprising thing on the above is that the fear of stigmatization is not just something that the majority imposes upon the minority – since persons with the minority status can also stigmatize other persons with similar statuses. Stigmatization appears to be a concept without borders and not even having the same minority group membership can stop it when it happens. Reasons for becoming stigmatized vary in their actual content but according to Green, Davis, Karshmer, Marsh and Straight (2005, 203) stigmatization and exclusion tend to happen when disabilities are so severe and visible that they make the deviation to stick out too starkly to be left unstigmatized. If the previous is indeed true then what is happening in Roni's case becomes a total mystery since he should have been fitting in just perfectly among other similarly disabled people – but he did not. One could always think that Roni's case is an exception to the rule and others do fit in just perfectly when there is a shared disability experience. Interestingly enough, the stigmatization that Roni experienced from others who were disabled did not come up as a sole case. Tuomo, a thirty-seven years old man in a wheelchair, continued from the topic:

> "When I was younger I had experiences where other people who had disabilities did not accept me as a part of their group. I was easily being teased by other disabled people because of my small size. When I now

look back I realize that I should have been braver in my youth but still I feel that I missed out from supportive friendships. The situations I experienced during my youth have left their marks as I realize that in some social situations I do not trust myself the way I feel I should."

The entries that Roni and Tuomo gave are both interesting because they seem to counter the idea that physically disabled persons could form deep reciprocal friendships more easily with other disabled persons. Easier friendship formation should be possible because of the shared disability experience, which should create a non-prejudicial environment for the relationships to develop. (Salmon 2013, 353.) Roni's and Tuomo's accounts above manifest all but easy and as such do create a dire need for explanation. What comes also more obvious is that the process of stigmatization should be at least partially reconsidered.

Stigmatization as it appeared for Roni and Tuomo was not a tool of injustice forced upon them by the non-disabled majority but it was mistreatment given to them by their own minority. Ervin Goffman noted already back in 1963 that individuals who are stigmatized, but still belong to a certain minority, might develop an ambivalent habit on fostering the treatment they have received from the normal population to other members of their own group – if an opportunity rises (Goffman 1963). The ambivalence explains the logic behind Roni's and Tuomo's cases but it also means that the power of stigmatization is widened and not only limited to the majority–minority relationships.

**4.2 Tragic characters and the risks of stigmatization – the art of being oneself**

Following the realization that stigmatization can happen more broadly, one question arises: How do the disabled people who are at risk in becoming stigmatized actually enter social situations without getting instantly labeled as unfit deviants? Veera, a twenty-one years old

woman in a wheelchair, gives some pointers about the topic when she talks about people who get to be labeled as tragic characters:

> "In my opinion those people just make themselves appear as very tragic characters or then they just stay out of groups because they have so much self-imposed fears about the ways they might be received. The tragic characters are also the ones who instantly start to talk about their physical impairments and make some huge numbers about them. It is obvious that the physical side will count as a big thing if the first impression is all about it. To avoid becoming a tragic character I would say that people with disabilities should try to introduce themselves just like everybody else."

Veera's entry above states that while having a physical impairment is a bodily fact it does not necessarily mean the same as being a social fact. While it is apparent that social deviancy can start from poorly thought presentations of character, it also seems that stigmatization of disability is not always so well thought either. Stigmatization is more like an ungrounded thought because on many occasions it is built around prejudices and negative stereotypes that are culturally and religiously constructed and remain stagnantly simplistic on understanding disabilities. (Claassens 2013, 169–171.) Valtteri, a twenty-seven years old man walking without supports, further highlighted the meaning of self-capability in tackling the stagnant views when he spoke about the topic of being himself:

> "My main rule has been that I should just be myself and honest to what I am and that is enough. I will not need to be acting any differently or become someone else even though people will certainly have some prejudices. I am what I am and I roam as I roam."

During this study there was a lot of discussion about the importance of self-capability and being just your own self rather than trying to be something you are not. Highlighting the meaning of self-capability becomes quite understandable as character integrity and being

true can hardly hurt during social interactions. While self-capability is no doubt an asset, the actual results of social interactions may vary greatly. In reality, social interactions are usually carried out by different participants with different attitudes and opinions. Nario-Redmond (2010, 473) has noted on the topic of being social that the participants and their attitudes actually increase or decrease the tendencies towards stereotyping and stigmatization. Sometimes it even occurs that the opportunities to communicate become dead and halted just because the impaired individual is seen as an undesired person or simply ignored as a part of communication.

All of the informants did have some experiences where they had their social interactions halted because they were seen as incompetent or otherwise undesired participants. There was however one case that was clearly more generic than others. What made the case generic was the nature of the situation, which was like taken right from the textbooks of classical stigmatization – similar to the ones that Goffman produced. Jonna, a woman aged twenty-six using supports from wheelchair to walker, had the following to say about experiencing stigmatization:

> "One episode I remember was the time when I was buying a television: The seller talked only to my father until my father said that I was the buyer not him. Then the seller just kind of froze completely and stared at me for a long time before actually communicating with me."

On Jonna's citation the quite classical experience of being ignored peaks as an example of social exclusion. Having a physical disability is of course not a crime as it is something that an individual has no control over. On the other hand, it can still lead to a rude form of social exclusion since a person with the disability cannot just become less disabled. The case of ignorance remains intriguing as it also came evident that having a disability did not seem to be even a remotely similar experience for all the informants – some had more stigma-

experiences and some had only few. What also remains interesting is that those who were able to move around better – or had an environment which enabled moving around – reported generally a lot less stigma and ignorance related experiences than those who were not able to move around so well. Valtteri, a twenty-seven years old man who was able to walk without supports, said that he never had any real long standing difficulties relating to social interaction:

> "During my whole life I have had a very big network of friends from youngsters to elderly people. In my childhood years I would say that I had a normal friendship network compared to other kids of similar age. I never felt that my disability would serve as a factor when it came to getting new friends. I was also never bullied or anything. I just welcomed life with an open attitude. My disability was nothing more to me than a small detail in a bigger picture and it had no need to influence my social relationships."

If the above is compared to a story, which Tuomo, a thirty-seven years old man in a wheelchair, gave from his earlier times the image becomes very different:

> "I had some people who hang out with me and came to visit my home but as I think about it I would have needed more friends. I think that the formation of social relationships was also made difficult by my disability because it prevented me from moving around like others did."

