

Master Thesis

Setting sail: An exploratory expedition towards understanding
disability, holidays and happiness



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Executive summary

“No one’s body works perfectly, or consistently, or eternally. We are all in some way impaired.”

– Shakespeare & Watson, 2002.

Disability is a part of human nature that has existed throughout history and across societies all over the world. It is a multidimensional phenomenon, as diverse and variable as any other characteristic that distinguishes one human being from another. Ideas of what disability is and how it should be dealt with have changed over time. In 2001, the World Health Organization developed the International Classification of Functioning and Health (ICF) a very practically oriented framework that attempts to provide a scientific basis for understanding and studying health and health-related states. The components included in this framework are categorized within the four main areas of body structures, body functions, activity and participation, and environmental factors.

The theoretical concepts of disability are based on an assumption that disability is a problem and leads to exclusion, or restriction to live a fulfilled life. This perception forms the outset of the idea that disability and (un)happiness have become inextricably connected. Previous studies have shown that holidays offer opportunities for individuals to feel happier. A large-scale comparison of studies that investigate this relationship has resulted in a set of five psychological mechanisms that reoccur most frequently and can be linked to well-being, namely detachment-recovery, autonomy, mastery, meaning, and affiliation.

The presented study combines the International Classification of Functioning and Health with theories on psychological well-being in a unique way and proposes an innovative method for analyzing how differences between a home and a holiday setting influence the perceived well-being of people with disabilities. As this way of framing the topics at hand has never been done before, the research project is of exploratory nature and employs a qualitative case study design that uses narrative interviews supported by photo elicitation and participant observation as data collection methods. The generated data offered an in-depth insight into the ways four individuals with disabilities experience their home setting and a week-long holiday.

The results of this study suggest that the way people with disabilities experience a holiday strongly depends on the circumstances they are used to at home, as well as on the whole set-up of the holiday.

Paying attention to the five psychological mechanisms and the ICF domains described in this study will lead to enhanced holiday experiences for people with disabilities.

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List of abbreviations

CRPD	Convention of the Rights of Persons with Disabilities
ICF	International Classification of Functioning and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
SDT	Self-determination theory
UN	United Nations
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organization

1. Introduction

People with disabilities constitute a large part of today's society that is estimated to count approximately 15% of the total world population (WHO, 2011). The EU alone counts more than 80 million inhabitants who are living with some kind of disability, ranging from mild to severe (WHO, 2011). Disability is a part of human nature that has existed throughout history and across societies all over the world. It is a multidimensional phenomenon, as diverse and variable as any other characteristic that distinguishes one human being from another. At the same time, people with disabilities form the largest minority group in the world (WHO, 2011). Policy makers, governments, and the general public have shown a rising interest in this population segment. 2016 marked the 10th anniversary of the adoption of the UN Convention of the Rights of Persons with Disabilities (CRPD) – with these Guiding Principles:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Yet today's society is far from reaching worldwide application of these principles. Also in the Netherlands and Germany, people with disabilities often face environmental, economic, or attitudinal barriers preventing them from fully taking part in society. While some of these barriers are visible, many others remain invisible and ignored by policy makers. Though many steps have been made to reduce these barriers, notably in Western Europe, social exclusion is often still omnipresent in the daily lives of disabled people, for example regarding access to the labor market, public transport, and the social environment (European Commission, 2008).

As wide the range of barriers people with disabilities face, as wide are the opportunities to change this situation. One actor in the field who wants to make a difference is a tour operator for specialized sailing holidays in the Netherlands. This tour operator, hereafter referred to as "the Sailing Organization", has set its goal to contributing to the development of empowerment, autonomy, and independence of

people with disabilities by pushing their boundaries by means of engaging them in water sport vacations. They claim that everyone can sail, also those with disabilities. Regarding the enthusiastic feedback the Sailing Organization receives from their clients implies that their strategy works – one way or another. As the interrelation between the engagement in water sport activities and the perceived added value for people with disabilities has so far remained a black box to the Sailing Organization, it has requested that a series of studies be undertaken to explore this phenomenon. This Master Thesis is embedded in this project initiated by the Sailing Organization.

The goal of this research project is to help the Sailing Organization understand the processes that the disabled participants go through when taking part in a sailing holiday, and what the underlying mechanisms are that influence these processes.

The presented report is structured as follows: After the introduction, the second chapter discusses how the topics of disability and psychological well-being are addressed and studied in social scientific research, forming the theoretical framework that provides the basis of this study and leads up to the research question. Subsequently, the research methodology that is used to approach the research question is presented in chapter 3. Chapter 4 analyses and discusses the results of this study. The report closes with chapter 5 that includes the conclusion, recommendations, and reflective thoughts.

2. Theoretical framework and literature review

2.1. Conceptual models of disability

Though times are changing, the history of disability is one of segregation, exclusion, marginalization, and disempowerment. In the past, and in many countries still today, being impaired by a disability means being a social outcast, living at the edge of society and often in poverty. In fact, the term “handicapped” derives from the old English expression “cap in hand”, referring to the act of begging for money in public spaces. The way the role of disability in society has changed over time is reflected in the way different theoretical models of disability evolved in academia. When talking about concepts of disability, the most prominent paradigms that exist today and that are the basis for research agendas, policies and laws can be divided into two general categories. Models related to the first paradigm treat disability as an individual issue and can therefore be categorized as “individual frameworks”, as opposed to “societal frameworks” that constitute disability as a social construct (Rothman, 2010). The two groups of models differ fundamentally in determining the sources of problems experienced by people with disabilities and how they should be solved.

2.1.1. The individual paradigm

One of the earliest representations of the individual paradigm is the moral model. It views the occurrence of disability as a consequence of sin and as a punishment for immoral behavior. Though modern thinking in most western societies has overtaken this idea, it remains present in some communities and is often reinforced by traditional religious belief systems. A typical example of the moral model way of thinking can be seen in the perception that HIV infections of homosexual men are to be understood as a direct punitive effect of acting against the will of God that forbids homosexual intercourse. On the other hand, the moral model also entails the notion that it is the community’s responsibility to take care of those who are disabled (Rothman, 2010). This perception of moral obligation significantly impacted the early development of aid programs and community services to provide help and care for people with mostly physical disabilities such as blindness or paraplegia.

As the significance of religious belief systems in societies decreased during the renaissance and people turned to scientific reasoning in explaining natural phenomena, the moral model made way for social Darwinism as the dominant mindset regarding disability. This model classifies disabled people as a side effect of evolutionary processes, marked by a deficiency of the body in contrast to the mainstream able-bodied majority of society. If the physical or mental deficiency could not be cured by medical treatment and sciences, this “survival of the fittest” mentality entailed the separation of disabled

people from society by admitting them into large, isolated, and impersonal institutions that provided minimal care (Rothman, 2010).

In its more extreme form, the social Darwinism framework evolved into the eugenics model that found its peak in the Nazi movement in the first half of the 20th century. The ideology of classifying people in terms of their genetic quality and race strongly stigmatized disability as an undesired trait and deemed people with disabilities unfit for reproduction or even existence in society. The end of the Second World War, when the terrific atrocities and crimes committed by the Nazi regime became publicly known, marked a significant point in history that pushed nations all over the world to reconsider the position of minorities within society (Rothman, 2010).

Today, the moral model, social Darwinism and the eugenics ideology are considered outdated and inappropriate by most social scientists to use as frameworks to conceptualize disability. They are the forerunners of the prominent model used by today's advocates of the individual paradigm: the medical model. The remaining feature that links these obsolete models to the contemporary medical model is the emphasis on a dysfunction of the body or mind that constitutes disability.

The medical model understands disability in terms of a physical or cognitive deficit that is inherent to an individual person and independent of external factors (Thomas, 2004; Jaeger & Bowman, 2005; Rothman, 2010). It is seen as a purely medical issue that is supposed to be treated, and if possible cured, by medical professionals using surgeries, therapies, and assistive devices. Relying on technological advances and modern medicine the medical perspective proposes a path of rendering disabled people functional according to the norm and ultimately eliminating disability (Jaeger & Bowman, 2005).

This way of thinking is rooted in a norm-based value system that defines certain standards of human functioning as "normal" and conditions that deviate to a certain degree from this norm as "disabled". For example, the standard for normal functioning of the eyes determines poor vision or blindness as graduations deviating far enough from the norm to be considered disabled. These norms are variable and prone to change in accordance with the socio-cultural climate of an era. Whereas it was for instance not necessary for people to be able to read and write during the middle ages to function in daily life, today illiteracy can be viewed as a major obstacle to fully fit into the structures of modern society.

To illustrate this issue, Jaeger and Bowman (2005) picture a world in which classifications of normal and abnormal are inverted: in which using a wheelchair would be the standard way of moving around instead of walking on two legs. Standing upright, people would find doorways too short and handles, buttons and other facilities positioned at inconveniently low height. There would be no chairs in public

spaces or on public transportation to provide for the “special need” of sitting down and resting the legs after walking. Wheelchair design would be technologically advanced and cars, roads and other infrastructure would be built to maximize mobility using wheelchairs. Walking people would probably feel incapable of keeping up with the pace of the wheelchair world. Everything would be designed to cater for the needs of wheelchair users while people not using wheelchairs would be “disabled”. As Jaeger and Bowman (2005: 27) frame it: “The types of conditions that are deemed disabilities say as much about the values of the society as about the medical conditions of the individuals.”

On the practical side, the medical model has a significant impact on the real lives of people with disabilities with regard to the accessibility of specialized services and social welfare. It serves as the gatekeeper to supportive programs such as financial benefits, employment at a protected workplace and housing in assisted living institutions by filtering out those who meet medically established criteria that fall outside the norm and therefore into the classification “disabled” (C. Barnes, Mercer, & Shakespeare, 1999). This principle of separation ensures that public funds reach those people who presumably need them, but it also places people with disabilities in the position of passive recipients, depending on the expertise of medical professionals who are in control of the system (Rothman, 2010). According to Barnes et al. (1999) this structure denotes both victimhood and a preassigned ‘care-attention’-dependency. Furthermore, objectors of the medical model criticize the underlying values of this position that can have a deteriorating impact on the way people with disabilities see and understand themselves (Oliver, 1996). In a simplified argument, the model suggests that something is wrong with them that needs to be fixed. Disability rights advocate Fries (1997: 6-7) claims:

“The damage done by this medical model of disability has been considerable. If an individual is defined by his or her ability to overcome a disability, he or she is viewed as a failure if unable to do so. Instead of seeing forces outside the body [...] as essential to a disabled person’s successful negotiation with an often hostile society [...] this view of disability, where cure and eradication of difference are the paramount goals, puts the blame squarely on the individual when a physical impairment cannot be overcome.”

Criticism of the medical model has evolved into the development of an alternative paradigm for understanding disability: the collective or social model that shifts the emphasis from the disabled individual to the disabling factors in society.

2.1.2. The collective paradigm

The social model of disability emerged in the 1970s under the umbrella of the Union of the Physically Impaired Against Segregation (UPIAS), a group of activists in the British disability movement. Especially

the work of Finkelstein (1980), Barnes (1991), and Oliver (1990, 1996) to the introduction and dissemination of the social model in both academia and politics. It has been called “the big idea” of the disability movement (Shakespeare & Watson, 2002) and still today the social model pervades the disability discourse. Oliver (1996: 22) frames the key elements of the social model as follows:

“In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called “disability”, of people with such impairment. Thus, we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.”

The social model claims that disability is to be understood as a form of social oppression that physically impaired people encounter, not as the physical impairment itself. It clearly separates impairment from disability, meaning that people are disabled by society instead of by their bodies (Shakespeare & Watson, 2002). Replacing the traditional medical mindset on disability, the social aspect that this model entails changed the ways in which both the disabled and non-disabled community look at the issues at hand. According to this view, the problem is not located in the disabled person, but in the structure of society. Therefore, it is not the disabled person who needs to change, but society.

This conversion from the medical to the social mindset, in which people started to see themselves in new ways, can be compared to the feminist movement in the seventies. With gays and lesbians stepping out of the shade and calling for equal treatment and acceptance, they opposed oppression based on gender and sexual orientation. Disabled activists showed similar anger and determinism, demanding attention for their situation and rights in an unaccepting society (Shakespeare & Watson, 2002).

Instead of pursuing a path of eradicating disability with the help of technology, modern medicine and rehabilitation, strategies for dealing with disability should be aimed at social change, inclusion and empowerment, or even the complete transformation of society (Shakespeare & Watson, 2002). Practically speaking, this translates to policies and laws of removing tangible barriers in the built environment and intangible barriers in institutional norms and attitudes in people’s minds. Examples of such barrier removals are the construction of ramps for wheelchair accessibility, information provided in Braille for blind people, or inclusion programs in schools and workplaces.

Though the social model of disability has had a massive impact on the empowerment of people with disabilities and has fueled processes of barrier removal in Western societies, it has also been criticized by scholars on multiple levels. Shakespeare and Watson (2002) state that the very success of the social model in its strong form is now its greatest weakness. They argue that it pictures the world in black and white, good and bad, and the prominence it has received due to this simplicity has turned it into a “sacred cow” that cannot be easily challenged.

A major line of criticism is based on the model’s tendency to avoid questions of embodiment of impairment and the causal relationship between the body and experiences of oppression. According to social model advocates such as Oliver, impairment is merely a physical state of the body: “impairment is, in fact, nothing less than a description of the physical body” (Oliver, 1996: 35), and society is to blame for not accommodating for non-standard physical bodies. Shakespeare and Watson (2002) carry on this thought towards the reasoning that in its logical extreme form, this argumentation says that impairment is in fact not something that should be prevented. Accordingly, concerns about any kind of security, such as traffic regulations or restrictions on the use of guns would have to be considered redundant, as having more disabled people in society would by no means be a bad thing.

A counter-argument could be that impairment should be distinguished from chronic illness, where medical treatment could be appropriate. However, as Shakespeare and Watson (2002) continue their line of reasoning, impairment and chronic illness hardly differ in their real impact on a person’s life. Most impairments are not stable and congenital conditions, such as blindness or deafness. It is more likely that impairments are acquired at a certain point in a person’s life and change over time. Subsequent variations may include chronic degenerative effects, pressure sores or other problems that require medical attention. Shakespeare and Watson (2002) fully agree that the removal of disabling barriers should be a political imperative, and that medical cure should not be pursued at all costs. Appropriate action on impairment prevention and medical relief however should co-exist with action to remove disabling barriers (Shakespeare & Watson, 2002), accepting the body and embodied experiences as a major influencing factor in a person’s life. After all, “no one’s body works perfectly, or consistently, or eternally. We are all in some way impaired.” (Shakespeare & Watson, 2002: 26).

It is problematic to frame disability as either a purely medical or a purely social issue. Also, impairment and disability cannot be separated as clearly as the social model suggests, but can better be understood as different points on a continuum. It can be concluded that there are more dimensions and aspects to the context of disability than the medical and social model cover.

