Master Thesis

The influence of specialized guided holidays on the empowerment of people with mild intellectual disabilities or autism spectrum disorders

Participant John parapenting off the Swiss mountain side for the first time in his life

February 2015

MSc Leisure, Tourism and Environment

GEO-80436

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The influence of specialized guided holidays on the empowerment of people with mild intellectual disabilities or autism spectrum disorders

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February 2015

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“If you imagine you can, you might.

If you imagine you can’t, you never will.”

(Anon.)

“A new location, offers new possibilities!”

(Flow Reizen)

“Perhaps I wouldn’t have climbed it at all, I wouldn’t have dared to at all. And now I try, I like to see how it goes. Back then I would have immediately thought ‘no, I can’t do that’.”

(Bram)

Personal note and acknowledgments

When I started thinking about a thesis topic two years ago there was one thing I knew for sure: it had to have something to do with people with a mild intellectual disability or autism, and preferably they had to play a big role in the research. However, when I started my master degree in Wageningen in 2011 my intention was to really specialize myself in the relationship between nature and people. Combining these two interests led to my initial thesis topic: the influence nature has on people with a mild intellectual disability. But somehow this just did not come together the way I had imagined. My supervisor, Meghann Ormond, then pointed out that my work as a tour guide for people with mild intellectual disabilities, offered a unique opportunity. Every summer, when guiding trips for Flow Reizen, I am surrounded by a group of possible research participants. This realization caused a very positive change in my thesis work and resulted immediately in a lot of energy and motivation. The mission of Flow Reizen: to improve independence and trust by experimenting with the abilities of people with a mild intellectual disability, had always inspired me, and led me to dive into this topic.

And here we are, one year later, with this thesis as the result of a lot of hard work (and tears), but also a lot of fun (and laughs). I could not have written this thesis without the help of so many amazing people around me. There are several people I would like to thank for their support and advice during the past year, making this thesis a professional and personal success. I could not have done this without you.

First of all, I would like to thank my supervisor, Meghann Ormond, for her amazing support. You have helped me to keep believing in myself. Your advice and support, but most of all your enthusiasm, has helped me through some difficult moments. It was great to know that I could always ask for your help and that you always took the time to get me through and get me smiling again. I will miss having ‘verse muntthee’ together at Café Orloff. Thanks for all you have taught me.

I would also like to thank my sister, Leontien Cremers, for spending most of her maternity leave reading my thesis proposal chapters and for reassuring me along the way that it was all going to be fine. You were right, sis! Thanks!

This thesis would not exist without the willingness and enthusiasm of the participants in this study. A big thank you to: Bram, Thom, John, Sarah, Benny, Harrie, Max, Martin, Frits, Matthijs, Sander, Sylvia and Liesbeth, for making time for me during your holiday and share your stories and experiences with me. I wish you all the best and many more happy holidays.

In addition, a word of thanks to the office staff and guides from Flow Reizen. I am blessed to have one of the best jobs in the world and even more blessed with so many amazing people as my colleagues. A special thanks to Martijn Riswick for his enthusiasm and help whenever I needed information from Flow Reizen. And Hinno, Kimberley, Janise, Thiro, Else, Sam en Sonja, thanks for letting me carry out my research during our trips this summer.

Finally, I would like to thank my friends and family, and, Rick in particular. You have been so patient and supportive, I know it has not been easy. Thank you all for standing by me.

Executive summary

Due to changes in governmental policy and changes in paradigms, it has become much more important for people with disabilities to be able to fully participate in Dutch society. There has been a fair bit of research on people with *physical* disabilities and how to improve their leisure and tourism experiences, but the area of leisure and tourism experiences for people with mild intellectual disabilities (MID) and Autism Spectrum Disorders (ASD) is one that still needs further exploration. To be able to better serve this group of people and to improve their sense of empowerment should positively influence the position of people with MID and ASD in society, with as result having equal opportunities to other members of society. However, what it is that people with MID and ASD want for themselves, is mostly neglected in all three dominant paradigms of disability studies (defect, development, and citizenship paradigm). Therefore, this study has the following research objective:

To study how Dutch people with a mild intellectual disability or autism spectrum disorder themselves, instead of experts, professionals or parents telling it on their behalf, experience specialized guided holidays in Europe, and identify how the different elements of their holiday contribute to - and whether elements can be improved to enhance - their sense of empowerment, which will contribute to their equal participation in society.