Tuomo's story highlights the problem of disability and shows that in addition to creating some social distances the impairment can also show up as real accessibility issues. If the accessibility issues happen then it also means that the opportunities to belong and integrate to social groups become quite effectively hampered. (Asbjornslett, Engelsrud & Helseth 2012, 481–483.) In practice, the accessibility matters become inhibiting factors to the deviant body and mean literally the same as access denied. For example, the entrances might be full of stairs and other structural solutions making the entries to social situations

next to impossible. There is also the danger that if the chances to become a member of a social group become inhibited then the tendencies, which increase the social habits to stigmatize the physically impaired ones might further increase.

Stigmatization could increase due to accessibility issues because people could have hard time getting used to hanging around physically impaired persons if they would have never even seen much of them in the first place. Unknownness is also one of the reasons why physical accessibility problems lead to harmful over-generalizations since it is quite easy to presume things erroneously from a person who looks physically different and remains a stranger. Even when it appears evident that some disabled people get excluded from accessing the actual social interactions that is not the whole picture. Having a disability should be by no means regarded  as the same as  an automatic mechanism leading to social exclusion since person's own social qualities also count among other things. Roni, a thirty-two years old male sitting in a wheelchair, highlighted the meaning of social qualities when he noted that:

> "I think that I had difficulties getting friends in the past because I was very silent not because of my disability."

Drawing from Roni's citation, it seems that the case of deviant body in social interaction is not completely hopeless – since the disability does not determine everything. The danger of stigma remains however in that it impacts most severely the disabled ones who are silent by nature and not so prone on defending themselves verbally. What also remains important is to point out that while disability experience does change – so does human-life with it. To understand physical disability is also the same as understanding that even when the deviant body is not for one's to carry today tomorrow might bring its conditions upon one. When all the pieces of the puzzle are connected  it seems that stigmatization of physical deviancy is

actually one way of trying to deny the fact that things in life generally change – but luck is not always kind and thus disability can occur to anyone. (Titchkosky 2000, 208–209.)

It is also worthwhile to remember that disability is happening to real people with real bodies and minds. What stigmatization does is that it tries to make the real disabled bodies to appear more like surreal and something that can be rightfully socially suppressed. Social suppression can make things difficult for those who carry physical disabilities – like the informants showed  – but situations are not likely to be hopeless for all eternity. Many of the informants did report that regardless of difficulties they currently enjoyed their lives as they were. To further illustrate the aspects of stigmatization this study will now move on to discuss the times of youth. In general terms youth is a time of freedom for many. Being young means becoming more independent and exploring the widening social world with all those new opportunities it provides. Youth certainly does introduce experiences to undertake life like never before and it remains an important step in the process of growing up and becoming an adult person[33]. Youth provides equally important segment in life for the physically disabled but the impaired bodies face some aditional challenges, which will be discussed next.

### 4.3 Not quite like everyone else – disability meets the left out experience

> "During my middle school I had a great and mature gymnastics teacher who was supportive and adapted things for me in a way that I could always participate. I still remember that  teacher with  great warmth. Then when my teachers changed I was not able to participate and this was because my later teachers were not so motivated  to get me involved. I have always liked to move and exercise but during my later school years the joy  of movement got slaughtered by my teachers who were  not motivated enough to consider me as someone who loves to move as well." –Amanda a nineteen years old woman using multiple supports from wheelchair to walking sticks.

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33 From youth cultures see for example: Tolonen, T., 2001. Nuorten kulttuurit koulussa.

Amanda's description drills right to the core of normalization, which is centered around the beliefs of what is normal and what is not – and apparently a physically active disabled student was not what Amanda's teachers considered as normal. It may have been that some of Amanda's teachers tried to protect her from feeling different but the exclusion happening made her feel uneasy and disconnected from an activity she used to enjoy. One of the problems of having a disability is also what appears on the above entry clearly: People may sometimes make rather exclusive decisions without actually considering the disabled one and how does he or she feel about things. Making decisions without a proper mandate on the behalf of the disabled person is something that may hamper the development of social relations and push the impairment one step closer in becoming a truly exclusive fact of life. (Bridgens 2009, 753–754.)

Fitzgerald and Stride (2012, 284–285) have also noted that inclusive education is not actually very inclusive at all since the adjustments made to education do not always seem to show up as improvements but remain more like publicity tricks, which in reality leave the physically impaired excluded from activities – just like before. The problem of exclusion is that if it gets to be a permanent status quo then it also opens up a door for stigmatization.

Since disability has never been a popular youth trend – like hip-hop – it does seem that coping in a social environment, which might be exclusive could get hard. In any case it appears that well-constructed self-esteem and self-acceptance of the disability do help if the goal is to cope with the impairment and to accomplish something successful in social terms (Nario-Redmond, Noel & Fern 2013, 482). It is less fortunate that there are no golden rules that would tell clearly how to build a good disability related self-esteem that does actually work in all those potentially stigmatizing social situations – in school and outside of it. At most, a person with a physical impairment can just try his or her best to accomplish

successful social position – just like everyone else.

The actual problem, which the physically disabled face is that for many of them attaining successful social positions does not always go well in the first place – because they do get branded as the physical misfits who are not like everyone else. Making things even more problematic is the fact that social positions are never fixed and eternal and a person can suddenly even lose his or her position due to disability if it gets labeled as an issue. Ville, a twenty-one years old man using multiple supports from wheelchair to walking sticks, told the following from the troubles he suddenly started experiencing:

> "Some of my friends changed during their youth and they became the so called cool people. I did not fit into their social networks and they isolated me. It is clear that my attitude towards life developed significantly during youth and I lost unconditionality as a part of my character. When I think about it I must say that my own attitude towards things might have influenced the way social interactions went on some parts of my youth before I matured."

What Ville seems to have experienced was a social barrier that appeared in a form of being uncool. Ville's situation was essentially connected to the stagnant practices that tend to exclude physically disabled from interaction – thus making them socially less equal than those without disabilities. (Bines & Lei 2011, 420.) Ville did say that he had some maturity issues but it is likely that his disability at least mediated the negative social position, which came to mean that some of his friends cut connections completely.