2.1.3. The International Classification of Functioning, Disability and Health

In an attempt to combine the most important aspects of both the medical and the social model of disability and to provide a practical system that can be used by different societal actors occupied with different aspects of disability, the World Health Organization (WHO) introduced the International Classification of Functioning, Disability and Health (ICF) in 2001. The WHO claims that it is the purpose of the ICF to “provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants and to establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities” (WHO, 2001: 5). The ICF as it was presented in 2001 is the successor and revised version of the WHO’s International Classification of Impairments, Disabilities and Handicaps (ICIDH) from 1980. This original concept was the first systematic approach towards an international nomenclature of disability and a significant breakthrough at that time (Hemmingsson & Jonsson, 2005). The old ICIDH is closely linked to the structures of the traditional individual paradigm, building on the three dimensions of impairment-disability-handicap, linking a dysfunction of the body to the inability to perform a certain activity and limitations to fulfil a role in life in a causal chain (Hemmingsson & Jonsson, 2005). Incorporating ideas of the social model and rejecting this simple linearity, the new system of classification of the WHO also includes personal and environmental factors as important determinants of a disabled person’s situation. Therefore, the ICF constitutes a more integrative understanding on the components of health and disability.

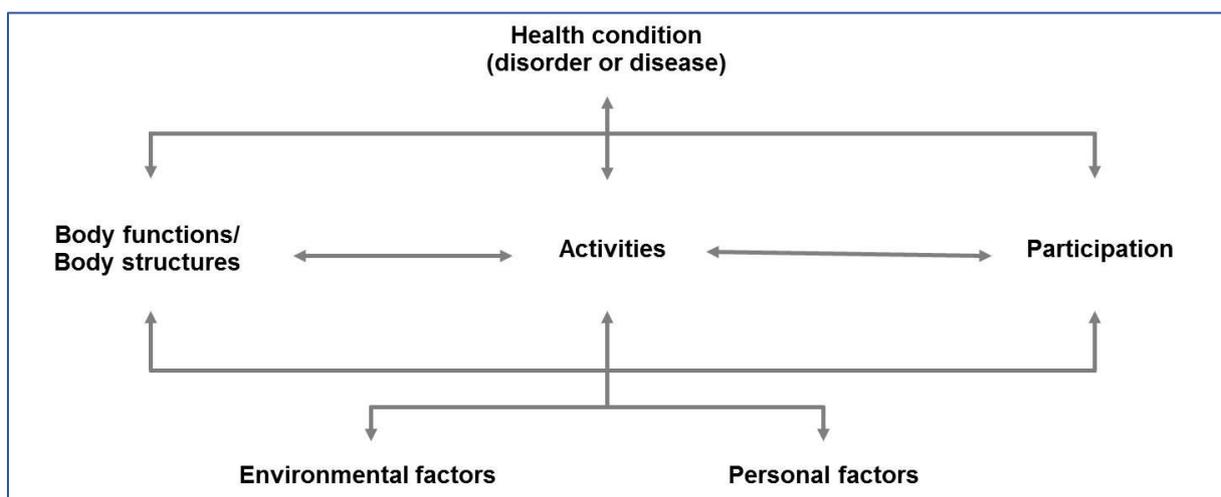


Figure 1: Interactions between the components of the International Classification of Functioning, Disability and Health (WHO, 2001: 18)

In order to be able to grasp the interplay between the different components, the WHO formulated a set of definitions (WHO, 2001: 12-16):

- **Body functions** are the physiological functions of body systems (including psychological functions). **Body structures** are anatomical parts of the body such as organs, limbs and their components. **Impairments** are problems in body function or structure such as a significant deviation or loss.
- **Activity** is the execution of a task or action by an individual. **Activity limitations** are difficulties an individual may have in executing activities.
- **Participation** is involvement in a life situation. **Participation restrictions** are problems an individual may experience in involvement in life situations.
- **Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure.
- **Personal factors** are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level.

For each of the single components the ICF provides a very detailed set of subcomponents at up to five levels, with the fifth level corresponding to the highest level of detail. Each component is matched to a specific code, forming a coding system that can describe a person's situation as holistically and as detailed as possible. This way the coding system can be used across countries and policy sectors and form a common ground for international comparisons and evaluations.

The following table provides an overview of the first level subcategories of the classification system:

Body	
Function	Structure
<ul style="list-style-type: none"> ▪ Mental Functions ▪ Sensory Functions and Pain ▪ Voice and Speech Functions ▪ Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems ▪ Functions of the Digestive, Metabolic, Endocrine Systems ▪ Genitourinary and Reproductive Functions ▪ Neuromusculoskeletal and Movement-Related Functions ▪ Functions of the Skin and Related Structures 	<ul style="list-style-type: none"> ▪ Structure of the Nervous System ▪ The Eye, Ear and Related Structures ▪ Structures Involved in Voice and Speech ▪ Structure of the Cardiovascular, Immunological and Respiratory Systems ▪ Structures Related to the Digestive, Metabolic and Endocrine Systems ▪ Structure Related to Genitourinary and Reproductive Systems ▪ Structure Related to Movement ▪ Skin and Related Structures
Activities and Participation	
<ul style="list-style-type: none"> ▪ Learning and Applying Knowledge ▪ General Tasks and Demands ▪ Communication ▪ Mobility ▪ Self-Care ▪ Domestic Life ▪ Interpersonal Interactions and Relationships ▪ Major Life Areas ▪ Community, Social and Civic Life 	
Environmental Factors	
<ul style="list-style-type: none"> ▪ Products and technology ▪ Natural Environment and Human-Made Changes to Environment ▪ Support and Relationships ▪ Attitudes ▪ Services, Systems and Policies 	

Table 1: Complete list of chapters in the ICF (WHO, 2002:16)

To clarify how the coding scheme works, an example can be given with the activity of preparing a simple meal. This activity falls into the following coding scheme:

- Level 1 *Activities and Participation (Code d)*
 - Level 2 *Domestic Life (Code d6)*
 - Level 3 *Household Tasks (Codes d630-d649)*
 - Level 4 *Preparing Meals (Code d630)*
 - Level 5 *Preparing Simple Meals (Code d6300)*

Each detailed body structure, body function, activity or environmental factor can then be evaluated with a qualifier that is added after the code. This qualifier indicates if a problem is experienced with regard to the individual component, and how severe the problem is. The scale ranges from non-existent to mild, moderate, severe, and complete (WHO, 2001).

Though the ICF is by now an established tool for decision making in policy schemes for people with disabilities, it has so far received little attention in academic research.

2.2. Happiness and subjective well-being

Looking at the different concepts of disability, one point is standing out that all of them have in common: According to each of these models, being disabled is linked to suffering in one way or another. In the medical model, this link between disability and suffering is based on the understanding of disability as a deficit or deformity from normal or expected standards (Sunderland, Catalano, & Kendall, 2009) that positions the disabled person as physically or intellectually inferior. From this perspective, physical shortcomings constitute a status of shortcomings in health, whereas the idea of "health" is perceived of utmost importance for living a happy life. Accordingly, illness is often associated with unhappiness. Though the medical model does not claim that disabled people cannot be happy people, it renders unhappiness based on disability as "true", in extreme cases even accounting for suicide, in contrast to able-bodied discomfort that is perceived to be rectifiable. (Verstraete & Söderfeldt, 2014).

The social model in contrast places potential sources of unhappiness not within the disabled people themselves, but attributes it to the limitations they experience. It denies the inferiority of people with a disability and claims a morally equal status for them in today's society. Nevertheless, it entails the idea that due to the incapability of the social environment to adequately cater for the needs of disabled people, they are unable to fully take part in society and living a fulfilled life (Sunderland et al., 2009).

This pejorative connotation is not only to be found in the basic ideas behind the concepts of these models, but has been institutionalized in the official professional and public discourse on disability. An analysis of policy texts, life story interview transcripts and focus group transcripts by Sunderland et al. (2009) shows a predominance of negative terms in the discursive patterns and features, such as "coping", "burden" and "abnormality". They see the institutionalization of negative representations of people with a disability as problematic as it "extends to the way that research is conducted on, with or for people with disability and the frames of reference via which people's lives are questioned and interpreted" by "removing moral agency from persons with a disability" (Sunderland et al., 2009: 704). While the relationship between disability and (un)happiness has been addressed in only a few studies,

once removing the aspect of disability, one enters the wide field of academic contributions studying happiness, quality of life, life satisfaction and well-being. Especially psychologists, sociologists and economists have expressed significant interest in the question of what happiness is, both looking at the individual and at society as a whole.

Lyubomirsky, Sheldon, & Schkade (2005) investigate the topic of chronic, sustainable happiness, referring to the question in how far people are able to increase their level of happiness over time. In this context, they state that happiness is composed of a genetically determined set point for happiness, happiness-relevant circumstantial factors, and happiness-relevant activities and practices. Moreover, they identify frequent positive affect, high life satisfaction, and infrequent negative affect as the three primary components of subjective well-being. According to Lyubomirsky, Sheldon and Schkade, the set point for happiness explains approximately 50% of an individual's happiness and is genetically determined, stable over time and immune to influence or control. The happiness-relevant circumstantial factors on the other hand are a combination of the relatively stable facts of an individual's life, for example place of residence, age, factors from the individual's personal history, explaining approximately 10% of an individual's happiness. The remaining 40% that determine a person's happiness are dependent on voluntarily chosen activities and practices. In order to achieve long-term chronic happiness, they suggest that an individual should focus on this last factor, as it is supposedly possible to influence and control. This increase of long-term happiness could happen by seeking accumulations of positive daily experiences that could enhance the subjective well-being by intentionally and actively engaging in activities and behaviors that fit the highly individual stimulators of positive emotions. Lyubomirsky, Sheldon and Schkade (2005) state that these activities that individuals actively engage in to reach a sustainable, higher level of chronic happiness require personal effort to initiate and maintain an activity. They name exercising in sports and religious engagement as examples. Opposing to this view on sustainable happiness one could pose the question why still so many people are unhappy, or even very unhappy; resulting in depression and the need for professional help if it was as easy to influence the 40% of self-determined happiness as they argue.

Furthermore, a study conducted by Diener and Seligman (2002) investigated in how far people with significantly high levels of happiness differ from those with significantly low levels of happiness. Inconsistently to Lyubomirsky, Sheldon and Schkade, Diener and Seligman found that activities such as exercising and religious engagement are no determinants of increased happiness, nor did the happiest respondents in the research project experience more objectively defined good events. Instead, Diener and Seligman assess that good social relationships as a major determinant that is a necessary, but not sufficient condition for high happiness, as the happiest people in the study spent comparably little time alone, were commonly highly social and more extraverted, more agreeable and less neurotic than less

happy groups. Furthermore, Diener and Seligman explain that the happiest people experienced most of the time rather positive and moderate emotions and moods, sometimes negative emotions, but rarely ecstatic emotions. Coming back to Lyubomirsky, Sheldon and Schkade, this could possibly mean that sustainable happiness could better be achieved by engaging in activities with high social interaction.

2.2.1. The role of leisure and tourism

An important aspect and promising pathway in the thriving for well-being is the pursuit of leisure activities. Scholars have argued that leisure can play a more important role in achieving psychological well-being than most other factors that have been tested as predictors of an individual's life satisfaction, such as sex, education, religiosity, marital status, age, health, employment status, and income (Riddick, 1985; Russell, 1990; Newman, Tay, & Diener, 2014). Recent research findings by Nawijn (2010) give evidence to this. Even though Nawijn focuses on moods of people in different phases of their holidays, which are longer in time than emotions or affect, it still becomes clear that people are significantly happier during their holidays compared to their general life satisfaction, especially in the core phase of a vacation. This core phase lies in the middle of the trip and covers approximately 70% of the vacation time. In the starting phase at the beginning of the holiday period and in the end phase before travelling home people appear to be less happy due to what Nawijn calls "holiday stress" that arises from organization problems, inconveniences and uncomfortable transport. Nawijn assesses that this increased level of happiness during holidays is not only independent from socio-demographic factors such as age, gender or income, but also from the activities that vacation takers engage in, according to Nawijn the mood does not differ across different types of holiday or different activities of the day.

2.2.2. Psychological mechanisms of well-being

A notable attempt to summarize and integrate the numerous theories that have been developed to study usually single aspects of well-being into one conceptual framework of psychological mechanisms has been made by Newman, Tay and Diener (2014) by screening peer-reviewed articles that all link leisure to subjective well-being. Using the search terms "leisure or recreation" and "well-being, life satisfaction, quality of life, emotion, or happiness" 3,620 articles were found, 363 of which mentioned specific theories as frameworks to analyze this relationship. 16 theories could be identified that were referred to in more than just one article. The ones that occurred most often are flow (Csikszentmihalyi, 1990), activity theory (Havighurst, 1961) and self-determination theory (Ryan & Deci, 2000).

As the next step, Newman et. al examined all 363 articles for re-appearing underlying concepts of psychological processes invoked by the theories used. The analysis resulted in the identification of five different psychological processes that were most prominently used to conceptualize the influence of leisure on subjective well-being: mastery, autonomy, affiliation, detachment-recovery, and meaning. Though not exactly the same words were formulated in all frameworks that were analyzed, often similar constructs that were termed differently in the various theories could be affiliated to one of the five expressions. Ryff's and Keyes' (1995) six dimensions of psychological well-being (autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, self-acceptance) for example can be are echoed in experiencing autonomy, mastery, meaning and affiliation. Another example can be drawn from self-determination theory (Ryan & Deci, 2000), that focuses on the psychological needs of autonomy, relatedness and competence, whereas relatedness can be mapped on to affiliation and competence can be construed as mastery (Newman et al., 2014).

The following paragraphs will look at each of the five components separately.

Mastery

Mastery refers to the feeling of overcoming challenges and learning from opportunities, as for example in achieving higher levels in a certain skill. Whereas autonomy focuses on the ideas of individuality, choice and freedom in a certain activity, mastery in contrast relates to the effort an individual puts into achieving success by exerting one's skill (Newman et al., 2014). Self-determination theory adverts to the same kind of mechanism as the basic need of competence, concerning the experience of efficacy an individual has with regard to both internal and external environments (Ryan, Huta, & Deci, 2008). A typical example of a questionnaire item that measures competence is "I have been able to learn interesting new skills recently", following Gagne's (2003) General Need Satisfaction Scale.

A similar concept is presented by Csikszentmihalyi (1990) as flow, a state of total absorption and concentration that can be reached by engaging in a challenging activity, whereas the level of challenge and skill need to be balanced (Newman et al., 2014), so that mastery can be achieved and ultimately lead to well-being. People's need for this balance between skill and challenge differs according to their competences in the different activities they engage in, both in leisure and working fields. The serious leisure model (Stebbins, 1997) additionally supports the importance of mastery in relation to well-being, as it points out that participating in serious leisure, meaning "the systematic pursuit of an amateur, hobbyist, or volunteer activity that is sufficiently substantial and interesting for the participant to find a career in the acquisition and expression of its special skills and knowledge" (Stebbins, 1997: 3), contributes to subjective well-being by stimulating feelings of accomplishment, meaning, growth, and other psychological benefits (Stebbins, 1997). Examples of activities that

potentially provide individuals with a sense of mastery and experiences of flow could include both intellectually stimulating tasks, such as learning a new language or a new cooking skill, as well as physically challenging activities, such as training for a marathon or acquiring sailing skills.