The following sub questions were used to answer the main research question of this research:

1. Who are the people participating and how do they characterize their MID or ASD and their position in society?
2. What kind of elements make up the specialized guided holiday experience and how can they be characterized?
3. In what ways do these different elements influence the participants?
4. How can these experiences be characterized relative to the defect, development, and citizenship paradigm?
5. What elements are considered most empowering by participants and what improvements can still be made to enhance this sense of empowerment?

The methodology chosen for this study is a qualitative case study. The fieldwork was carried out during four trips of Dutch tour operator Flow Reizen during the summer of 2014. Data was collected from 13 participants by means of structured interviews, participant observation and photo-elicitation. This data was analyzed by means of segmenting the data into parts and reassembling them into a coherent whole. The different phases of a leisure experience (anticipation, travel to, on-site activities, return travel and recollection) were used to provide structure to the findings.

This study shows that each of the five phases of specialized guided holidays consists of many different elements that offer opportunities for people with MID and ASD to improve their sense of empowerment. It also shows that all three paradigms are still visible within present-day tourism leisure experiences for people with MID and ASD. The influences of the citizenship paradigm are most prominent, which is in line with the developments in Dutch society in general.

This study tries to answer a question that is related to the call of 'world-making'. 'World-making' gives people with MID and ASD a chance to have their say and by doing so influence their way of living. To come to a society with more equality and better understanding for each other, it is recommended to continue this type of research.

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List of abbreviations, tables and figures

Abbreviations

AAID - American Association on Intellectual and Developmental Disabilities

AAMR - American Association on Mental Retardation

APA - American Psychiatric Association

ASD – Autism Spectrum Disorder

CDTE - Consumer-Directed Theory of Empowerment

DSM - Diagnostic and Statistical Manual of Mental Disorders

ICD-10 - International Statistical Classification of Diseases and Related Health Problems

MID - Mild Intellectual Disabilities

NBAV - Nederlandse Branchevereniging Aangepaste Vakanties (Dutch branch union for customized holidays

PDD – Pervasive Developmental Disorder

PDD-NOS – Pervasive Developmental Disorder- Not Otherwise Specified

SCP – Sociaal Plan Bureau (The Netherlands institute for Social Research)

WHO - World Health Organization

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1. Introduction

There are no exact numbers of people with mild intellectual disabilities (MID) and autism living in The Netherlands, but according to the Sociaal en Cultureel Planbureau (SCP, The Netherlands institute for Social Research) The Netherlands has around 110,000 people with a MID (SCP, n.d.). The number of people with autism in The Netherlands is based on research carried out abroad. But it is expected that of the 4 million people less than 20 years old living in The Netherlands, at least 11,000 have an autism spectrum disorder (ASD), also called pervasive developmental disorder (PDD). Recent research, with a broader set-up, even shows that at least 25,000 children in The Netherlands suffer from an ASD (van den Berg, et al., 2004). It is clear, however, that due to societal changes and paradigm shifts people with MID and ASD are starting to participate more and more in Dutch society. This can be seen in living arrangements, job opportunities and spending leisure time. All these changes do not occur without a shrug. Over the past few years, people with MID and ASD have been the topic of quite a bit of research, but there is still a lot to be explored about what it is they want and need. The area of leisure time and people with MID and ASD is one that still needs further exploration to be able to better serve this group of people and by doing so improve their role and position within Dutch society. This study hopes to contribute in this exploration.