Ville's situation can be further explained through the concept of associated stigma. As a whole associated stigma offers a possible explanation to the discriminatory state where physically disabled people are just being ignored or avoided. Associated stigma in its essence is understood as a fear of being labeled as one of a kind with someone who carries

a stigma. (Goldstein & Johnson 1997, 497, 501–502.) In practice the fear of stigma by association could mean the same as sharing the label of a loser. Impairment can easily become a losing position since physical stigma gets attributed with all sorts of negative qualities, which all vote bad when trying to appear as the winner of the day.

Intuitively thinking it could seem reasonable that some people might be negatively tuned towards interacting with a physically disabled because they fear the associated stigma. Fear of stigma does exist but still things are not so hopeless in reality. Hope emerges because there are entries, which suggest that stigmatization in all its negativity could be at least partially countered by being physically active and as independent as possible. So, if a physically disabled person wants to be portrayed as a capable individual then displaying some actual physicality along with independence might provide help for diminishing the fear of associated stigma in other people[34]. (Gainforth, O'Malley, Mountenay & Latimer-Cheung 2013, 252–254.)

Being active is a good thing but it is still no magic trick because stigmatization is inherently and deeply social in its associations. Social surroundings do matter and because of them it just happens that some people are ignored as persons who are eager to move[35] but it happens as well that there are people like Valtteri. Making Valtteri's situation particularly interesting was the fact that this twenty-seven years old man walking without supports reported less stigma-experiences than anyone else from the informants. He told the following about his school times:

> "I never experienced teasing. I think that my own personality and character, which are open for experiences have made things a lot easier. Disability is just one part of my life and I do not see it as something that would

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34 Subsiding the associated stigma by showing activity can be a vessel for popularity-contest if taken too far.
35 See Amanda's citation appearing in the beginning of this chapter.

actually influence my social relationships."

When the informants talked about their deviant bodies they echoed the tendencies that appear in the multitudes of therapy practices promoting the recognition of individual's skills and competences as pathways towards proactive changes. Quite paradoxically Vehmas (2009, 112–113) voiced out the concern that if disability is understood individualistically the opportunities to conceptualize impairments more widely will become limited and blurred.

Regardless of how the impairments are understood, the practical results of disabilites are nevertheless apparent. About a half of the informants reported that they had experienced some sort of social exclusion from all kinds of groups during their youth – notably because of their physical deviancy. The most common cases of exclusion were the ones done by simply ignoring them. What remains interesting is that none of the informants reported that they would have been teased repeatedly and systematically by the non-disabled people during their school times – they were just mostly ignored or left out from the social cliques.

## 4.4 Social values and impaired bodies: Tensions and ignorance experiences as mechanisms of stigmatization

In order to explain the apparent lack of direct teasing one could easily side with a notion claiming that people are more than often trying to be perceived as explicitly open towards progressive and favorable social norms. Social norms do neglect open stigmatization of the groups like physically disabled, which have gained protected positioning in the current societal values. If upfront stigmatization thus appears it likely becomes a socially devaluing experience for the stigmatizers themselves[36]. In reality  people still seem to exhibit subtle

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36 Some social groups do manifest their hate for minorities and see direct discrimination as a their norm.

behaviors, which are more or less negatively charged towards persons or groups that have been traditionally perceived as stigmatized. (Madon, Smith & Guyll 2005, 573–575.) Even when the direct attacks towards physically disabled people have decreased the fact that other less obvious social ways are still in fashion speaks in favor of the case that stigmatization is vividly alive – and this is hardly news.

The informants reported mostly having experienced stigmatization that erupted as ignorance treatment. Still, ignoring the physically impaired just because he or she is carrying a different kind of body does not make stigmatization any more just. There practically seems to be no equality or kindness in ignorance or uneagerness to associate with the physically impaired. What makes things even worse is that being disabled does not mean the same as being uneager to communicate with the ones who are not disabled. It is clear that individual's own attitude matters when it comes to social interactions but not even a good attitude can fix everything if it is one-sided. Tuomo, a thirty-seven years old man in a wheelchair, exemplified the meaning of one-sided attitude when he told that he would have wanted more friends but when it came to non-disabled people getting friends was quite challenging:

> "There was never any teasing coming from non-disabled peers. They just blocked me and left me out from their groups."

Whether the actual stigmatization appears as a visible fear of association or as a subtle form of ignorance is in most cases meaningless – since the exclusive result hardly changes. The thing that is important to notice is that stigmatization does have negative influences. All the informants thought that stigmatization and social isolation it brought were bad things. Some of the informants also expressed that they suffered from the aftermaths of stigmatization by ignorance even long after youth and school times[37]. According to Russell (2009, 462) the

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37 Most notably by having self-trust issues and loneliness.

danger of becoming excluded because of physical impairment is that the experience can create additional problems such as failures to attain meaningful social interactions later on, which in turn results to elevated feelings of loneliness. In contrast to ignorance, direct teasing was a lot rarer – but still it appeared as well. Laura, a twenty-nine years old woman in a wheelchair, told that she had some experiences relating to direct teasing:

> "There was some teasing but it was mostly calling with names. The school did its best to cut it out and I was not the only one to experience that since it was kind of a common phenomenon back in the days."

Laura's description on the above seems similar to the entries that Tuomo and Roni gave in the chapter 4.1. The difference in Laura's teasing experience came from the fact that she was teased by her non-disabled peers while Roni and Tuomo were targeted by their disabled peers. A notable difference was also that while Roni and Tuomo reported that they were teased by the more popular disabled kids, Laura reported being teased by non-disabled individuals who were not popular themselves – and remained quite unpopular as well. Within the previous lines one could see some of those echoes coming from the social norms, which state that it is socially vague and not always good for the popularity to directly tease physically disabled – unless you are also one yourself (Madon et al. 2005, 574).

As the informants told stories about their youths it became very apparent that the actual social experiences relating to disabilities were something that quite clearly differentiated these individuals from each other – while some similarities did appear. More surprisingly, the variety of the consequences of being physically impaired – and treated differently because of it – did not get limited to the problems of social relationships with peers or gymnastics. Unfavorable situations did also exist within the more general education events. Veera, a twenty-one years old woman in a wheelchair, told a chapter from her youth

highlighting the occasionally apparent streak of unfavorable attitudes towards persons with disabilities:

> "The problems which I had, especially during my early school years, were related to the teachers. Many of them had an attitude towards me, which meant that they decided automatically what I could or could not do. My teachers' actions led me many times to become an outsider and I do feel that more than once they actually managed to create social tension and alertness among other students towards me. The creation of tension was quite common during ground school but it got lesser in middle school and upper secondary school."