Autonomy

The term autonomy can be literally translated to "self-governing", indicating the experience of regulation by the self (Ryan et al., 2008). The notion of autonomy is most extensively addressed and discussed in self-determination theory (SDT), developed by Ryan and Deci (2000) who consider autonomy as one of the three basic needs required for psychological well-being, next to competence and relatedness. The theory assumes that individuals are "by nature active and self-motivated, curious and interested, vital and eager to succeed because success itself is personally satisfying and rewarding." (Deci & Ryan, 2008: 14). At the same time, the theory also acknowledges the opposite: that people can be alienated and mechanized, passive and disaffected. The difference between these two extremes of the spectrum can be accounted for by differences in motivation and the social environment that either supports or counters the active nature of people. Here, Ryan and Deci distinguish between intrinsic, or autonomous, and extrinsic motivation. An activity that is performed as a result of autonomous motivation involves a sense of volition and choice, and is perceived by the individual as interesting in itself and is spontaneously satisfying because of the positive feelings resulting from the activity itself (Deci & Ryan, 2008). Extrinsic motivation is characterized by external control and the experience of pressure and demand to perform activities that have a specific outcome determined by forces outside of the self (Deci & Ryan, 2008). Punishment avoidance or activities purely directed to achieving material rewards can be considered as typical examples of extrinsically motivated behavior.

Apart from self-determination theory, also continuity theory (Atchley, 1976), innovation theory (Nimrod, 2008), compensation theory (Chick & Hood, 1996) and the leisure and well-being model (Carruthers & Hood, 2007) are identified by Newman et al. (2014) as supporting the idea that autonomy is a necessary requisite and essential mechanism for achieving an increased sense of well-being. These theories tap into the ideas of control over one's choices, self-direction and independence. Ryan and Deci (2008) however recognize that a distinction has to be made between acting autonomously and acting independently, though some researchers have interpreted the two terms as coinciding. Acting independently however means functioning alone and not relying on others, which might be a result from extrinsic pressure to appear as competent and mature or to avoid contact and help from others. Either way, independent behavior based on these motivations cannot be considered autonomous, as it lacks a sense of choice and volition.

Intrinsically motivated behavior can thrive in social environments that offer autonomy support, for example in schools, homes, workplaces and leisure settings. Autonomy support "involves one individual (often an authority figure) relating to target individuals by taking their perspective, encouraging initiation, supporting a sense of choice, and being responsive to their thoughts, questions, and initiatives." (Deci & Ryan, 2008: 18). Parents, coaches, teachers and supervisors can therefore be considered to play an essential role in providing a fruitful setting for autonomous behavior, that is a prerequisite for achieving an increased sense of psychological well-being.

Affiliation

The mechanism of affiliation covers feelings of social belonging, being part of a group, and experiencing emotionally rewarding relationships (Newman et al., 2014). It is the psychological mechanism that appears the most often in different theoretical concepts of subjective well-being, in comparison to the other mechanisms discussed. Therefore, it is arguably the strongest and most consistent predictor of wellbeing across different contexts (Newman et al., 2014).

One of the earliest references to affiliation as an essential component of human psychological health can be found in Maslow's hierarchy of needs (Maslow, 1954). In his theory, love and belongingness take the third rung in the hierarchy of needs, after physiological and safety needs. Other theories that also suggest affiliation as an important mediator of wellbeing are for example activity theory (Havighurst, 1961), disengagement theory (Cumming & Henry, 1961) and socioemotional selectivity theory (Carstensen, 1992). Though formulated in different ways, all of these theories claim that social activities may help to build meaningful relationships, evoke positive emotions, and in the long run have a positive effect on overall quality of life. (Newman et al., 2014).

Detachment-Recovery

The general idea of this mechanism refers to the process of detaching and recovering from work in the time spent on leisure. Newman et. al (2014) perceive this notion to be reflected in the conservation of resources theory (Hobfoll, 1989), the effort-recovery model (Meijman & Mulder, 1998), the attention-restoration theory (Kaplan, 1995), and the compensation theory (Chick & Hood, 1996). It is probably the item that is most uniquely linked to looking at subjective well-being through the leisure sciences lens. The other four mechanisms of autonomy, mastery, meaning and affiliation can readily be applied to and studied in relation to other aspects of a person's life, for example to work and employment, while detachment and recovery are specifically bound to the use of leisure time.

The effort-recovery model for example is based on the idea that the recovery process works more efficiently, if the resources tapped on during leisure activities are different from those that are needed

for work related activities. Following this logic, a person who pursues an intellectually demanding job that challenges his or her mental resources, will find more recovery in for example playing sports during leisure time that mostly draws on physical resources. Chick's and Hood's (1996) compensation theory argues that individuals tend to follow this structure in favor of compensating the energy spent at work with complementary leisure engagement and accordingly satisfying a larger range of needs and improving subjective well-being (Newman et al., 2014). The conservation of resources model adds that resources can be deliberately built up during leisure activities in order to overcome stress at work (Newman et al., 2014), while Kaplan's (1995) attention-restoration theory mentions that time spent in nature specifically helps to facilitate recovery and coping with the negative effects of stress.

All of the above-mentioned frameworks share the view that work draws on people's physiological and psychological resources. Depending on the effort and time spent on work, this can negatively influence well-being, and in extreme cases lead to burnout (Schaufeli, Taris, & Rhenen, 2008), which in reverse is mediated by the psychological mechanism of detachment and recovery experienced in leisure.

Meaning

Like mastery, also meaning is promoted both by the flow model and by the serious leisure model. Meaning-making through leisure or work-related activities implies the idea that individuals experience a feeling of importance, value and purpose in life (Iwasaki, 2008). It is closely related to ideas of self-actualization, or to the feeling that a person is developing his or her potentials and making life meaningful (Church et al., 2012).

Ryff (2013) summarizes the characteristics of a person who scores high in the satisfaction of the basic need of meaning as someone who "has goals in life and a sense of directedness; feels there is meaning to present and past life; holds beliefs that give life purpose; has aims and objectives for living". In contrast, a person who scores low in the satisfaction of the need for meaning is someone who "lacks a sense of meaning in life; has few goals or aims, lacks sense of direction; does not see purpose in past life; has no outlooks or beliefs that give life meaning" (Ryff, 2013: 12).

2.3. Synthesis and research question

Ideas of what disability is and how it should be dealt with have changed over time. Today, a main divide exists between the individual or medical paradigm, that assigns the problem of disability to the individual person and suggests medical treatment as solution to the problem, and the social paradigm, that places the problem within society instead of in the individual, demanding societal change and barrier removal. A very practically oriented framework that attempts to combine aspects of both the

medical and the social framework is the International Classification of Functioning and Health (ICF) developed by the World Health Organization (WHO), that provides a manual tool for describing and assessing the life situation of people with disabilities. The components included in this framework are categorized within the four main areas of body structures, body functions, activity and participation, and environmental factors.

The theoretical concepts of disability are based on an assumption that disability is a problem and leads to exclusion, or restriction to live a fulfilled life. This perception forms the outset of the idea that disability and (un)happiness have become inextricably connected (Söderfeldt & Verstraete, 2013), suggesting that people with disabilities face additional challenges in their pursuit of well-being and happiness that can take the form of individual health issues or societal barriers and attitudes of other people. Qualitative studies attracting notice to the perceptions and experiences of happiness and well-being of disabled people can hardly be found.

Within the context of studying happiness and well-being, it is largely accepted by the existing literature that holidays offer opportunities for individuals to feel happier (Nawijn, 2010; Newman et al., 2014). A large-scale comparison of studies that investigate this relationship has resulted in a set of five psychological mechanisms that reoccur most frequently and can be linked to well-being, namely detachment-recovery, autonomy, mastery, meaning, and affiliation (Newman et al., 2014).

The combination of the International Classification of Functioning and Health (ICF) with the framework of psychological mechanisms for well-being appears to be an innovative and promising approach towards understanding how people with disabilities experience well-being on holidays. To be able to better understand the situation on holidays, it is essential to also take the home situation as a point of reference into account. Only by investigating both the home and the holiday setting, it is possible to compare the two and allow for conclusions on the how and why well-being might be enhanced on holidays.

Therefore, it is the objective of this research project to study how people with disabilities experience subjective well-being at home and on holidays by identifying and comparing how the different components of the ICF, namely body structures, body functions, activity and participation, and environmental factors, relate to the psychological mechanisms of detachment-recovery, autonomy, mastery, meaning, and affiliation at home in comparison to the holidays setting.

Combining the research objective and theoretical framework leads to the following main research question and sub-questions for this study:

Main research question

How do people with disabilities experience the relationship between the components of the ICF, namely body structures, body functions, activity and participation, and environmental factors, and the psychological mechanisms of detachment-recovery, autonomy, mastery, meaning, and affiliation at home in comparison to a holiday setting?

Sub-questions

1. Which components of the ICF are at work in the home setting of people with disabilities?
 - 1.1. How do they relate to the psychological mechanisms?
 - 1.2. How are they experienced by people with disabilities?
2. Which components of the ICF are at work in the holiday setting of people with disabilities?
 - 2.1. How do they relate to the psychological mechanisms?
 - 2.2. How are they experienced by people with disabilities?
3. How do the two settings compare regarding the composition of ICF components and the corresponding psychological mechanisms?

3. Methodology

The following chapter will present and discuss the chosen research design, data collection methods, ethical considerations in doing research on and with participants with a disability, the structure of the data collection process, and the analysis strategy.

3.1. Research design and data collection methods

For this research project a qualitative case study design was chosen, as the project follows an exploratory approach that aims at gaining in-depth insight into a phenomenon that very little research has been conducted on so far.

The data collection methods align with the qualitative nature of the research design and include narrative interviews supported by photo elicitation and participant observation. These methods cater for the circumstances of this research project and the involvement of persons with intellectual and physical disabilities. Narrative interviews are particularly suited for interviewing people with a disability as the act of telling a story is fairly simple and a natural form of telling others about themselves and their experiences (Riessman, 1993). Instead of following a pre-determined interview guide, the narrative interviews evolved around the photographs that the participants produced. This way the participant was in full control over the topics that were addressed in the interviews – they could create their own stories and explanations of their experiences. This way only themes that were important to the participants were discussed, as opposed to a strategy in which the researcher imposes his own pre-defined interpretation of what might be important to the participant.

3.2. Recruiting the participants

In the light of the fact that this MSc thesis research project is embedded in a larger series of research project initiated by the Sailing Organization, the participants for this study were selected in collaboration with the director of the Sailing Organization from a pool of groups that booked a vacation with the Sailing Organization in the summer season of 2016. As the researcher herself is German, an additional inclusion criterion was the nationality of the participants. By choosing German participants, the data collection could be carried out in the native language of both participants and the researcher, avoiding Dutch-German language barriers and fostering greater mutual understanding. These two initial selection criteria filtered out a group of potential participants who booked their holiday with the Sailing Organization via a facility for assisted living in Germany (in the following referred to as *the Facility*). The group booked a sailing week from 18 till 24 June 2016 and consisted of eight participants

with varying forms of intellectual and physical disabilities and four institutional employees who would accompany the trip.

Within this group four people permanently live in the Facility with 24-hour stationary care, three live in apartments attached to the institution receiving ambulatory assistance and one person is an external friend of the institution. The Facility has already booked sailing vacations with the Sailing Organization twice before, one week in 2015 and one in 2008. As the trip was highly appreciated by the participants last year, some of them were so eager to go again that they spread their excitement about the trip back home, so that the employees of the institution readily decided to book another sailing week for the institution with the Sailing Organization in the summer season 2016. This already existing relationship between the Sailing Organization and the Facility was interpreted as a promising base for finding participants who are enthusiastic about taking part in the project, and supportive supervisors within the Facility.

The initial contact between the researcher and the Facility was established by the director of the Sailing Organization. After being granted permission, the researcher personally contacted the employee from the Facility who booked the holiday trip with the Sailing Organization for the group. In the following, she will be referred to as Julia (*pseudonym*). She is employed by the institution and is responsible for providing accompanying and psychological services to the disabled residents. She invited the researcher to visit the institution in Germany to get to know each other and learn more about the project. This first-time visit took place in an informal atmosphere in the main building of the Facility and provided an opportunity for the researcher to explain the general goal and methods of the project.

As the chosen data collection methods required participants 1) to be able to operate a photo camera to take photos of their daily lives and their holiday experiences and 2) to be able to verbally express their reflections on the photographs they take, after consultation with Julia five of the eight sailing participants were invited to take part in the project: Alexander, Tina, Ilse, Lena, and Thomas (*pseudonyms*). The other three participants of the sailing trip were excluded due to the following reasons: The first one could neither operate a camera due to a spasticity in his hands, nor articulate himself in an interview due to a speech impairment, the second one does not live in the Facility, so it was not possible to include him in the first phase of the data collection, and the third one only recently moved to the Facility and still had difficulties accustoming to the new environment. Later in time it might have been possible, but at the given moment engaging with the research was considered too much by the supervisors of the Facility. Though those three sailing participants were not included in the actual data collection, everyone in the group was welcome to watch and follow the research process and to interact with the researcher.

In retrospect of the data collection phase, the data derived from Thomas were excluded from the data analysis, as the researcher could not understand his articulation in the audio recordings of the interviews. It already proved to be difficult for the researcher to understand Thomas, who has Down's syndrome, in the face-to-face interviews as he speaks very unclearly. Without eye contact and gestures to support the things heard, it was not possible for the researcher to transcribe the audio recordings of Thomas' interviews reliably.

3.3. Ethical considerations

As people with disabilities are considered a vulnerable social group to include as participants in a research project, the given project has been submitted for ethical review by the Social Sciences Ethics Committee. After reviewing the project proposal for 1) fair and respectful treatment of humans involved as subjects of research, in terms of inconvenience, consent, and privacy; 2) professional handling of data on human research subjects; and 3) acceptability of potential risks caused by the study¹, the committee has granted ethical approval prior to the start of the data collection process. The letter of ethical approval can be found in appendix 1.

Also the participants themselves, as well as their legal guardians were fully informed about the aims of the research and how the material generated from the research project would be used and disseminated. The information letter that they received can be found in appendix 2. The participants and their legal guardians received the form in German.