Here I combine two of my passions and fields of expertise: working with people with MID and ASD and tourism studies. This combination led to this study about how people with a MID and ASD, who participate in a specialized guided holiday, experience different elements of their holiday and how these influence their sense of empowerment. This research was carried out during four trips that I guided for the tour operator Flow Reizen during the summer of 2014. What follows in this chapter is some background information on this tour operator and its mission. Then a more general perspective is used to clarify the problem statement for this thesis, which will lead to the overall thesis objective. I then present an overview of the report.

1.1 Background information

Flow Reizen is a Dutch company set up 24 years ago by Richard Ruiter and Roger Olislagers. They wanted to create a link between recreation, improvement of well-being and people with mild intellectual disabilities and other minorities within society. Their wish was to provide active and adventurous holidays as an addition to the already existing holiday market and give this group of people the opportunity to experiment with their own abilities. By doing so, they believe that independence and trust can be improved. They believe that recreation offers the perfect situation for this, because people are more relaxed, free of daily life constraints and are more open to change. For three years they carried out extensive research for the set-up of their own company and during this time they also visited the Calvert Trust in Keswick (United Kingdom), which had been carrying out these kinds of activities since 1978.

The Calvert Trust is an idea of John Fryer-Spedding, whose vision was to enable people with disabilities to benefit from outdoor activities in the countryside. He realized that, even though Harold McMillan (U.K. Prime Minister) had claimed in 1951 that *"National Parks are for all people for all time"*, this was not quite true in reality. He got together with some other like-minded people and it did not take long before they made the decision to set up a Trust. The Fryer-Spedding family donated two family farmsteads and in 1978 the Little Crosthwaite Adventure Centre was formally opened. Back then the centre had just one warden, a secretary, one instructor, two horses and two dinghies. Today the centre employs 35 permanent staff and has many more facilities. They welcome over

3,000 people every year. This success resulted in two more locations being opened in Kielder (1984) and Exmoor (1996). The Calvert Trust continues to concentrate on challenging disability through outdoor adventure and helping their visitors find out *"it is what you can do that counts"*.

Ruiter and Olislagers were very inspired by this Trust and their way of thinking and decided to do a couple of try-outs for the Dutch market. These were very successful and inspired them to continue with their idea. In 1995 their first official brochure came out offering 3 active trips to the Ardennes (Belgium). Now, in 2014, they offer 66 summer holidays to different places in and outside of Europe, both active and more relaxed (sun and sea). In winter they offer around 15 winter holidays, including skiing/snowboarding holidays and city breaks. New trips and destinations are introduced every year. Flow Reizen distinguishes itself from other organizations in The Netherlands by the following points:

- Flow Reizen only targets people with mild intellectual disabilities who can handle 1 to 5 guidance (moderate or severe intellectual disabilities or physical disabilities require a completely different approach and more attention)
- Flow Reizen works with professional, well-trained staff, who are getting paid to do their job. This results in young, active and enthusiastic staff, which is highly appreciated by most participants. (Most other organizations work with volunteers, which results in older people guiding the trips, because they can often afford the unpaid time)
- Flow Reizen offers a get-together before and after the summer. During the pre-summer get-together participants can get to know each other, their guides, and talk about their upcoming holiday together, which can take away some of the anxiety participants might have, but it is also just nice to have some pre-fun. After the summer there is the yearly reunion during which the different holiday groups get together again and exchange stories, memories and/or photos and party to the music of the Flow band afterwards.