Veera's segment does have similarities with the one that came from Amanda in the beginning of the chapter 4.3. What Veera told above pointed towards the case that teachers did not really know how to handle her as a pupil and thus by accident worsened social situations by presuming too much. Veera's situation is parallel to that of Amanda's since teachers did not know how to handle her either. It is not a surprise that a research done in Hungary has reported that teachers are expressing a lack of competence in handling socially problematic situations – and physical impairments also certainly fall into a category of problematic[38] (Kiss, Szeger & Hera 2013, 284–285). Similar results could well be found in a country like Finland because roughly about a half of the informants did report that there had been events where educators lacked skills to handle things properly just because the informants had apparent impairments. Here again it is notable that those who used more physical supports – like walkers and wheelchairs – seemed to recall a lot more of these experiences than those who roamed more freely.

Overall, the majority of the stigmatizing presumptions seem to boil down to the term of competence. Presuming what an impaired individual can do or cannot do is essentially the same thing as making a judgment about the competencies of that individual – only the

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38 Problematic is meant here as something that creates social distance or generates social tension.

casing of the word is different while the practical meaning is the same. One could easily try to explain that the misguided competence attributions have happened because the impaired ones have been socially withdrawn or behaving otherwise weirdly in the eyes of their communities. The previous remains a half-baked explanation at best since it is more than likely that stigmas and stereotypes are the ones that make disability look weird in the first place. The people who carry their impairments every day see them as normal parts of living and hence having disabilities is not something that they are always thinking about – unlike the ones who gaze upon their bodies and stare only the parts that remain impaired (Bridgens 2009, 754–755). If the misguided competence attributions rise because the physical impairment seems weird it is still stigmatization that happens – no matter what the actual explanation given to the scenario might be. The tragedy of the stigma is thus that in any case it is a brand that is far from fairness. Judging people based on their physical impairments is however very common even today. Why? Because we live in a physical world where every single body is under scrutiny.

As a whole, youth days brought up one interesting detail: Even though Finland has been notably high on promoting equality for a quite some time, it seems that being included does not always mean the same  as being a real and accepted participant in the action. As youth is bound to end when people grow older, the adulthood  arrives sooner or later. The widespread belief of youth is that when you become an adult things will be different and better than they were before. When you are having a physical disability things turn out to be pretty much the same. The disability does not just magically disappear when the  age of adulthood comes – and neither does the danger of stigmatization. What actually happens is that the disability remains there and the danger of stigmatization will still exist. In adulthood things just have slightly different forms but they still mount to mean the same as access denied, which means that the same notorious show of stigmas and prejudices continues much like before.

## 4.5 Access denied: Stigmatization, work and adulthood

> "Many times I have met people who think that I have some sort of fault in my head since I move differently. They also reckon that I should be cured from it so that I could live a full life. There has also been more than a few encounters with strangers where they have started a conversation by asking: Hey, do you understand me? Nevertheless, I always take curiosity as a good thing because when I can talk and be honest and tell things to people I am doing my share in getting rid of prejudices." –Ville, a twenty-one years old man using multiple supports from wheelchair to walking sticks.

On the above the things that are clearly visible are nothing new: Disability gets to be seen as a deviation that should be cured and the impaired one gets to receive doubts about his or her mental conditions. Generally, the majority of the informants noted that adulthood did not bring any special changes to their social climates and thus there were no big magic tricks that would have fixed the stigmatization issues either. Things actually turned out to be somewhat reversed for a small number of informants to whom adulthood meant that stigmatization increased.

One of the prime examples of stigmatization appearing in adulthood was related to the theme of having a job. Working has been traditionally taken as a signal of maturity and self-capability. Getting a job is never an easy task and it is a fact that the individuals with physical disabilities have some extra difficulties in securing job positions because of the stigmatization. The scenario becomes even more trickier in practice than it first seemed on the paper. For starters, it has been pointed out that it is harder to get a job if you are not having the right variety of social networks that are already well connected to work-life (Trimble & Kmec 2011, 166–167). But how can an impaired and stigmatized individual cope in this scenario if he or she does not have any notable social networks? The dilemma remains a very tough one since there is no easy way to fix the social damages of stigma if they have been born earlier. It is undeniable that there are some substantial difficulties on

the horizon if a need rises to suddenly pull up work-life connected social networks since those might take years to develop[39]. Perhaps the most practical way for the damage control, which the informants pointed out, is that a person needs to believe in his or her own doing and try to be proud of himself or herself.

In labour market it is beneficial to believe in oneself but the problems of stigmatization do not simply end with some well directed beliefs. The danger of stigma remains almost constantly present and also shows up when entering to a job interview, which is all about proving one's competence to a potential employer. What makes job interview particularly troublesome is the following question: How can a possibly stigmatized person abolish the expectations of his incompetence and appear as an individual who is a worthy employee? One way to tackle the disability stereotypes and appear as more competent would be to tell about the nature of the physical impairment during the interview. Research findings have suggested that acknowledging the visible stigma during the early minutes of the interview could significantly help to foster a more positive social interaction. Announcing the disability early on at least seems to open up possibilities to discuss about it if needed. (Hebl & Skorinko 2005, 2487–2488.) Opening up the doors for conversation is also a good strategy since the majority of disabled individuals know by their experience that it is not uncommon that some ordinary people actually do not know if they can start asking things about the impairments without been seen as offensive brutes.

The ordinary art of not knowing gives all the more reason why speaking about the disability is a good thing to clear the air. Clearing the air does not however mean that the following strategy would be advisable since indiscretion is unlikely to help: Hello, my name is mister X. I have a physical disability, which does this and this. It is evident that when stigmatization happens it happens because of cultural viewpoints, socially structured

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39  Here the talk about social networks resembles the ideas of Pierre Bourdieu relating to social capital. For a Finnish overview see: Purhonen S. & Roos, J.P., 2006 (ed.). Bourdieu ja minä.

expectations or just because of the maladjusted fears that get attributed to disability – and job interview gone awry is no exception to this rule (Phelan et al. 2008, 362–363). Regardless of the previous, the risk of discussing the physically apparent and stigmatized qualities is worth having since there are notions suggesting that people tend to value a person if he or she openly discloses his or her visible stigma. It is also likely that openly admitting the situation signals important and valued qualities such as self-confidence and good mental well-being. (Hebl & Kleck 2002, 224–225.)