Moreover, both written and oral consent from the participants and their legal guardians has been requested. The consent form in English can be found in appendix 3. The participants and their legal guardians received the form in German. A group meeting with all participants and accompanying supervisors took place prior to the beginning of the data collection process in which the researcher personally explained the goals of the research project, answered potential questions, and asked for oral consent. The signed consent forms were returned to the researcher upon the beginning of the first data collection phase.

As the research touches upon sensitive and personal issues, a certain risk regarding the emotional response of the participant could not be avoided. The participant were provoked to think about issues he or she has not thought of before, or see aspects of his or her life in a different light. Moreover, the participants knew that they are taking part in a study before, during and after their holidays, which might have made them experience their trip differently and potentially as more stressful than normally. To keep this potential feeling of stress at a minimum level, the interviews regarding the

¹ Application Form Review Social Sciences Ethics Committee, Wageningen University

sailing week did not take place during the week itself, but after the trip has been concluded. The researcher's role was limited to participant observation over the time of the trip.

As an additional measure to minimize or mitigate these risks, the participants were informed that they could receive psychological assistance from Julia, the mediating supervisor in the Facility, throughout the entire research process as well as after the project was concluded. Her job was to provide the institution's residents with accompanying support and assistance in their daily life. She was present both during the researcher's field work in Germany and in the Netherlands and agreed to play a mediating role between the researcher and the participants, and she

- ensured that the participants could always turn to her if they felt uncomfortable in any way,
- ensured that the participants remained aware of the fact that they participate voluntarily and were free to leave the research process without consequences if they wished to do so,
- ensured that the participants' holiday pleasure was not compromised by the research process,
- helped the researcher to identify moments in the home setting that are relevant for the researcher's understanding of the participants' daily lives,
- supported both the researcher and the participants in the interview process, as this is the first time the researcher interviewed people with a disability.

3.4. Data collection process

The data collection process was divided into three phases:

Phase 1 The first phase focused on the home setting of the participants, an assisted living institution located in Germany. The participants received digital photo cameras from the researcher and were encouraged to take pictures of their daily lives and normal activities for one week prior to the holiday. The process of gaining insight into the daily life at home was supported by participant observation during participants' daily duties, work, and leisure activities. At the end of the week, in the form of narrative interviews the participants were invited to tell the story of their week with the help of the photographs they took, to elicit reflection on their experiences.

Phase 2 In phase 2 the same procedure was repeated during the sailing holiday week in the Netherlands, where the participants went sailing on day tours with a catamaran. The researcher could join the group during all activities, both on the water as well as on land in the accommodation for daily activities such as breakfast, dinner and camp fires in the evening. Also this week included participant observation. To not impair the holiday experience of the participants, the narrative interviews supported by the photographs the

participants took during the week took place directly after the group returned to Germany instead of during the holiday week itself.

Phase 3 The aim of phase 3 was to perform a reflection with the participants approximately 2 months after the holiday has been concluded to discuss perceived differences between the home- and the holiday setting. Moreover, the participants were asked to pick three favorite photographs from phase 1 in their home environment and phase 2 in the Netherlands during their sailing holiday. This activity helped them to reflect on both weeks in comparison and gave insights into an evaluation given by the participants themselves rather than estimated by the researcher. As a final step, the participants received all photographs they took as print outs, as well as an empty photo album, to equip them with a physical memory of the research project.

The following table gives an overview of the amount of data collected during the three research phases:

Name	Phase 1		Phase 2		Phase 3	
	Length interview	No. of photographs	Length interview	No. of photographs	Length interview	No. of favorite photographs
Alexander	00:55	33	01:15	33	00:31	6
Lena	01:19	31	01:06	67	00:40	7
Tina	01:11	39	01:10	52	00:43	6
Ilse	01:35	90	01:19	119	00:49	6

3.5. Analysis strategy

With permission of the participants, all interviews were audio recorded and subsequently transcribed. As a first step of analysis, the transcripts were divided into text units using the pre-defined ICF categories as thematic codes. The narratives of the participants were analyzed in their entirety, to get a complete picture of the situation at hand. A side effect of this analysis strategy was that it also partly implied a content analysis of the photographs produced by the participants, as the participants discussed all their photographs in the interviews. In the next step, the identified thematic text units were reinvestigated for evidence of the five psychological mechanisms mastery, autonomy, affiliation, detachment-recovery, and meaning. Where evidence was found, the corresponding ICF component of the respective text unit was evaluated as having either a facilitating or a hindering effect for the psychological mechanism at work.

The following table shows an exemplifying excerpt from the thematic analysis scheme:

Text Item	Thematic text unit	ICF Level 2	ICF Level 1	Mechanism	Load
Is01	Da war ich auf dem Schiff. Da waren wir Segeln. Und da ist die Landkarte, da zeigt das Segelboot, wo man hinfahren muss.	Products and technology	Environmental Factors		
Is02	Ja und hier, das ist mein Freund, das ist der Hans. Weil der mir wichtig ist, mein Freund. Ich fand's super, dass wir mit den Pärchen da waren. War mal was Anderes. Ich war mit ihm noch nie Segeln zusammen. Wir waren das erste Mal segeln. Und da fand ich das toll, dass ich mit ihm zusammen beim Segeln da war.	Support and Relationships	Environmental Factors	Affiliation	+
...					
Is18	Das ist wo wir da Urlaub gemacht haben in Holland. Das war toll. Da haben wir uns selber versorgt. Da hatten wir selber Frühstück da, haben wir Frühstück gemacht. Und wenn wir da gefrühstückt haben, haben wir da abgeräumt. Da haben wir das in eine... ach wie heißt das, in so ein Ding da gestapelt, dann in eine Spülmaschine getan, dann die Spülmaschine zugemacht. Also da haben wir uns selber da versorgt. Gut. Ich fand das gut. Ja ich fand das auch mal gut, dass wir uns da selber versorgen. Fand ich auch mal gut.	Domestic Life	Activities and Participation	Autonomy	+
...					

4. Results and analysis

The following chapter first addresses analysis of the home setting and the holiday setting, before comparing the two and discussing the results' implications.

4.1. The home setting

The four participants of this study all live in the same assisted living facility for people with disabilities in the west of Germany. To ensure the participants' anonymity, their names have been replaced by pseudonyms that they could pick themselves: Alexander, Tina, Lena and Ilse. Due to the same privacy reasons the assisted living facility will herein be referred to as "the Facility".

The Facility was founded in 1999 as an initiative of young adults with varying disabilities and their families with the aim of creating a living space that answers to their wishes and ideas of a self-determined life and at the same time provide support where it is needed. The activism of the initiative lead to the construction of the main building in 2002, a fully accessible housing facility that caters for the needs of the impaired occupants with space for three group homes with six residents each. In these three groups in the main house at least one supervisor per group is always present. In 2012, the housing offer has been extended with four individual apartments on the same property that provide a more independent form of housing. The four residents of these apartments are living alone and receive ambulant assistance. The latest addition to the housing offer since 2016 is a shared flat in a neighboring building that offers space for five residents, also with ambulant assistance.

The overall concept of the Facility is formulated as follows:²

"People need people – some need them more, and some need them less. We are rising to the challenge to construct a framework that enables participation for everyone.

We want to: - be a home to people with disabilities

- be a special place where residents can develop and try themselves*
- provide space for individuality, wishes, and active and socio-creative lifestyles*
- accompany and support the residents on their path of life*
- live the everyday life*
- unleash resources and abilities"*

The normal living situation within the home setting of the participants is comprised of time spent at home in the afternoons, evenings and weekends, and time spent at work during the day. In their free time, all residents of the Facility can make use of openly accessible equipment in the common areas

² Cited from the conceptual publication of the Facility, translated from German by the researcher

of the main house such as a game console and TV, a tablet computer with game apps, a soccer table, books, drawing stationery, and board games. Moreover, multiple supervised group leisure activities are offered on a weekly basis, including wheelchair basketball, fitness trainings, pottery, cooking, swimming, and musical instrument and singing practice. Extraordinary trips are also organized regularly, for example visits to concerts and festivals or cycling tours. It is also possible for the residents to spend a weekend at their family's houses from time to time.

Most residents of the Facility work in sheltered workshops in the nearby areas. These workshops are part of Germany's policy on the integration of people with disabilities into a working environment, employing people with disabilities separately from the regular labor market. In 2015, 305.000 people with disabilities work in such sheltered workshops all over Germany, organized by the "Bundesarbeitsgemeinschaft Werkstätten für behinderte Menschen", which can be roughly translated to "German Community of Workshops for People with Disabilities" (BAG WfbM, 2015). The jobs offered in sheltered workshops cover different areas of manual production, from very simple to more complex tasks, depending on the abilities and interests of the individual. Apart from their regular work activities, the workshops also offer additional educational programs for their employees. These take place during normal working hours, so that they do not form an extra burden for the participants, but instead aim at learning, relaxing and having fun.

4.1.1. Introduction of the participants

The following paragraphs will introduce the four participants of this study. Taking their position in the given home environment into account will help to better understand their perceptions and experiences of daily life. The names mentioned here are pseudonyms that the participants picked themselves.

Alexander was born in 1980, so at the time of the fieldwork he is 35 years old. He is one of the initiators of the housing project for disabled people and has lived in the Facility since its beginning. Upon completion of the apartment complex he moved to his own apartment on the grounds of the facility in 2013 where he now lives by himself, supported by ambulatory assistance. He cannot move his legs and also experiences difficulties with his arms and hands because of a polyneuropathy, a disease affecting the peripheral nerves. Most of the times he uses a manual wheelchair and sometimes an electrical wheelchair when his arms and hands get tired. To counter the physical impact of the polyneuropathy Alexander's week is filled with multiple physiotherapy sessions to move and stretch his arms and legs. He is struggling with the decreasing strength and functionality of his arms and hands that is caused by his disease and receives especially pedagogic and motivational support from the supervisors. Alexander is also

diagnosed with a mild intellectual disability that comprises his learning abilities and asks for marginally guiding assistance in managing his daily life.

Alexander works in an integrative kindergarten in the neighboring village. He drives there with his own car and works from 7:30am until 11:30am on four days of the week. In the kindergarten, where he already used to go himself as a child, he holds an assistive administrative position. His tasks include paperwork at the computer in the office of the kindergarten and ordering the lunch catering for the children. Furthermore, he gives wheelchair training to two children at a time once a week, supported by the physiotherapist of the kindergarten. In his free time, Alexander likes to play the keyboard, work on the newspaper that the Facility produces, make pottery, and spend time with his girlfriend Tina.

Tina is a young woman born in 1981, at the time of the fieldwork for this study she is 34 years old, and Alexander's girlfriend for five years. Since 2009 she occupies a room in one of the three housing groups in the main building of the Facility, where supervisors are permanently available to assist the residents. Even though Tina would prefer to move to an ambulatory assisted apartment like Alexander, it is not possible at this point because of her epilepsy. As she gets epileptic seizures every night, sometimes more mild ones but sometimes more severe ones, a skilled night watch needs to be around at all times. Thanks to her medication the epileptic seizures only occur when she is asleep.

Tina works in a sheltered workshop in a group of peers where she assembles small parts for cars, for example tank caps. Together with one other colleague she also takes over the task of distributing the meal vouchers within the group before lunch time. In the educational program offered by the sheltered workshop Tina follows a knitting class. Her work day starts a bit later than that of her colleagues, at 9:15am. This arrangement has been made to cater for her additional need for sleep resulting from her nightly epileptic seizures. In her free time after work and in the weekends, she likes to sing in the women choir of the Facility, dance, play games on the tablet computer, go into town, and play wheelchair basketball. Normally she does not use a wheelchair, but this sports program is open for everyone, also those who can walk. Moreover, Tina likes to visit her family from time to time in the weekends.

Lena is with 44 years the oldest of the four participants, born in 1971. She used to live in the main building of the Facility since 2014 but recently moved to the newly finished shared flat very close to the grounds of the Facility in May 2016. She shares the apartment with three other peers and a supervisor visits the group every afternoon until evening to help with dinner preparations and other domestic tasks. Lena has a visual as well as an intellectual disability.

She cannot estimate distances and distinguish details, but can see enough to orientate herself in familiar immediate environments. During the photographing assignment connected to this study, she received the camera with the largest display and with some practice could complete the task successfully.

Lena works in a different sheltered workshop than Tina, but her working environment is comparable. She is employed in the packaging section, where she and her colleagues sort and package all kinds of production components. In her educational program at the workshop Lena practices her writing and reading skills. Also Lena sings in the women choir in her leisure time, plays wheelchair basketball and likes to spend time together with her boyfriend Thomas, a resident of the main house of the Facility.

Ilse is 41 years old at the time of the fieldwork, born in 1975. After living in the main house since 2013, Ilse lives in a one-person apartment that is directly attached to the apartment where Lena is living with her housemates since May 2016. By simply opening or closing the connecting door she can choose between staying for herself and joining the group. Ilse is using a wheelchair due to a tetraparesis that affects all her four limbs. An operationally inserted Baclofen pump that constantly releases certain medications into the spinal cord helps to release the tension of the spasticity bound muscles. Next to an intellectual disability, Ilse struggles with an eating disorder and has difficulties to maintain her body weight. This puts a lot of pressure on her.

Ilse's working day starts early in the morning when she is picked up at 7:00 in the morning and is brought to the workshop by an assisted transport service, that also provides space for her wheelchair. At the workshop, Ilse is one of the few women who work in the metal processing unit. Here she operates machines or manually treats small metal parts. Ilse likes to spend her free time with drawing and crafting, singing in the women choir, or with trips to the city center. Together with her boyfriend Hans she enjoys travelling to other cities or special events such as concerts.

The following table gives an overview of the participants:

Name	Age	Housing situation	Working situation	Leisure activities	Type of disability
Alexander	35	One-person apartment with ambulatory assistance	Integrative kindergarten: assistive administrative employee	Keyboard, newspaper, pottery, socializing	Polyneuropathy Intellectual disability <i>Uses a wheelchair</i>
Tina	34	Room in group home with stationary assistance	Sheltered workshop: Assembling unit	Dancing, singing, wheelchair basketball, socializing	Epilepsy Intellectual disability
Lena	44	Room in group home with ambulatory assistance	Sheltered workshop: Packaging unit	Singing, wheelchair basketball, socializing	Visual disability Intellectual disability
Ilse	41	One-person apartment with access to group home with ambulatory assistance	Sheltered workshop: Metal processing unit	Drawing, crafting, singing, travelling, socializing	Tetraparesis Intellectual disability Eating disorder <i>Uses a wheelchair</i>

Table 2: Overview of participants

4.1.2. Overview of the results

The data collection phase of this study covered an exemplary week in the lives of the participants in their normal place of residence and work. At the beginning of the week, the participants received digital cameras and were instructed to take photographs of their normal activities and environment with the purpose of telling the researcher all about their normal daily life. At the end of the week the participants told the story of their week to the researcher in a narrative interview supported by the participant's photographs. The transcripts resulting from the interviews were thematically analyzed using the second level elements of the ICF system as coding categories. In the next step, the identified text units were reinvestigated for evidence of the five psychological mechanisms mastery, autonomy, affiliation, detachment-recovery, and meaning. Where evidence was found, the corresponding ICF component of the respective text unit was evaluated as having either a facilitating or a hindering effect for the psychological mechanism at work.

This analysis strategy resulted in the following accumulated counts of the single ICF elements and matching psychological mechanisms in the home setting:

ICF Component Level 1	ICF Component Level 2	Count	Mastery		Autonomy		Affiliation		Detachment - recovery		Meaning	
			+	-	+	-	+	-	+	-	+	-
Activity & participation	Learning and applying knowledge	6	4	1							3	
	General tasks and demands	1	1									
	Communication	0										
	Mobility	2										
	Self-care	8	2		2						1	
	Domestic life	6	2		2	1						
	Interpersonal interactions and relationships	19			2	1	6					
	Major life areas	22	3	2							3	1
Community, social and civic Life	35	10			1	4		13		10		
Total activity & participation	99	22	3	6	3	10		13		17		
Environmental factors	Products and technology	29	3		5		2		3		2	
	Natural environment and human-made changes to environment	7						2				
	Support and relationships	35			1		9	2	1		2	1
	Attitudes	1										
	Services, systems and policies	7			3	2						
Total environmental factors	79	3		9	2	11	2	6		4	1	
Body function	Mental functions	3										
	Sensory functions and pain	2										
	Voice and speech functions											
	Functions of the cardiovascular, haematological, immunological and respiratory Systems											
	Immunological and respiratory systems											
	Functions of the digestive, metabolic, endocrine systems											
	Genitourinary and reproductive functions											
	Neuromusculoskeletal and movement-related functions	2		1		1						
Functions of the skin and related structures												
Total body function	7		1		1							
Body structure	Structure of the nervous system	2										
	The eye, ear and related Structures											
	Structures involved in voice and speech											
	Structure of the cardiovascular, immunological and respiratory systems											
	Structures related to the digestive, metabolic and endocrine systems											
	Structure related to genitourinary and reproductive systems											
	Structure related to movement	3		1								
Skin and related structures												
Total body structure	5		1									
Total overall	190	25	5	15	6	20	2	19	0	21	2	
Total facilitating psychological mechanisms (+)		100										
Total hindering psychological mechanisms (-)		15										

Table 3: Overview of home setting results

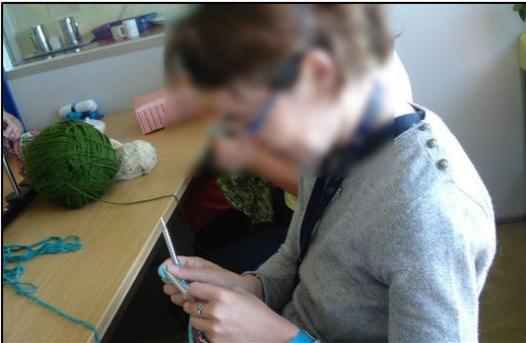
A few points directly stand out when first looking at the results. Firstly, the two categories “activity and participation” and “environmental factors” take up much more room in the stories of the participants with 99 and 79 matching text units than “body functions” and “body structures” with 7 and 5 matches. Secondly, all five psychological mechanisms seem to be at work in the home setting with relatively little differences in perceived frequency. Thirdly, both in all individual cases, as well as in total, the different ICF components are more facilitating than hindering the mechanisms, with 100 facilitating combinations in comparison to 15 hindering ones. Fourthly, differences can be detected in the distribution of which ICF components link the most with which psychological mechanisms: mastery for example seems to be mostly facilitated by elements that fall within the category of activity and participation with 22 matches, compared to the category of environmental factors with only 3 matches.

After this initial overview, the next step is to investigate how the different ICF components link to the different psychological mechanisms, and how the participants experience those connections.

4.1.3. Mastery

Overall, the home setting provides a wide range of opportunities for experiencing mastery that challenge the individuals’ skills and provide learning opportunities (Newman et al., 2014). According to the present results, the strongest facilitator for experiencing mastery in the home setting of the participants lies in the pursuit of leisure activities, categorized as “community, social and civic life” within “activity and participation”. Also other aspects of the same main category, such as “learning and applying knowledge”, work related tasks in “major life areas” and “domestic life” and “self-care”, as well as “products and technology” as an environmental factor add to opportunities in which feelings of mastery can be achieved. In practice, participants expressed their experiences of mastery by saying that they are good at something, in most cases referring to a voluntarily chosen leisure activity. This is an aspect of their lives that all participants assign major importance to. All four participants fill their free time with a range of different leisure activities, which can be either organized in a group and coordinated by supervisors, such as wheelchair basketball, pottery, and choir practice, or pursued individually, such as knitting or drawing. Moreover, the participants linked the feeling of mastery to several other positive emotions, such as feeling calm, feeling proud, or simply having fun:

“Yes, I like to draw. I am an artist and I like to draw. I draw the sun, and houses, trees, the beach, flowers, horses, cats. I feel good when I’m drawing. It is a calming work. I always calm down when I’m drawing.” – Ilse



“Here I had a photo taken of me knitting. Here I was knitting. Because it is so nice. You have to pay attention and look very closely at what you are doing. How do you continue. It is really nice, but also thoughtful. You also have to think. What did I do last and what will I do next.” – Tina

“We are playing in a band, here in the Facility. And every week on Wednesday night we are practicing. And I’m also playing in the band, piano. That’s something that is fun and I am also proud of myself that I manage to do this. And it is fun to play together with the others. We also published a CD, a production of the Facility. That was great.” – Alexander

„Here I put on the song on CD and we were singing it to Agnes, we were singing it for her on the phone. And she was really happy about it when we called. And we just turned on the CD and sang along. And Agnes said that: “Wow, you are so good at singing!” Yes, really!” – Tina

However, mastery is not only limited to leisure activities. Also work related activities as subcategories of “major life areas” and “learning and applying knowledge” offer opportunities of accomplishment that are important to the participants, represented in very detailed descriptions of their working tasks:

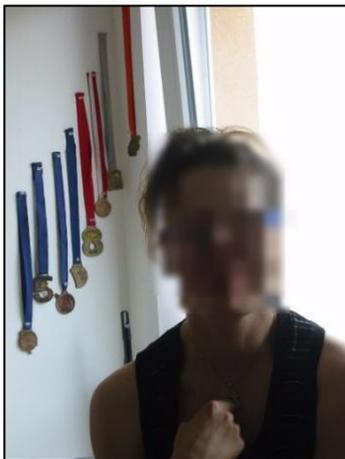
“These are the signs for the different components. Springs and so forth. That has to go into there. Sometimes it jumps out, so you have to watch out that it is the good spring. You have smaller springs and bigger springs. Next you have to add the stopper and turn it around. And with the stopper on top of it will “click”. Then it’s closed and at the end the lid goes on top. If it goes “click” it means that it’s ready. Then you have to check it again.” – Tina



“Here I am at the workshop, I work in metal processing. This is the threshing machine. We are making everything for roofs, that is what we are making. It is nice, I like it. It’s something different. And I like to go there. I am unstoppable at work. I feel good there.” – Ilse

“I like to work at that machine. I have to push down both handles. I’m good at this, I am doing my work well. I am very accurate with my work. There I did not make any mistakes yet, I am doing great.” – Ilse

Though the text units identified with supporting factors for mastery predominate, the participants also describe moments in which they feel hindered from achieving specific goals. Ilse’s tetraparesis and Alexander’s polyneuropathy have deteriorative effects on what their bodies’ functioning. Both of them used to be able to do things they cannot do anymore, due to their bodies as a hindering factor:



“These are my medals. I cycled the marathon in Cologne with my hand bike, eight times. My best time was 1:39 hours. That was in 2001. And then it was the last marathon. Yes. And because of my handicap I didn’t have the strength anymore. My hands left me unfortunately. It is not like that anymore.” – Alexander

“I am glad that I have the job in the workshop. In the past when I was fitter I also managed to work in the kitchen. There I was in the kitchen, I didn’t have the spasticity back then. And then I could also have done an internship outside. But since my foot operation that’s not possible anymore, to work in the kitchen”. – Ilse

4.1.4. Autonomy

In comparison to the other psychological mechanisms, autonomy is the one that occurs the least often in the narratives of the participants about their home setting, with 15 identified text units that describe situations that support autonomy and 6 that depict a hindering effect. A positive relationship was assigned to utterances of individuality and perceptions of being free to make one’s own decisions, whereas a negative relationship was detected when the participants experienced barriers to this.

Within the ICF framework, both “environmental factors” as well as “activity and participation” have enabling effects on the perceived autonomy of the participants. Especially “products and technology” play a supporting role in this. Practically speaking, this category mainly refers to the physical housing environment that is adjusted to the needs of the residents. The way the housing facilities are constructed and equipped enables the participants to “do their own thing”:

„Here in my apartment I am even more autonomous. Everything is accessible for me, so that I can cook better. And do the dishes better. That I could not do in the main building. There I always had to ask. There I could not reach the tea pot and had to ask if someone could get it down for

me. That was not good. And here it is all accessible, so that I can reach everything myself, all the things. That's great.” – Ilse

“I live here in this apartment for three years now. Assisted living, that is. It is part of the Facility, this apartment, and I rent it from them. And here I feel at ease. In my own rooms. Here I can do what I want. And I am not dependent on others. I can go over there as a visitor. And I then I can close my door again. That's very comfortable.” – Alexander

Also handy objects such as a cell phone or a house key are small additions to increasing the participant's perceptions of autonomy:

“When I'm outside of the house I can call, and tell that I am still somewhere, I will be home late. When I am outside with Anna or Ilse and they are waiting for us for dinner, then they can just call me and ask. I am not going outside without smartphone anymore. I have it for using it.” - Lena

“I also have a key for the front door, so that I can get inside. I also have one. Then I can let myself in and out. When there is nobody around I can unlock the front door. Because sometimes the supervisors are busy or outside as well, or wherever, or upstairs. And then I can go in myself.” - Tina

Alexander is the only participant of this study who has a driving license and owns a car. He mainly uses it to drive to work, and he appreciates the freedom of autonomous mobility. This example shows that autonomy also easily links with mastery:

“This is my car. I really like the independence of having a car. Not being dependent on others or that they have to give you a ride. That makes me happy. That is a really good thing, where you can see that I am capable of something. It was not easy to get the driving license, but I also achieved that.” - Alexander



Another aspect of a living environment that is characterized by autonomy relates to the provision of assistance by pedagogic supervisors where it is needed. This element also falls into the ICF category “environmental factors”, into the subcategory “services, systems and policies”. The residents are encouraged to perform domestic tasks as autonomously as possible:

“This is Tabea, and this is Andrea. They are supporting us in the group. That is going well. They always come at a specific time, I don't remember at what time. And then they help us with the groceries. I decide what I want to have and they help me with buying it.” – Ilse

Conversely, the systems that are in place to help the individuals are sometimes also experienced as a limitation to autonomy. For instance, Alexander's afternoons are filled with numerous appointments for physiotherapy sessions that he perceives as a restriction to organize his time in the way that he wants:

"During the week, I have a lot of appointments, a lot of therapy appointments. [...] That's the difficult part about my day, to plan my leisure time. It is just very time intensive. It can be very long and then I have to see what I can do." - Alexander

Another hindering factor to autonomy, just as to mastery, can be the own body. Hereby the body functions can restrict an individuals' choices, for example when the decision of using a manual or an electric wheelchair is dictated by the strength of one's hands:

„I find it hard to deal with that. Sometimes I even have to use my electric wheelchair for long distances. And that is... I am struggling with that. I mean, it is also fun to go with the electric wheelchair, but the other wheelchair is much more fun. You are actually doing something and not just sit and move your fingers." - Alexander

4.1.5. Affiliation

The psychological mechanisms of affiliation, or the feeling of social belonging, naturally relates strongest to the ICF categories that tap into social relationships: "interpersonal interactions and relationships" in the category "activity and participation", and "support and relationships" as an element of "environmental factors". The participants included both the active engagement with others, as well as the passive presence of others in their stories. Links to the psychological mechanism of affiliation were made in situations in which the interviewee explicitly mentions feelings of belonging or affection. As all participants share a romantic relationship with a partner, this formed one important facilitating factor in experiencing affiliation:

"My boyfriend is very important to me. I know him for three years now and we are a couple for two years. It is really fun with him. I am happy to have him. I don't want a different one anymore."
– Ilse

"This is Tina, my girlfriend. We are together for five years already. And yes, we get along really well." – Alexander

"We are together for something like five years. Being a real couple. I like it that we are together so often. And that we relax together. That is good. That is nice." – Tina

Moreover, the group of housemates or peers in the home environment provide social environments that the participants experience as supportive and feel emotionally attached to:



“This was yesterday. Because I wanted to photograph Sandra, and then Jenny said: “Sit down, I will photograph you both.” [Sandra and Jenny are both housemates of Lena] And that’s what she did. Because Sandra, Jenny and I, we, and I mean also with Ilse, we get along pretty well, actually. We get along really well, Jenny and me. She is a really good

friend of mine. We are all supporting each other. Really everyone who is living here, we stick together. We are... how can I say this? We are a good group, let’s say. All those living here.” – Lena

“Here we were singing with Julia. [Julia is a supervisor in the Facility and in charge of the choir] So this is our women choir. We are singing in the women choir with Julia. And that is nice, the music is nice. And when we are singing together, that is also nice. Sitting together and singing together. Then we are only together with girls, with women. No boys.” – Tina

Also the contact with colleagues as work contributes to affiliation as a supportive environmental factor, in which people help each other:

“I get along very well with my colleagues. No problem. It is really harmonious. We get along well. When the boxes are too heavy, then I ask my colleagues if they can help. And then they do that, it is not like they would say no.” – Lena

“This is Robert, he is my bodyguard. [Robert is a colleague of Ilse] He always helps me to push the wheelchair. In the lunch break he is helping me. And after work, he brings me to the front. And when I don’t feel like, because I am still finishing my work, at the end of the work day I ask him to get my jacket for me. Then I give him the keys for my locker and he gets my jacket for me. He’s doing that really well. I think that’s great.”



– Ilse

4.1.6. Detachment-Recovery

The psychological mechanism of detachment-recovery is the item that is most directly linked to the category “community, social and civic life”, which contains the third-level subcategory “recreation and

leisure”, as it refers to the process of detaching and recovering from work in the time spent on leisure. The other four mechanisms of autonomy, mastery, meaning and affiliation can also be applied to other aspects of a person's life, for example to work and employment, while detachment and recovery are specifically bound to the use of leisure time.