Disclosing the apparent physical stigma is obviously a great thumbs up if done correctly but there is no guarantee that chances for it will always appear in practice. All the informants who had entered to the work-life reported that they had suffered some unequal treatment, which they thought was caused by their physical disabilities. Valtteri, a twenty-seven years old man walking without supports, gave the following example from his experiences on job hunting:

> "Once when I was applying for a telephone marketing position I was told that I cannot do that job because I have a physical disability in my legs. I did not understand why but I concluded that it was an ill and attitude based evaluation from the employer."

Valtteri's disability is in legs and it is rather odd that he is being seen unfit to work as a telephone marketer since the common consensus is that the phone is used with hands and not with legs. Valtteri's case remains one of the clearest examples of stigmatization that can happen to the physically disabled when they try to enter labour market: They get access denied because of the disability stigma – even when they have proper education with right skills to get the job done[40]. Access becomes denied because people with disabilities get treated differently and compared unjustly to the non-disabled work-force. The problem of

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40 Here it is not suggested that all work-places discriminate. The discussion refers only to the ones that do.

comparison is that it is prone to create access discrimination. In practice access discrimination means that the actual process of getting a job might become a discriminatory nightmare for the ones who appear to be more physically impaired than others. Comparison combined with access discrimination can thus lead to a never-ending ranking match were some perfectly capable but physically impaired workers are being denied from even having an opportunity to try[41]. (Perry, Hendricks & Broadbent 2000, 939–940.)

## 4.6 So you think you can work – visible impairments and competence expectations

Access discrimination relates closely to ableism, which is all about seeing disabilities as signals of incompetence. Ableism in labour market boils down to the idea that a healthy worker is in a healthy body, which means that the more normal the body is the more worthier the individual can be. (Loja, Costa, Hughes & Menezes 2013, 193–195.) Different kind of disabilities can be stigmatized differently and the result is access to some and denial to many. The one who is losing when the comparison starts is the person who has a more serious looking disability. Being stigmatized differently thus means that the evaluation happens according to the levels of noticeable impairments and the levels of threat or fear those impairments produce[42]. At the same time the evaluated individual himself or herself might get no chance to explain his or her condition, which most certainly amounts to more than a simple outsider's gaze can ever capture. (Towler & Schneider 2005, 1–2.)

What comes out from the above is a potentially unfair situation where the one who is in a wheelchair could get labeled as unfit to work while the other who is walking with a minor physical disability gets the job because resembling more closely the ideal image of a worker. The impairment status of the body hardly ever tells a true story about individual's

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41 I have never seen a physically disabled model or a public relations person who would be in a wheelchair.
42 It is not suggested here that stigmatization would be right or just.

competences. Jonna, a woman aged twenty-six, told the following segment from her life where she felt that her competence had gotten devalued because of her impairment:

> "When I was once trying to get an internship I remember the reception I had, which was full of those contemptuous looks. I guess it was because I used a walker and had a physical disability. Later on I did not get the internship position and I did feel like it was because of my impairment – even though nobody ever said it out loud."

Holm and Hopponen (2007, 15–17) noted that while the impaired people were eager to work the practical outcomes depended on the local employers and their attitudes – and those attitudes still have some room for improvement. Because of the negative attitudes a person with disabilities can get pushed aside as a potential work-force. There exists a real problem since being unemployed hardly improves anything. According to O'Brien (2013, 330–332) the specific danger is that if the disability experience gets linked strongly with the unemployment then the individual becomes also socially more disabled. Linnakangas et al. (2006, 40–41) have further noted that there exists mismatches in the distribution of wealth and social opportunities, which are divided in such a way that ordinary and impaired people are everything but equal. As unfairness of stigmatization appears also in labour market it means that those who are physically impaired need to be very outspoken to prove their worth as workers. The art of self-marketing oneself as a someone who is a competent worker remains obviously important for getting a job but the downside is that there are no golden catch phrases that would undo the problematic spawns of stigmatization completely. In some cases it does happen that the attitude issues can be so severe that no amount of speech is enough to undermine the prejudicial and stigmatizing negativity. Laura, a twenty-nine years old woman in a wheelchair, gave an example of those occasions when all was said and done before things had even really begun:

"My ability to cope in work has been questioned by some potential employers who have been asking how can a disabled person work in their companies, even though the jobs would not have been requiring any walking ability. The employers have also questioned my ability to work by asking things from my assistant instead of me."

On Laura's case there are multiple already familiar elements present. Her competence and abilities are doubted because she has a disability and she got ignored as a valid source of information. Foster and Wass (2013, 706–708) have explained similar situations by clarifying that the dilemma for physically impaired is that they rarely fit to prototypical worker ideals, which take able-bodiness as a rule rather than a preference. The glitch that remains between the labour market and physically disabled is that the impaired body is seen anything but productive since it is heavily devalued by stigmas and stereotypes.

Getting a job is hard these days for anyone as the current market situation favors no one. However, the time of the diligents is not over yet. It is clear that disability does add difficulties to the picture but the informants said that a person should always try to get a job nevertheless – because there would at least be a chance to success. Getting a job was also an important theme for many of the informants all the way to the point that it appeared as one of the core blocks towards their ideal lives:

"I want to work and I consider that to be one of my top priorities. I will also want to graduate and start a family of my own and get some kids. My big dream is that some day I will work in some position that is international."

The above quote came from Ville, a twenty-one years old man using multiple supports from wheelchair to walking sticks, but as such it is a very apt summary from the world-views of the informants as they all valued the idea of getting some work. What remained clear for the informants was that there is no need to cower when trying to enter to labour market

since the meek shall not inherit the work. A better solution is to express opinions out loud. Majority of the informants were more than ready to raise their voices if the situation demanded such actions. One particularly interesting question, which rose during an interview with Ville, was whether or not a person with a disability should omit the details pointing towards the impairment when sending out job applications. Ville had this to say:

> "I do put all my activities on my curriculum vitae and I do take pride from every single thing I have done. I do not mind if my disability appears in my application but I do not overkill things by highlighting the fact that I have a disability since I am a person and the disability is just a thing that I happen to have."