Analyzing the accounts of the participants, 13 out of the 35 text units concerning their community, social and civic life could be identified as supportive representations of detachment-recovery. Often, they describe a leisure activity as having a calming and relaxing effect:

„Pottery is a great way to leave the day behind. You can find yourself, for example. It really calms me down, doing pottery. It is also tiring, because you are just with yourself. That makes you think and you can calm down doing that.” – Alexander



“Sometime I am watching TV. When I’m tired in the evening, I go lie in my bed and watch TV from my bed. Then I’m automatically falling asleep, in front of the TV.” – Ilse

“When you are going outside, you can just sit on a bench and unwind. That is nice, that is relaxing. Not only hurry, stress, but instead something different. That you can do very well in this town, there are many possibilities. Just go for a walk, just go outside. Sometimes together with Tina, and with Hans sometimes. But sometimes alone, also.” – Alexander

4.1.7. Meaning

The psychological mechanism of meaning-making refers to the process by which an individual gains something important or valuable in life (Newman et al., 2014). Regarding the analysis of the participants’ narratives, “meaning” was identified when the person describes an intrinsic sense of purpose and feelings of engagement. In total, this attribute could be assigned to 21 text units, of which the majority of 17 fall into the category of activity and participation and the minority of 4 into the category of environmental factors.

Within activity and participation, most items are linked to the subcategory “community, social and civic life”, which includes leisure activities, and some to “major life areas” (work), as well as to “learning and applying knowledge”. This distribution of matches slightly resembles the one of the psychological mechanism of mastery. This might suggest that activities that challenge the participant’s abilities and

in which he or she masters a certain skill are also characterized by purpose and contribute to a meaningful life.

In practice, the most meaningful leisure activities are those in which the participants aim for a certain goal, for example practicing for a performance with the women choir, writing articles for the Facility's newspaper, or producing pottery that can later be sold or used as decoration:



"Here we are practicing with the women choir. We are practicing for the summer festival in August. That is what we are practicing for. So that we can do it on the summer festival. It is also fun in the women choir. I like to sing. I feel good when I'm singing, I feel strong." – Ilse

"I always write news articles for the newspaper and get some money for it. And when we sell the newspaper, then we earn some money with that. Because the printing costs also got more expensive. It is nice to help and to write a nice article about what happened and so on." – Tina

"With pottery, something gets done. I mean, you make something that you can put into your room afterwards, or in your apartment, or sell it maybe. Then the ambition is much bigger than if you say to yourself that it goes to the trash anyways. That is what I like about pottery." – Alexander



4.2. The holiday setting

The Sailing Organization is a Dutch tour operator that offers water sport programs in the Netherlands for people with physical and/or intellectual disabilities. Their work philosophy evolves around the idea that water sports and active holidays on the water are great ways to contribute to the development of empowerment, autonomy and independence of people with disabilities or chronic diseases, because the diversity of water sports provides challenging opportunities for everyone. Moreover, they argue that water sport vacations are an efficient tool to get people with disabilities out of possible social isolation by fostering integration and pushing their boundaries. The Sailing Organizations formulates their guiding principles as follows:

“Our goal: To foster societal well-being, the physical and mental independence, and the integration of people with a disability, using accessible facilities in the area of water sports and stimulating people with disabilities to take part in water sport activities.

Our vision: Active and autonomous water sport activities contribute to the physical and mental independence of people with a disability.

Our mission: To help people with a disability discover and extend their capabilities by the means of accessible water sport activities in a stress-free and safe environment for everyone.”³

To achieve their goal and mission by offering both financially and physically accessible water sport vacations, the Sailing Organization relies to a large extent on donations and volunteer work. A pool of approximately 2000 volunteers and 22 permanent employees make it possible to put a wide range of different water sport programs into practice. The different kinds of water sport packages that can be booked by groups and individuals are distributed over three main facilities owned by the Sailing Organization: A small island in an inland lake with accessible group accommodation for 23-30 people as a basis for more individual activities such as canoeing, water skiing, sailing with small boats, or surfing; a fully accessible clipper ship with four two-person bedrooms and three four-person bedrooms that is used for tours that can last several days; and a newly renovated accessible land based group accommodation for 12 people that serves as the starting point for day tours with a fully accessible catamaran. “Fully accessible” with respect to the clipper and the catamaran means that the pathways on the ships are wide enough for wheelchairs, that rope winches are placed at wheelchair height and that they are equipped with technology such as joysticks that also enables participants with reduced muscle power or movement control to steer the ship.

The tour that the participants of this study booked took place in the land based accommodation with catamaran day tours on the surrounding inland waters.

The group was spread over six two-person bedrooms in the newly renovated front part of the house, with the three couples sharing one room each, and the two leftover bachelors in one room, and the four supervisors that came along from the Facilities staying in two rooms. The researcher and the two crew members, one fully employed captain and one volunteer ship steward who guided the tour, slept in the old back part of the house. This back part used to be used for accommodating the sailing guests until the newly renovated part was recently opened in 2016.

Upon arrival of the group, the crew sat together with all participants to plan the schedule for their vacation week. Under considerations of the group’s wishes for visiting specific villages or islands, the

³ Website of the Sailing Organization, translated from Dutch by the researcher

days were structured in such a way that the group had breakfast together in the accommodation, then went on a sailing day tour, including visits to surrounding villages for lunch and shopping, or barbecuing on a small recreational island, and return to the accommodation in the evening for preparing and eating dinner together. The days were concluded with an evening program that the participants could join voluntarily, such as sitting around a campfire and singing songs, or playing games.

4.2.1. Overview of the results

The analysis of the interview transcripts resulted in the following accumulated counts of the single ICF elements and matching psychological mechanisms in the holiday setting:

ICF Component Level 1	ICF Component Level 2	Count	Mastery		Autonomy		Affiliation		Detachment - recovery		Meaning	
			+	-	+	-	+	-	+	-	+	-
Activity & participation	Learning and applying knowledge	2	1								2	
	General tasks and demands	1	1									
	Communication											
	Mobility											
	Self-care											
	Domestic life	9	2		2		1					
	Interpersonal interactions and relationships	49	2	1			20	5	1		1	
	Community, social and civic Life	40	9	1	2		1	14			2	
Total activity & participation	101	15	2	4		21	6	15		5		
Environmental factors	Products and technology	17	1		3		1		1			
	Natural environment and human-made changes to environment	82							13			
	Support and relationships	35			1	1	18		1			
	Attitudes											
	Services, systems and policies	1				1						
Total environmental factors	135	1		4	2	19		15				
Body function	Mental functions	5								1		
	Sensory functions and pain	6		4							1	
	Voice and speech functions											
	Functions of the cardiovascular, haematological, immunological and respiratory Systems											
	Immunological and respiratory systems											
	Functions of the digestive, metabolic, endocrine systems	1		1						1		
	Genitourinary and reproductive functions											
	Neuromusculoskeletal and movement-related functions	3		2					1			
	Functions of the skin and related structures											
Total body function	15		7					1		1		
Body structure	Structure of the nervous system											
	The eye, ear and related Structures											
	Structures involved in voice and speech											
	Structure of the cardiovascular, immunological and respiratory systems											
	Structures related to the digestive, metabolic and endocrine systems											
	Structure related to genitourinary and reproductive systems											
	Structure related to movement											
Skin and related structures												
Total body structure												
Total overall	251	16	9	8	2	40	6	31	2	6	0	
Total facilitating psychological mechanisms (+)		101										
Total hindering psychological mechanisms (-)		19										

Table 4: Overview of holiday setting results

4.2.2. Mastery

The holiday setting gave room to 25 identified items linked to “mastery”, of which 16 can be considered as facilitating processes of experiencing mastery and 9 as hindering them. The facilitating factors are almost completely accounted for by the level 1 category “activity and participation” with the prominent level 2 category “community, social and civic life”.

Activities that belong to this subcategory and that can be identified as supporting the mechanism of mastery mostly refer to sailing related tasks that offer opportunities for the participants to challenge their skills and learn something they couldn't do before. Especially the activity of steering the ship, sometimes with support of a crew member, left a lasting impression on the participants:



„This is the steering wheel. There you have to steer to the right and to the left, if you want the ship to go left. That was also not easy, sometimes you have to turn very slowly and sometimes fast. But it was really fun. The steering. I felt like a captain, there on the ship.“ – Ilse

“I thought it was good that we were all allowed to steer the ship at some point. That was really cool, that I could

steer the ship. And not just alone, but that Johanna also helped me. That was good.” – Lena

“This is Tina steering the ship. She was also good at that. And she liked doing that. I took the picture to show her that she is also good at that.” – Alexander



“I really liked the turns. Then you had to let go the front sail or pull it, depending on the direction of the wind. You always needed to have the wind against you. And then pull a little bit and wait till the wind is coming, then it

was doing the rest. That was great. And in the end, you could do it much better than in the beginning, of course. But it was interesting to see how fast you could learn it. Great.” – Alexander

Next to sailing related activities, also domestic tasks such as preparing meals or making coffee gave the participants the opportunity to use their skills:

“I am good at making coffee. It is not like in a hotel, there you cannot make coffee yourself. I thought it was good that I could do that, making coffee. I like to make coffee. And I make a very good coffee, the others like to drink it.” – Ilse

“That day we also peeled potatoes on the ship, that I have never done before. Peeling potatoes on a ship, also nice. I am also good at that. And we made salad, peeled cucumbers and cut them. Yes, we made salad on the ship, that was also nice. And we ate it in the evening. Was something different, peeling and cutting cucumber on a ship. Was also great. Never done that before.” – Ilse

The identified factors that hinder mastery and imply limitations for the participants almost all arise from the category “body functions”, with the strongest match in the subcategory “sensory functions and pain”. Practically speaking, this categorization translates pain in the hands and hurting muscles as a result from physically demanding sailing tasks such as pulling ropes or turning the steering wheel:

“It was exhausting for the arms. Like a tennis elbow. You can really feel it. I already have problems with it anyways, it was very difficult. So exhausting for the arms, that was not easy. It wasn’t easy, it was quite difficult. I tell you, I feel the tennis elbow. With the steering you have to push against it, that wasn’t easy. My hand is still hurting now, from the steering wheel. I still notice it here at home that it hurts, my hand. With the spasticity, I still feel it today.” – Ilse

“With sailing, when you had to pull the sails to the inside of the boat – I did that a few times, and after some time it was okay. But I really thought “oh, my poor hands”. Because you have to pull, and then you get pain in your hands. It is really hurting your hands.” – Lena

4.2.3. Autonomy

Compared to the other mechanisms, autonomy receives relatively little attention in the narratives of the participants, with 8 supportive and 2 hindering situations mentioned. The supporting elements divide equally between “activity and participation” and “environmental factors”.

One example where the participants experience autonomy is related to the self-catering situation during the vacation week, falling into the subcategory “domestic life” in “activity and participation”:

“In the house where we stayed we took care of the food ourselves. With breakfast, we made the breakfast ourselves. And after breakfast we had to clear the table. We had a big dishwasher where we stacked the plates, and then closed the dishwasher. So we took care of ourselves, that was good. I liked that. I like it when you have to do things yourself.” – Ilse

“In the apartment, upstairs we could have cooked by ourselves as well, taking care of ourselves, so to say. That was also possible. You didn’t have to cook downstairs if you didn’t feel like. But we did cook together downstairs, which was also nice. That we cooked ourselves, prepared the meals ourselves, and of course we also had to do the dishes ourselves.” – Alexander

Also during the sailing excursions, for example to a small island where the group spent the day with playing games and having a barbecue, the participants had the feeling that they were free to choose what to do:

“This was the barbeque. [...] That was actually nice as well. You could also just do the things you wanted to do. You could play, but you could also simply sit in the sun and enjoy. That is what I mean. That you did not have any duties, but that you could move around freely and use the time we had for oneself. Very nice, that was good. That you could also retreat from the group. Or play along.” – Alexander



Regarding environmental factors, the facilities of the accommodation that belong to the subcategory “products and technology” also enabled autonomous behavior:

“I liked the bathrooms a lot, they were very nice. And the elevator was very nice. The rooms were very big for two people. And in the bathroom, there was an accessible shower, a shower chair where Alexander can sit down. Because otherwise he cannot shower. Otherwise he would have to stand.” – Tina

4.2.4. Affiliation

Affiliation is the mechanism that appears the most often in the participants’ stories, compared to the others. It adds up to 27 counts in the category “activity and participation”, 21 of them with a facilitating effect, and 19 counts in the category “environmental factors”, with no hindering effect detected at all. In both categories, the shares accumulate within the subcategory that are naturally associated with social relationships. These are “interpersonal interactions and relationships” representing active engagement with others, and “support and relationships”, signifying passive feelings of relatedness as an element of the individual’s social environment.

As all participants spent the vacation together with their partner (Alexander and Tina, Ilse and Hans, Lena and Thomas), spending time together as a couple was the most prominent theme that strengthened the mechanism of affiliation. The photographing assignment served as a popular means to get involved with both partners and peers:

“Here I photographed Hans and Ilse because they looked so nice. And because they are also a



couple. Hans and Ilse are also a very good couple. They fit well together. Was really good, to be together with couples. That you are together. When you are together you can help each other. And I like it, when Alexander is there. Then we are a couple. Like Hans and Ilse, like they are a couple, and Lena and Thomas as well.” – Tina

“This in my boyfriend, this is Hans. He is important to me, my boyfriend. I thought it was great that we were with all the couples. Was something different. I have never been sailing with him. We went sailing for the first time. And that as great, that we went sailing together.” – Ilse

“Who is that, Alexander? Yes, here we took pictures of each other. To see who is faster. That was funny. He got me and I got him. That was really funny. Alexander is also a guy who likes to make jokes. He is kidding you without you noticing. I believe everything he says.” – Ilse



“Thomas with his mmmh [makes kissing sounds]. With Thomas I thought, now you have to photograph him. Because it always looks so funny when he is doing this. I always find it funny. [...] Because with Thomas, we both get along really well, let’s say. Otherwise he would not... you saw it yourself, how much he is attached to me. You can see that. I mean, he likes me and I like him.” – Lena

Also the relationship with and among the supervisors of the Facility who joined the trip, and the crew members from the Organization played an important role in the narratives as supporting factors during the holiday:

“With Marie and Tanja [supervisors of the Facility], there was a nice harmony. The get along well, and you could talk to them easily. They were one team. Peter, Marie and Tanja were one Team, you could see that they could work together. I mean, it can also happen that a team does not work well together, and then you notice when a bad mood is coming up. I always notice when there is a bad mood, that you start shouting at each other or so, and that didn’t happen at all.” – Alexander

The general group spirit during the holiday was experienced as a positive element by the group members:

“Yes, it was all very, very nice with the others. We all got along really, really well. I didn’t expect that, actually.” – Lena

“Like a box, you have to fit together.” – Alexander

However, this did not always seem to be an easy and smooth process. The participants also describe a number of situations that challenged the positive group spirit and appear to constrain the psychological mechanism of affiliation.

The vacation was structured in such a way that the participants spent almost every entire day together as one group, with group excursions during the day and group meals for breakfast, lunch, and dinner. Time to be spent individually was limited to the mornings before breakfast, the time in the afternoon between returning from the excursion and eating dinner, and the late evening after dinner. During the day, the naturally restricted space on the boat left very little room to retreat from the group for a moment. Dealing with this close continuous contact with the other participants was stressed by the behavior of one specific group member, Mario (pseudonym), a young man with an intellectual disability who only recently moved to the Facility and was still in the process of accustoming to his new social surroundings. Especially in new situations like going on a vacation with a relatively new social group to a new environment, he has difficulties to adapt and his insecurity manifests itself in vociferous and uninterrupted monologues. For Mario himself it was very difficult to control his behavior and the other group members had to find ways to deal with it:

“It is a problem that you cannot change, but you have to deal with it. You cannot change it, but that person still has to learn a lot, let’s say. It is a difficult process, that was also very exhausting for the group. You noticed that people lost their patience, that they didn’t want to listen to him anymore. That people were stressed. [...] There is a certain line that you need to draw, where it doesn’t go any further. Where you are fed up. A red line. That is the line where I tell myself to leave, but on the ship that was not possible. But then I would say: “Mario, leave me alone.” That is how I deal with it. [...] Sometimes there is some trouble. You had to be very considerate of the others, that was very difficult for me. Very considerate to get through the week and then you are happy to be back home where you have some peace and quiet. ” – Alexander

“With Mario, it was not so nice. Because he is very loud. And he goes on and on. And he tramples like an elephant.” – Tina

“Well, he is a chatterbox, or how you would say that. He jabbers and jabbers and jabbers, such a jabber-head. You get a headache from that. I have to cover my ears from time to time. Just so that I don’t hear him anymore. Even Marie asked him to be quiet. At some point it’s enough. I mean, he also just keeps on saying the same things. At some point, you cannot hear that anymore.” – Ilse

4.2.5. Detachment-recovery

After affiliation, the mechanism of detachment and recovery is the second strongest mechanism appearing in the accounts of the participants. The matches with ICF categories are relatively evenly distributed between “community, social and civic life” (14 counts) in “activity and participation” (15 in total), and “natural environment and human-made changes to environment” (13 counts) in “environmental factors” (15 in total). The subcategory of “natural environment and human-made changes to environment” stands out in this relation as it only matches with detachment-recovery, and no other mechanism.

This element is characterized by descriptions of the landscape and built environment that the participants experience as “something different” that they normally don’t see at home. Moreover, the feeling of “being outside” and experiencing the natural environment, including sunny or rainy weather and natural elements such as the water, appears to enable feelings of detachment and recovery:

“Here we are on the ship and we are feeling the motion of the water. It’s rocking a bit up and down. That was still quite okay on the lake, going up and down. It wasn’t so bad, I really loved it. Wasn’t bad. [...] I felt very comfortable on the boat. Especially... I was often in the front, because there you could just forget all your thoughts and just enjoy. That was nice.” – Alexander



“Windmill! Those houses were also great, in Holland. How people live there. That’s amazing. Very different houses, you don’t see that here. How the live there, very different, also nice. They have really nice houses, directly at the water. They can watch the ships pass by. Those houses are nice, I took I nice photo of them, and of the windmill.” - Ilse

“The Beetle car is also nice, you don’t see that a lot anymore, the Beetle. I had to photograph it as well. You don’t see it anymore nowadays, a Beetle. I only saw it in Holland. Here you don’t see it. Was also really nice.” – Ilse



“Here we went out to have a drink. Because this you also don’t have in Germany. You also call it differently. How do you call it? Chocomel! Also nice. And delicious.” – Tina

According to theory, detachment-recovery refers to processes of detaching from work and recovering during leisure activities. One could argue that the holiday might be considered as one long phase of detachment-recovery, as it completely excludes the normal work duties and supposedly only includes leisure activities:

“I always like it that on holidays, you can just wind down. Wind down and do nothing. You actually go on holiday so that you can do nothing. And that is what I actually like about going on holidays.” – Lena

Even though the participants didn’t have to go to work, also in the holiday setting a distinction can be made between activities that are more stressful and demanding, and those that have a relaxing and recovering effect. It does not only include recovering from the more stressful life at home by and large, but also had direct implications in the immediate situations. Detachment in the holiday setting also meant detaching from the busy program and retreating from the group. Especially to Alexander, who is used to living alone and always having peace and quiet in his own space, this environmental factor was an important aspect, that the facilities of the house allowed:

“Also interesting, how the different parts of the house were also so nice, and easy to find, and not too complicated in a way. That the house was completely accessible, logically. Well it is not logically like that, it is special, I think. Special, I think, that there were even electric doors. And that you also had space to retreat. I really liked the house. I didn’t expect that, so big and great, all for us alone. And we could just close the door, then we were alone. Then we were alone and could retreat for a moment. Very good that that was possible.” – Alexander

In addition, the reinforcement of the mechanism of detachment-recovery evoked by the involvement in activities and the confrontation with new environmental factors also worked as a distraction from bodily problems:

“We also had breakfast on the ship, and there I kept the break inside. I had two slices of bread. I didn’t spit it out. I kept it inside. I was really relaxed on the ship. There I didn’t throw up. No, I felt really nice and relaxed. Was also a change for once, sailing. I didn’t even think any more about spitting it out. That was also some progress that I made, what I achieved there. It was not easy, somehow, I did have the urge, but I kept it inside. On the ship.” – Ilse

4.2.6. Meaning

With a total count of 6, meaning is the least represented the mechanism in the narratives of the participants, scoring twice in “Learning and applying knowledge” and “Community, social and civic life”.

The participants gain a feeling of purpose in actively helping with setting sail and having a task, rather than just passively taking part:

“It was nice that you could do something. Could help with the sailing. That you were busy and could help, and contribute. And sometimes steer.” – Tina

Alexander puts the experience of sailing as a disabled person into a meaningful bigger picture:

“Sailing is something that frees you. Sailing means freedom, and I think that’s really nice, because you can learn a lot of things. You learn things, also from each other. And you can show that, doesn’t matter if you have a handicap or not, you can sail. Even if you have a handicap. That’s what I mean. That is why I find it very good and very interesting. That you can see: Oh, people with disabilities can sail anyways! I think that you don’t see that so often. It is unusual. At least that’s what I think. And there are not many tour operators that are doing that. And the Organization is a very good tour operator. You are doing a lot and you are all working together in a group, so to say.” – Alexander

4.3. Comparison and discussion

To be able to compare the two sets of data from the home and the holiday setting, the total counts were converted into percentages. This was necessary because during the data collection phase on holiday, apart from Alexander all participants took more photographs on holiday than at home. This

pattern has also been recognized in other studies on tourist photography (Gillet et al., 2016) and can be explained by the notion that on holiday photography is a culturally established and expected behavior that the participants might as well have shown even if the researcher did not specifically instruct them. People tend to take photos at home significantly less often (Gillet et al., 2016) if nothing special is happening. Also in this project, even though the researcher reminded the participants every morning to use their camera, in some occasions the participants simply forgot to take pictures because it is not something that they usually do at home. Another explanation indicated by the participants is that they enjoyed the photographing exercise at home and were eager to show their photographing skills in their vacation week.

As all photographs that the participants took were addressed in the narrative interviews, any categorical item of the ICF could appear more often in the data generated on holiday than in the data generated at home, but this does not necessarily mean that the participants assign more importance to those photos. If a participant for example took 5 photos of windmills on holiday and talks about it 5 times, but only 1 photo of the local park and mentions it only once, this representation of landscape as an environmental factor can best be evaluated in relation to the total number of photographs they took on holiday and at home respectively. Changing the total counts to percentages indicates how much room the participants gave to each category and mechanism in their stories relative to the others. This resulted in the following overview of percentages in the distribution of ICF categories and psychological mechanisms:

ICF Component Level 1	ICF Component Level 2	At home %	On holiday %
Activity & participation	Learning and applying knowledge	3.2	0.8
	General tasks and demands	0.5	0.4
	Communication		
	Mobility	1.1	
	Self-care	4.2	
	Domestic life	3.2	3.6
	Interpersonal interactions and relationships	10	19.5
	Major life areas	11.6	
	Community, social and civic Life	18.4	15.9
Total activity & participation		52.1	40.2
Environmental factors	Products and technology	15.3	6.7
	Natural environment and human-made changes to environment	3.7	32.6
	Support and relationships	18.4	13.9
	Attitudes	0.5	
	Services, systems and policies	3.7	0.4
Total environmental factors		41.6	53.7
Body function	Mental functions	1.5	2
	Sensory functions and pain	1.1	2.4
	Voice and speech functions		
	Functions of the cardiovascular, haematological, immunological and respiratory Systems		
	Immunological and respiratory systems		
	Functions of the digestive, metabolic, endocrine systems		0.4
	Genitourinary and reproductive functions		
	Neuromusculoskeletal and movement-related functions	1.1	1.2
Functions of the skin and related structures			
Total body function		3.7	0.1
Body structure	Structure of the nervous system	1.1	
	The eye, ear and related Structures		
	Structures involved in voice and speech		
	Structure of the cardiovascular, immunological and respiratory systems		
	Structures related to the digestive, metabolic and endocrine systems		
	Structure related to genitourinary and reproductive systems		
	Structure related to movement	1.5	
	Skin and related structures		
Total body structure		2.6	0
Overall total		100	100

Table 5: Comparison of ICF components

Mechanism	Facilitating		Hindering	
	At home %	On holidays %	At home %	On holidays %
Mastery	13.2	6.4	2.6	3.6
Autonomy	7.9	4.2	3.2	0.8
Affiliation	10.5	15.9	1.1	2.4
Detachment-recovery	10	12.4	0	0.8
Meaning	11.1	2.4	1.1	0
Total	52.7	41.3	8	7.6

Table 6: Comparison of psychological mechanisms

To start from the bottom: in both settings, the participants hardly talked about their bodies, represented in the categories body function and body structure. The share of these two categories is even less on holiday than at home. This observation might be attributed to the experiences of novelty and excitement of the unfamiliar holiday setting that effectively distracts from the self and bodily problems, as Ilse describes in relation to the mechanism of detachment and recovery. From a theoretical perspective, Smith-Chandler and Swart (2014) address this issue when discussing methodological considerations in narrative disability research. They claim that we, as non-disabled researchers, expect the body to play a major role in the narratives of people with disability, because we construct the participant's identity from a non-disabled perspective, in which we might consider the disabled body as something unusual. For the participant however, this state forms the normal point of reference when thinking about the self, and possibly not even the most relevant one. Smith-Chandler and Swart therefore suggest that "foci on one aspect of the individual self (e.g., the physical body), rather than the construct of the uniqueness of an individualized identity that considers the human being as a holistic organism (physical, emotional, social, political, spiritual), might additionally fragment the disabled identity as a part object. This possibility adds to our contention that adopting a narrative inquiry approach, whereby participants are encouraged to coconstruct their personal experience stories (with emphasis on personal identity formation), is a way to counter such challenges" (Chandler and Swart, 2014: 242).

Looking at the distribution of the categories "activity and participation" and "environmental factors", the percentages show a reverse pattern: While "activity and participation" reach 52.1% at home, a similar share of 53.7% is reached by "environmental factors" on holiday. The same way, the 41.6% of "environmental factors" at home resembles the 40.2% of "activity and participation" on holiday. A closer look at scores in the different subcategories of the two components reveal possible explanations for this phenomenon.

One aspect of "activity and participation" that is present in the home setting, but completely absent in the holiday setting is the subcategory "major life areas". On the third level categorization that the ICF coding scheme provides, this area includes "education", "work and employment", and "economic life". Therefore, the reason for the absence of this item is a natural attribute of the holiday setting, in which the participants take time off from work and employment. Accordingly, the participants did not include work-related themes in their stories about their holiday. However, as work related activities contributed to some extent to the experience of mastery in the home setting, the absence of this factor in the holiday setting is reflected in the lower scores of facilitating opportunities for mastery on holiday (6.4%) in comparison to at home (13.2%). In both settings leisure activities are the most important facilitator of mastery, for example described by the participants as "feeling like an artist" when drawing

at home or “feeling like a captain” when steering the sailing boat on holiday. Nevertheless, the lack of accomplishments derived from work can apparently not be filled with other elements that might be unique to the holiday setting. A contributing factor could be that the activities performed by the participants on holiday, especially those related to sailing maneuvers, are mostly new to the participants and require more effort to master. The home setting offers more opportunities for practicing certain skills over a longer period of time, by doing the same tasks at work every day or following the same pottery class and choir practice every week. Another difference between the activities at home and on holiday that may be related to the difference in the perception of mastery is that at home all leisure activities are all freely chosen and it can be assumed that the participants mostly chose those activities that they are good at and therefore perceive as rewarding. This may also be the case for most activities experienced during the sailing holiday. Of course, the participants decided voluntarily to go on this specific trip, the weekly program is planned according to the wishes of the group, and no one is forced to help with sailing tasks. But as the holiday is set up in a group structure, all activities are to a certain extent predetermined and offer less room for individual preferences and planning compared to the completely open structure at home. This point also accounts for the difference in perceived autonomy at home and on holiday. The percentages of 7.9% and 4.2% suggest that autonomy is more readily facilitated at home than on holiday. Though also the crew members who are supervising the vacation stimulate autonomous behavior and encourage the participants to do as much as they can themselves, the home setting simply offers a wider range of life areas that facilitate autonomy because the participants spend less time as part of a group.

Closely related to this is the difference that can be detected within the category of “activity and participation” in the sub-category “interpersonal interactions and participation”, which scores almost twice as high on holiday (19.5%) than at home (10%). The cause of this change may be found in the group structure of the holidays in comparison to the individualized structure in the home setting. As the participants spent almost their entire vacation week as a group, they could constantly share their experiences and impressions with their peers in direct social interaction. In the home setting, they also spend time in groups, for example at work or during leisure activities, but in general every individual has their own daily planning and routine. Hereby the relationship with others takes the form of an environmental factor in the social environment of the person, as reflected in the shares of 18.4% in the category “support and relationships” at home, compared to 13.9% in the same category on holiday. The constant direct contact with the partner, peers, and supervisors also explains the higher score of facilitating elements for affiliation on holiday (15.9%) in comparison to at home (10.5%), as this psychological mechanism is directly linked to the ICF categories “interpersonal interactions and participation” and “support and relationships”. The data suggests that the participants experience

more feelings of belongingness on holiday, which may be caused by a sense of group spirit and the frequent opportunities for direct social interaction with people they feel attached to.

The share of 53.7% of environmental factors on holiday is mostly attributed to the sub-category “natural environment and human-made changes to environment”, making up 32.6%. This sub-category stands out because it scored only 3.7% in the home setting. It is the element that shows the biggest difference between the home and the holiday setting. This significant share indicates that the landscape, meaning the natural and built environment in the surroundings of the holiday setting, plays a major role in the holiday experience of the participants, translated to seeing something new that does not exist at home. Though most text units that were included in this category are a mere description of the surrounding landscape, this point may explain the difference between the scores in detachment-recovery with 10% at home and 12.4% on holiday. The peace and quiet of the home environment provides space for recovering from work, but the natural landscape and climate of the holiday environment, which can be experienced with all senses, seems to add in a unique way to the process of detaching from home.