Given that the informants were all very keen on working it was not surprising that a half of them reported that they had been in some sort of work during the recent months. In practice things might be slowly changing for the better but it is still a long way to the promised land of labour where there would be no stigmas on the market.

## 5. ALL SAID AND DONE: STIGMATIZATION INFLUENCING THE LIVES OF PHYSICALLY DISABLED – CONCLUSIONS

When we look at another human the first thing we see is his or her body. The danger arises when the presumptions and expectations, based on the received inputs, start to crawl into mind. Physical disability – as I have tried to show in my work – is a very prone ground for making stereotypical presumptions and the deviant body is never quite free from the dangers of becoming stigmatized when people gaze upon it.

There is also no formula to predict and prevent the negative outcomes of social encounters as every social situation is unique by itself. Uniqueness also goes for physical disability and stigmatization since the informants of this study evoked the conclusion that there is no such thing as a unified disability experience. The actual consequences of being stigmatized varied in quantity and form as the informants verified that having a physical impairment can show up as lack of friends and as lack of social opportunities. Having a stigma of this kind can thus cause difficulties to create relationships. Difficulties appeared as tendencies to ignore the impaired ones as participants in social actions. Behind the ignoring might reside some harsh moral evaluations branding the disability as inferior and thus a quality of a person that can be ignored. (Phelan et al. 2008, 362–363.) In the case of the informants the ignorance treatments appeared in mixed forms: Sometimes they were done by accident and sometimes in purpose. Becoming ignored influenced negatively to obtaining and maintaining social relationships by limiting the broadness of social interactions.

Direct verbal stigmatization was rare. The most apparent forms of it happened in competence related situations where disabilities brought mismatches that erupted as stigmatizing dialogs. The dialogs questioned the abilities of the disabled individuals. The fact that nobody liked being stigmatized was hardly surprising. What remained interesting was the finding that stigma is a concept without borders and it does not limit itself to

majority-minority relations alone since it can happen inside the minority itself.

The activities that the informants took to counter stigmatization remained practical and effective, but only to a certain limit. They explained things to those who asked and they showed to the doubters that they can really handle things by themselves. Most of the informants also said that it was only a good thing if someone just came to ask them a question rather than presuming to know the answer. Presenting realistic information helped against some stigmatizations but it had its limits as well. Presenting realistic information became the road that was never traveled on those few labour related occasions that included persons who had already predetermined that a person with a disability cannot handle things. In these situations the informants felt quite powerless to change things since they saw no point in arguing with persons who already "knew" how things were.

The general issue with the disability is that it is quite difficult to find opinions, which would resonate the fact that persons with physical impairments are just healthy and normal human beings who have a bit different bodies. While the conclusion from the disabled person's end is that he or she is healthy – like it was in the case of the majority of my informants – the logic is usually reversed on the other end. The ordinary people rarely see the physical deviancy as a mark of health and it is no wonder that when the disabled body gets compared against the normal one things get worse. The problem of physical impairment is that the game of comparison is rigged and the disability gets easily branded as the mark of unfit (Goffman 1963, 47; Loja et al. 2013, 193–195).

The practical examples that the informants gave relating to the competence evaluations resonated the above thoughts. Comparing did not end well for the disabled – at least – when it came to job interviews. Roulstone & Williams (2014, 17–18) have also noted that disability makes rising to higher job positions harder. The overall situation thus indicates

that stigmatization works in both ends of the scope: It is difficult to get a job because of the stigmatization and then it might be harder to climb up also because of it.

When the informants told their stories, the levels of disability did have effects on the social interactions and the ways they turned out to be in the end. The informants who were less impaired had less stigmatization experiences – even though they did have theirs as well. The conclusion that gets crafted follows the ideas of Goldstein and Johnson (1997, 496) as it appears that stigmatization creates social distances and some forms of disabilities are easier for people to accept than others. The level of experienced distance also related to the role expectations that were imposed upon the informants: On some scenarios people clearly did not expect or approve that certain talents or social positions could bundle with disabilities[43].

The problem of disability is that it is often seen as an issue rather than as a part of life that just happens. When the informants spoke about their lives and their future hopes it was apparent that since the focus had shifted to consider their future dreams there was hardly any disabilities in sight. Future dreams for many included things like getting more friends, finishing education, traveling the world, remaining healthy and starting a family of their own. What remains impaired for the physically disabled is on the body and not on the mind – and this is something that seems to be forgotten in stigmatization.

There are at least few ways to inhibit the possibility of stigmatization and control the risk of it. The clearest one that appeared during this study was that of "just being yourself and trusting yourself". For many becoming their own person and taking pride from what they are served as a protection against what could have otherwise been a negative feeling of becoming branded. Some informants also kept clear control with whom they spent their

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43 This happened during school times and job interviews.

time. Majority of the informants also expressed the importance of the fact that a person should choose his or her company in such a way that life could be enjoyable. Living with physical stigma mark makes things hard but the informants did highlight clearly that there is light even beyond the negativity it brings.

Overall, it is clear that stigmatization is a negative thing and it does spawn many problems to the lives of physically impaired people. While physically impaired are at risk in becoming branded the actual results of the possibility remain quite unique experiences inter-playing with social surroundings and individual histories[44]. This study has been aiming to show that stigmatization and disability are never just mindless social processes as they also impact the physically disabled persons negatively on individual levels. So, as it is safe to say that stigmatization is still an ongoing problem the question is: What can be done to improve things? An answer for that dilemma will be sculpted next as this study moves on to consider the possibilities to reform the stigma-based disability thinking.

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44 Gender as such does influence the ways by which people live and experience their lives. In this study at hand gender was an area where no solid conclusions could be drawn or introduced from. On the topics of gender and disability see for example: Reinikainen M-R., 2007. Vammaisuuden sukupuolittuneet ja sortavat diskurssit.

## 6. DISCUSSION: FROM DISABILITY TO THIS-ABILITY

It appeared in this study that having impairments can create unequal opportunities for the impaired individuals. There also exists quite many ways to conceptualize the possible limitations that the impairments produce. One further problem with the limitations is that they do not mean the same thing for everyone – someone's barriers are thus accessibility for another  (Mabbett 2005, 217–219).

The limitations are in fact conceptually as challenging to map as stigmatization since persons do experience their disabilities very differently[45]. As an example just think about two people who are both in a wheelchair and have about the same level of education but they live in a different area. Is their disability similar? On the surface the answer would be yes but their individual definitions might be very different. Let us think further that the second person would have been physically disabled since birth but the other one would have been disabled later because of some accident that happened. Sure enough, these two might have drastically different meanings attributed to disability. The one who would have accidentally gotten impaired might think it as a personal tragedy – a viewpoint much like that of the medical model of disability. The one who would have been born with it might cope  just fine and think that things are mostly good – since everything needed is available regardless of occasional obstacles. It is also certain that the social circles of the persons in the fictional example are different to the extent that the one who acquired disability later on might be feeling a bit outsider – since non-disabled people do not design their social activities with the possibility of disability in mind.

Even when the personal experience is important the problem of disability is not all about it. The problem of disability is also about the fact that still in many arenas of life it is seen as a

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45 This also appeared with the informants as they contributed a series of unique viewpoints with some similarities.

signal of illness. Contrasting disability with health has long traditions and writers like Donoghue (2003, 200–201) have pointed out that the history of disability remains far from equality. Up to the present day the problem of disability is that being physically impaired does not mean the same as becoming equal. Lack of equality can mean that people with impairments get discriminated with ad-hoc reasons that at worst are in the same category as: How can you possibly work here since this is a telephone company and your legs are disabled?[46]

It seems that the general understanding about what it means to be a physically disabled might be a bit lacking – even in Finland. The informant entries telling about ignoring a person or thinking that a person with a physical impairment is somehow less competent are all manifestations of misunderstanding. The question is: Where do these misunderstandings actually come from? When browsing this study the answer is evident since it appears that the misunderstandings are results of lacking social interactions. Some better chances to create social interactions between the physically disabled people and the non-disabled people are needed. Daruwalla and Darcy (2005, 557–558) showed that regular social contacts could improve the attitudes and the behavior towards persons who have physical impairments.

It is promising that stigmatizing attitudes can be countered with regular social interactions but the problem is how to create those conditions in the first place. Currently the situation is that there seems to be very few common grounds, which would connect the ordinary people and the disabled people to each others lives. Think for example the following fictional example. It is a Friday night and a group of young adults decides to have a night out. They visit many restaurants and go to some bars as well and finally they end their night with a late-night snack in the local pizza place. If the situation is altered and the point of view changes to that of a person who is in a wheelchair the story becomes quite different. The

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46 See Valtteri's job hunting experience on chapter 4.5.

difference appears since many places from restaurants to pizza places have accessibility issues, which are not so easy to handle if a person happens to be in a wheelchair. The general atmosphere might also suffer if everybody worries about how the one with the impairment copes during the night. The presented fictional example sounds harsh but unfortunately accessibility still remains an issue for many physically disabled and creates social exclusion.

As the physical disability has been addressed during this study it has become clear that social interaction does create scenarios that can lead to stigmatization. All in all, stigmatization never amounts to any good results and it does have negative consequences to the lives of physically disabled people in Finland – and elsewhere. What is needed is a redefinition of physical disability, which is free from the negative concept of stigma. There is no need to imply that either the social model of disability should be abandoned because it has unfair results for the non-disabled citizens or that the medical model should be abandoned since it has unfair consequences for the impaired citizens (Swain et al. 2003, 138; Cox-White & Boxall 2008). There exist a third way of seeing things, which comes from the phenomenology[47].

As phenomenology's statement was that phenomena can be understood when their meanings to the individuals are known it does open up some interesting possibilities (Eberle 2012, 281–282). While stigmatization did happen it was notable that none of the informants saw physical disabilities as their defining characteristics. The informants actually made strong remarks towards the point that disability was only one part of them and had taught them to become headstrong and confident in their own doing. For many of them the disability had actually become to mean the same as this-ability: An extra feature, which did impose some difficulties but also gave something back – like believing in own

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47 The problem of the current definition of disability is also that it is a negation of fitness. The negation does quite naturally link having an impairment with the concept of unfit or ill.

doing and skills.

When it comes to disability it is more beneficial to conceptualize it as this-ability: A one feature among many. The problem of the current disability and stigma discussions remains in that they overstate the meanings of impairment and make it seem like having one is the same as being in a non-stop eternal combat against evil prejudices and stigmas. In reality things are different since for many physically disabled people having impairments is just part of their lives. As the informants of this study were impaired from the early points of their existence it meant that for them having a disability was also the only life they knew.

The confusion that reigns between the ordinary people and the disabled people seems to be large when it comes to understanding disability and its actual influences on the quality of life. For the non-disabled people the impairment might be a menace but for the disabled people it is just a normal experience among many. Stigmatization of disability inhibits the opportunities to understand impairments as anything but misfortunes. It is also likely that the coercive force of stigmatization will not end until the physical disability gets redefined more positively. The need for a redefinition comes from the  fact that the ordinary people need to be guided towards paying attention to the persons behind the impairments – and currently what the terms of disability and stigmatization do with their negativity remains quite the opposite. If disability is conceptualized as this-ability instead, the focus of the current viewpoints changes for the better. The improvement comes since the inner meanings of the phenomenon of disability will be included more fully to the perceptions, which now focus mainly to the outer impaired exterior and forget the vibrant interior of a person. The concept of this-ability was originally born as an experiment when I decided to test how the usage of words influences the tendencies to become perceived. I discovered that the used language improved the ways by which people treated me during social interactions[48]. I later concluded that the change was because the term of this-ability is a

48 I do use two walking sticks as supports and my impairment is noticeable.

positive one and as such it counters the influences, which the negatively loaded term disability would bring.

The informants of this study showed that having impairments is not the end of the world. Many of them referred to themselves as persons with their unique talents but none of them saw that the statuses of their bodies would be the defining parts of their future to come. The need to redefine disability to this-ability rises because there is more to life than an impairment – and everybody need to realize this. The current situation hardly serves no-one since disability is commonly and falsely seen as a big overall disaster, which influences both the present and the future of a person.