5. Conclusion

This research project set out for answering the following research question:

How do people with disabilities experience the relationship between the components of the ICF, namely body structures, body functions, activity and participation, and environmental factors, and the psychological mechanisms of detachment-recovery, autonomy, mastery, meaning, and affiliation at home in comparison to a holiday setting?

To approach this question, the research project used a qualitative case study design to gain in-depth insights into the experiences of four individuals with disabilities. The four participants of this study live in a facility for assisted living in Germany and went on a week-long sailing vacation in the Netherlands provided by a tour operator specialized in assisted water sport vacations. The data collection methods employed in this project were participant observation and narrative interviews supported by photo elicitation, using photographs that the participants took themselves to document their daily life at home and their holiday experiences. The narratives produced in relation to the home setting and the holiday setting were subsequently analyzed using the ICF categories as a framework. In the last step of the analysis the text units that were assigned to the ICF categories were investigated for matches with the psychological mechanisms of mastery, autonomy, affiliation, detachment-recovery and meaning.

The analysis of data showed that in both the holiday and the home setting the two categories “activity and participation” and “environmental factors” take up much more room in the stories of the participants than “body functions” and “body structures”. This indicates that the participants assign almost equal importance to their physical and social environment as to their daily activities related to social interaction, work, leisure, and domestic life, while their bodily conditions receive only little or no attention.

Both settings offered a wide range of facilitators for experiencing each of the five mechanisms. In all individual cases, as well as in total, the different ICF components are more facilitating than hindering the mechanisms in both the home and the holiday setting. A few major differences between the home and the holiday setting could be detected:

- Mastery scores twice as high at home than on holiday:
The participants “master” their professional work in the environment of the sheltered workshop well – and enjoy this. They also select leisure activities at their home setting which they master well. Compared to these day-to-day experiences of success the holiday setting

provides less opportunities for “mastering” activities. Nevertheless, where possible these activities were perceived very positively.

- Autonomy at home scores nearly double compared to the holiday setting:
This can be explained by the day-to-day environment in which the participants strive for the maximum possible autonomy. During holiday the daily programs are structured by the vacation provider and autonomy of the individual participant is somewhat limited.
- Affiliation scores 50% higher on holiday than at home:
- In the holiday setting, nearly the whole time was spent together – whereas in the home setting the participants spend a significant amount of time alone. The more intensive social contact to others on holiday offers more opportunities to share lived experiences.
- Detachment-recovery scores about 25% higher on holiday compared to the home setting:
During a holiday setting detachment-recovery should be higher because leisure time spent away from work and the normal day-to-day environment focuses on detachment-recovery. The home-setting nevertheless provides significant time and activities for detachment-recovery. Therefore, the difference between holiday setting and home setting is not significant, though the participants clearly enjoy the change of physical environment makes them feel detached from home.
- Meaning scores about five times higher at home than on holiday:
This large difference can be related to the perception of the participants of meaningful work at their workplaces and specifically selected leisure activities at the home setting. At the holiday setting the activities are not per se meaningful to the participants; activities are group activities and therefore foster affiliation, but are somehow limited in their deeper meaning to the individual.

It can be concluded from the above-mentioned results that the way people with disabilities experience a holiday strongly depends on the circumstances they are used to at home. In the presented case study, the psychological mechanisms of mastery, autonomy, affiliation, detachment-recovery, and meaning are not experienced more intensively on holidays than at home, even though this is what the literature suggests and what the Sailing Organization aims for. The reason for this is that the participants come from a home environment that already very intensively stimulates these mechanisms, so that the difference between the home and the holiday environment is not so big. It can be assumed that people who normally live in a very dull, unchallenging, and unstimulating environment – which might very well be the case for other facilities for assisted living in Germany and the Netherlands – experience the tours offered by the Sailing Organization much more empowering and inspiring.

5.1. Recommendations

The presented study has combined the International Classification of Functioning and Health with theories on psychological well-being in a unique way and proposed an innovative method for analyzing how different environments influence the perceived well-being of people with disabilities. As this was the first explorative study to make use of the presented form of analysis, it opens up a wide range of opportunities to further test its practical application. For tour operators such as the Sailing Organization it would be interesting to further develop this scheme for statistical analysis, so that it could be applied to investigate the holiday experiences of larger groups of clients to optimize the visitors' experiences. Moreover, as this exploratory study was limited to the in-depth analysis of four individual cases in the given environment of the home facility in Germany and the sailing vacation in the Netherlands, it would be interesting to employ with same methods with different groups of people. This way the conclusion that the way people with disabilities experience a holiday strongly depends on the circumstances they are used to at home could be explored further to understand how and why this might be the case for different groups of people.

At first sight the results of this study may appear disappointing to the Sailing Organization if they are interpreted in such a way that a lot of effort is made with little effect for the participants. However, this might be the wrong way to look at it – the Sailing Organization does a great job with their work as they accomplish to not disappoint a group of participants who are innately used to a very stimulating and supportive environment. The fact that they can match the high standards of the residents and supervisors from this specific assisted living facility in Germany of treating people with disabilities makes a holiday with this tour operator attractive for such groups. However, the goals mentioned by the Sailing Organization, namely contributing to the development of empowerment, autonomy, and independence of people with disabilities by pushing their boundaries by means of engaging them in water sports, can be reached more effectively if the difference to the home environment is bigger. If the boundary is already far ahead, it is hard to push it even further. Accordingly, recommendation for the Sailing Organization could be to optimize their marketing strategies to specifically target people who live in unchallenging and unstimulating circumstances, so that a more significant effect can be achieved.

5.2. Reflection

Though it is the first time the researcher conducted scientific research with and on people with a disability, she was already experienced in working and communicating with people with intellectual disabilities, as she is regularly involved in integrative summer camps of a youth organization in Germany. Moreover, she has three adopted brothers and one sister who all suffer from fetal alcohol

spectrum disorder, who live in a similar assisted living institution in Germany. The type of setting was therefore not unfamiliar to her and throughout the research process she was able to draw on her earlier experiences in both fields of institutional assisted living and assisted holidays.

After initial contact with the residents of the Facility was supported by a mediator, one of the supervisors working there, the trust grew very quickly. While most participants first insisted on doing group interviews instead of alone with the researcher, at the end of the week all of them agreed to have individual interviews. For one participant, at the end of the home week the mediator was present during the interview for her confidence, because she is very shy and doesn't easily open up to strangers. But at the end of the sailing week, also she felt comfortable with doing an individual interview alone with the researcher. At the end of the home week the mediator gave feedback to the researcher, that she thought everything went very well and that the researcher treated the participants with respect and interest. The successful first data collection phase in the Facility was very useful for building up a good relationship with the participants, so that the participants were even looking forward to the researcher joining their holiday. As the participants were already familiar with the researcher as well as with the photographing assignment at the beginning of the holiday, the distraction caused by the project could be minimized, so that the participants could still enjoy their holiday to the fullest. In fact, the photographing assignment seemed to give added value to their holiday. It was experienced as a fun social interaction, and as a way to appreciate the moment even more by capturing it. Only one of the participants owned a camera before, and at least one other was so enthusiastic about photographing that she repeatedly told the researcher throughout the week that she will buy one herself as well when she is back home.

The method of photo elicitation proved to be very useful during the interviewing process. The photos helped the participants to remember what all happened during the week, that they already forgot about. Another positive effect of structuring the interviews this way was that it made the participants stick to the topic. Especially one participant often wandered off in her story to tell about the past and issues that had nothing to do with the current situation, but once she went to the next photograph, she was back on track.

The method of using photography was a great way to attract the attention of the participants to the research at hand. It made people feel involved. It was interactive, they could actively contribute, and the responsibility for which topics would be addressed in the interviews was in their hands. Last, it offered a very round frame to embed the research process in, ending with a photo album that the participants could keep as a tangible memory of the project.

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Appendices

Appendix 1: Confirmation of ethical clearance



WAGENINGEN UNIVERSITY
WAGENINGEN UR

For quality of life

Ethical Clearance

To whom it may concern

The following project proposal has been reviewed by the Social Sciences Ethics Committee (SEC):

Applicants: Paulina Schmitz, Meghann Ormond, Pieter Nel
Cremers
Title of the research project: Enabling happiness at home and on holidays – The impact of sailing vacations on the subjective well-being of people with a disability
Location: Germany; Netherlands
Funding sources: Science Shop Wageningen
Period: 01.03.2016 – 30.09.2016

The Committee has concluded that the proposal deals with ethical issues in a satisfactory way and that it complies with the Netherlands Code of Conduct for Scientific Practice.

With kind regards,

A handwritten signature in black ink, appearing to read 'M. Verweij', written over a light blue horizontal line.

Prof. Dr Marcel Verweij
Chair Social Sciences Ethics Committee

DATE
29-06-2016

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Wageningen UR (Wageningen University and various research institutes) is specialised in the domain of healthy food and living environment.

Appendix 2: Information letter

Dear participant, parent or legal guardian,

Thank you for your interest in this research project! In this information letter I hope to answer your most important questions about the project. If anything is unclear or if you have any other concerns, feel free to contact me, Paulina Schmitz, or (*name assisted living facility coordinator*)

Paulina Schmitz
coordinator

German phone number
Dutch phone number
email address

Name assisted living facility

phone number
email address

What is it all about?

This is a research project initiated by (*name of the Organization*) because they would like to know more about the added value that their sailing holidays have for their participants.

This project examines how people with a disability experience subjective well-being at home and on vacation by identifying and comparing how the different psychological mechanisms of detachment-recovery, autonomy, mastery, meaning, and affiliation are at work and contribute to their sense of well-being in the two different settings.

Who is doing this?

The research project will be organized together with (*name of the Organization*) and Wageningen University.

I am Paulina Schmitz, and I am a 24-year-old student at Wageningen University in the master's program Leisure, Tourism and Environment. This research project is part of my master's thesis, and when it is finished I will graduate from the university with a master's degree.

I come from a small village in Western Germany near Düsseldorf, and I have myself three adopted brothers and one sister with fetal alcohol spectrum disorder. Growing up together with them, I have seen a lot of challenges they had to face due to their disability and I am keen to explore how holiday trips, such as the sailing week with (*name of the Organization*), can influence the feeling of well-being of people with a disability.

What can the participants expect?

I would like to visit the participants in the institution and spend the week with them, accompanying people during their work and leisure activities. During this time, I would like to ask the participants to document their daily lives with the help of a digital photo camera that they will receive from me. At the end of the week I would like to interview each participant and use the photos they took as a point of departure for discussion.

During the sailing week with (*name of the Organization*) I would like to repeat the same procedure of joining the group, asking the participants to take pictures and interviewing them at the end. As there is only a limited number of spots available on the ship, I will stay in the accommodation and join the group only in the mornings and evenings. Of course I will make sure that the research project will not get in the way of participants enjoying the sailing vacation to the fullest.

Last, I would like to visit the group in Germany again 3-4 weeks after their trip in order to talk about what I found out and to reflect together with the participants on my preliminary findings. The exact date for this is still open.

On behalf of the institutional team, (*name assisted living facility coordinator*) will accompany the project from the beginning till the end, including my week in Germany, the sailing week, and the reflection session at the end of the project. She will keep an eye on what is going on and function as a mediator between me and the participants whenever necessary.

Is it voluntary?

Yes, the participation in this project is completely voluntary. In case a participant feels uncomfortable at any point, for example if the project keeps him or her too much from fully enjoying the vacation, I will be glad to hear about it and I am sure we will together find a solution for the problem. If the participant prefers to not address me directly about it, (*name assisted living facility coordinator*) will be there to assist us during the entire project and participants can always turn to her for an open ear and help with concerns of any kind.

Always remember: Even if participants first agreed to take part in the research and later change their mind, they are free to leave the research project at any time if they wish to do so. There will be no negative consequences.

Is it confidential?

Yes. Participants can tell anyone they like about the research, but I will treat everything the participants say or show me as confidential. I will write about it in my report, but I will change the names of all participants and also not mention the institution by name.

If the participants agree, I would like to digitally record the interviews and transcribe them later in order to make it easier for me to recall what has been said. The audio recordings and written transcripts will be accessible only to me, my supervisors from Wageningen University (Dr Meghann Ormond and Pieterel Cremers), to the project coordinator of the WUR Science Shop (Dr Francien de Jonge), to the departmental chair (Prof Dr Claudio Minca), and to the departmental data manager (Dr Maarten Jacobs) who will ensure that the data is stored securely.

If photographs are integrated into my study report and eventual academic publications, I will ensure that they do not contain any identifying information (e.g. faces will be blurred). If (*name of the Organization*) wishes to use photographs that were produced in relation to this research project e.g. for marketing purposes, consent has to be requested from the participant who took the picture and the person(s) in the picture and, where applicable, their legal guardian(s). You are guaranteed that no pictures of participants will be published without your express permission. Of course the participants are allowed to keep the photographs they take. Only the cameras will have to be returned at the end of the study.

The final report of the study will be distributed to Wageningen University, (*name of the Organization*) and (*name of the assisted living facility*), including the participants and, where applicable, their parents or legal guardians. The results may also be published in the form of an academic contribution.

I hope that I could address all your questions and concerns about the research project. I am sure that the project will be fun and that it will deliver a valuable contribution to sciences!

Groetjes (as the Dutch say),

Paulina Schmitz

Appendix 2: Information letter

Titel research project: Enabling happiness at home and on holidays – The impact of sailing vacations on the subjective well-being of people with a disability

Responsible researcher: Paulina Schmitz
Student
MSc Leisure, Tourism and Environment
Wageningen University

By signing this consent form, I, the study participant, agree that I...

- ✓ understand that participation in this research project is voluntary.
- ✓ understand that participation may be withdrawn at any point without negative consequences of any kind.
- ✓ understand that everything that will be said during the interviews may be used in the research report that will be written by Paulina.
- ✓ understand that no names or other identifying information will appear in the report.
- ✓ understand that photographs taken during the project may be used in the report. Images of people will be blurred to render them unrecognizable.
- ✓ understand that my permission must be requested and granted before any photographs can be used for a different purpose than the research report.
- ✓ have been well informed about the goals, methods, outcomes and risks of this research project.

Name participant: _____

Signature participant: _____ **Date:** _____

Signature parent/legal guardian (where applicable): _____ **Date:** _____

To be filled in by the responsible researcher

I have informed the participant and, where applicable, his or her parent or legal guardian about the goals, methods, outcomes and risks of the research. I agree to answer all questions before, during and after the project according to my best ability. I agree that the participant may withdraw from the research project at any point without negative consequences of any kind.

Name researcher: Paulina Schmitz

Signature researcher: _____ **Date:** _____