Redefining disability to this-ability creates fresh chances to conceptualize the impairment experience more realistically. The redefinition also captures the personal aspects of the impairment, which do not show fully in the current discussions. Nowadays there is still a blind spot in vision when it comes to understanding that there is a person behind the disability. What is needed now is a fresh way of looking into things and that can be found from phenomenological way of this-ability. As the informants of this study enjoyed their days with their friends, hobbies, girlfriends and boyfriends they actually verified in practice that life is more than physical disability and stigma-reality can ever capture. Redefinition is needed and it should come from the phenomenologically oriented term this-ability since many physically disabled already turn their impairments into their abilities as they go and live their daily lives.

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**Attachment 1: Kutsukirje haastatteluun**

Hei.

Olet ilmoittanut halukkuudestasi osallistua sosiologian gradututkimukseni haastatteluosioon. Kiitos siitä! Tutkimukseni käsittelee liikuntarajoitteisten elämää ja heidän kohtaamiaan erityishaasteita ja ennakkoluuloja. Haastatteluun osallistuminen on vapaaehtoista, ja osallistumisensa voi perua tai keskeyttääkin. Olen suunnitellut haastattelemani jokaista pyyntöön suostunutta yhden kerran. Graduhaastattelussa noudatetaan yleisiä hyvän tieteen tekemisen periaatteita. Tutkimusraportissa ei paljasteta kenenkään henkilöllisyyttä. Haastatteluihin osallistuvien oikeusturvaa suojellaan huolehtien myös siitä, että taltioituja haastatteluja ja tunnistamisen mahdollistavia tietoja ei vuoda kolmansille osapuolille.

Suunnittelemani haastattelut ovat luonteeltaan elämänkerrallisia. Haastatteluun on hyvä varata aikaa noin 1-1,5 tuntia. Haastattelu nauhoitetaan luvallasi ja pyritään tekemään kasvokkain paikassa, joka sopii sinulle parhaiten. Toivomuksena olisi kuitenkin, että mahdollisuuksien mukaan haastattelupaikka sijaitsisi noin 15 kilometrin säteellä kaupungin keskustasta riittävien kulkuyhteyksien mahdollistamiseksi.

Jos olet edelleen valmis osallistumaan tutkimukseeni, laita minulle vahvistusvastaus (vastaamalla tähän viestiin) tai ota yhteyttä alla olevien yhteystietojen kautta mielellään 7.9.2012 mennessä. Vahvistuksen jälkeen otan sinuun yhteyttä ja sovin kanssasi haastattelupaikan ja -ajan.

Ystävällisin terveisin

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**Attachment 2: Haastattelukysymykset**

**Alkutiedot**

Ikä, sukupuoli, koulutustausta, ammatti.

**Lapsuus 6-12 v.**

1. Kerro lapsuudestasi

-Missä asuit?

-Oliko veljiä/sisaruksia tai läheisiä ystäviä?

-Millaisen koulun kävit?

-Tarkentava kysymys: -Hankaloittiko vammasi kaverien saamista?

-Mitä harrastit?

2. Jäitkö mielestäsi lapsena paitsi joistain asioista vammasi takia? -Kerro mahdollinen esimerkkitilanne, jos sellainen esiintyi.

3. Mahdollinen tarkentava kysymys, ellei haastattelussa muuten käy jo ilmi: oletko aina ollut liikuntarajoitteinen vai oletko vammautunut jossain elämänvaiheessa?

**Nuoruus 13-17**

1. Kerro millainen oli nuoruutesi?

-Missä asuit?

-Millaisen koulun kävit?

-Millainen oli kaveripiirisi ja sosiaalinen verkostosi nuorena?

-Mitä harrastit?

2. Tuliko nuoruudessasi vastaan ennakkoluuloisuutta tai ulkopuoliseksi jättämistä muiden ihmisten taholta, koska olit vammainen nuori?

-Miten ennakkoluuloisuus mielestäsi näkyi, jos sitä esiintyi?

3. Pelkäsitkö nuorena, että sinut leimataan porukan heikoimmaksi lenkiksi, koska olet

vammainen?

-Miten pyrit nuorena välttämään porukassa leimaantumista, jos siis pelkäsit sitä?

-Miten vältät nykyisin leimaantumista, jos pelkäät sitä?


4. Mistä tunnistaa mielestäsi ihmisen, jolla on taipumusta leimata muita?


5. Esiintyikö nuoruudessasi mielestäsi tapauksia, jossa kykyäsi suoriutua jostain asiasta epäiltiin, koska olit vammainen mies tai nainen? Kuvaile ja kerro esimerkkitapaus.


6. Kohtasitko koskaan tilanteita, jossa sinua ei hyväksytty tai sinut hyväksyttiin osaksi porukkaa, koska olit  nimenomaan vammainen mies tai vammainen nainen?

-Kuvaile kyseisiä tilanteita ja kerro mitä niissä tapahtui.


7.Jouduitko koskaan nuoruutesi aikana kiusaamisen tai ahdistelun kohteeksi vammasi takia?


**Aikuisuus 18+**

1. Kuvaile elämääsi aikuisena.

-Opiskeletko tai käytkö töissä?

-Miten rakentuu normaali arkipäiväsi?

-Mitä harrastat?

-Miten vietät vapaa-aikaasi?


2. Millaisia ennakkoluuloja olet aikuisuutesi aikana havainnut ihmisillä olevan liikuntavammaisia kohtaan?


3. Oletko aikuisuutesi aikana ollut tilanteissa, joissa muut ihmiset ovat erheellisesti alkaneet olettamaan mitä pystyt ja et pysty tekemään, koska sinulla on vamma?

-Millaisia tilanteita?

-Missä?

-Miten reagoit?

-Miten reagoisit nyt jos vastaan tulisi kuvatun kaltainen tilanne?

4. Luuletko, että sukupuolellasi saattaa olla vaikutusta siihen, miten ihmiset sinut ja vammasi näkevät?

-Millaisissa tilanteissa tämä voi tulla ilmi, jos tulee ? Kerro esimerkkitapaus.

**Nykyhetki ja tulevaisuus**

1. Koetko nykyhetkestä käsin ajateltuna, että olisit jäänyt joistain asioista paitsi aikaisemmissa elämänvaiheissasi vammasi vuoksi?

2. Miten luonnehtisit elämääsi nykyhetkellä?

3. Millaisia asioita odotat tulevaisuudelta?