In 2012 I started working as a guide for Flow Reizen and I was inspired and intrigued right from the start about the influence these holidays seemed to have on participants. I noticed the reaction from so many people around me who were surprised about this group of people taking these kinds of holidays and often seemed to doubt their capabilities to do so. Also during the holidays I regularly encountered situations which clearly showed society did not seem to be ready for people with MID and ASD to fully participate in daily life at the destination and in certain leisure activities. And to be honest, participants sometimes also surprised me by doing or wanting certain things, which made me realize that even I sometimes doubted their capabilities or did not seem to be ready to recognize them as complete equals. These encounters and thoughts made me think about how participants would experience this and what influence this would have on them. I fully embrace the idea of Flow Reizen that, by experimenting with their abilities, trust and independence of people with intellectual disabilities can be improved. At the same time I also realize that this is something that we, as 'normal' people, like people with MID and ASD to be able to achieve, but that we are not sure whether they really want the same. Changes in society mean that care for people with disabilities has also changed and will keep on changing over the years to come. The focus is now on a participatory society in which citizens should become more involved in society and take on a more democratic attitude (Hooijmans, 2012). The Wet op Maatschappelijke Ondersteuning (Social Support Act), which got introduced in 2007, set in motion the decentralization of care and support responsibilities, These now lie with city councils instead of national government, which should result in care and support that is better tailored to the individual and making it possible for this individual to participate in society longer, by staying in his/her own home instead of going to care facilities. The Act calls upon the ability of Dutch society to support and care for their fellow members of that society and by doing so ensuring that also the more vulnerable people, such as elderly and people with disabilities, can participate as much as possible in their society (Koops & Kwekkeboom, 2005). This participation also counts for people with intellectual disabilities. A nice example of this participation and acceptation was the first appearance of a special square at the holiday fair held in Utrecht in January 2015, where organizations offering holiday products for people with disabilities could present themselves. This is only a small start, because so far there is not enough information known about what this group of people really want and how they can participate more in society and tourism leisure experiences. This made me want to get to know more about this topic and the seed for this thesis research had been planted.

1.2 Problem statement

Bregha (1985) considers leisure as the most precious expression of our freedom, which makes it clear that leisure is an inalienable human right (Dattilo, 2002). However, in our Western culture the most valued 'human' characteristics are profoundly biased towards whiteness, maleness, wealth and a conception of rationality free of emotion. This is seen as 'normal' within our culture and is constructed against those identified as the 'Other' (Fullagar & Owler, 1998). Discourses of leisure and outdoor environments identify the 'Other', as women, lower socio-economic groups, older people, disabled people, and minority ethnic populations (Aitchison, 2003). As a result of this 'Othering', people with an intellectual disability have been excluded from the norm because of having less 'rational intelligence', in a society where intelligence acts as a measurement of humanness. Also people with ASD, who are often socially withdrawn, tend to be excluded from this norm. This has led to individuals with MID or ASD being positioned as the 'other', excluded and ridiculed as inferior or treated patronizingly as 'special' (Fullagar & Owler, 1998) and not getting the chance to participate in 'regular' leisure activities.

This has been changing over the last few decades with new paradigms on disability developing. After the defect and development paradigms, in the current citizenship paradigm it has become very important for people with MID and ASD to integrate more in society, on many different levels and in different kinds of activities. The defect, development and citizenship paradigms will be explained in more detail later on in this thesis. One of the things that has become very important for people with disabilities, is the right to have and spend their leisure time equal to people without disabilities. Because of this, it is important that leisure providers, care workers and family and friends make every effort to help people with disabilities to become involved in active leisure participation. The challenge lies in finding ways to remove barriers to participation while at the same time providing opportunities to develop the skills, awareness, and understanding needed to freely choose participation in various leisure experiences (Dattilo, 2002). To be able to do this, more research is needed to investigate the wants and needs of people with MID and ASD, with regards to their leisure experiences. Because of my work and my education in tourism studies, specialized guided holidays will be chosen as the type of leisure activity for this research. Tourism is defined as a subset of leisure that is only different from other leisure activities insofar as: a) some of the services tourists need (e.g. accommodation) are not needed in other leisure contexts; and b) tourists with disabilities, being away from their everyday life aids, practices and routines, may be more vulnerable to a lack of accessible services compared to people with disabilities in other leisure contexts (Nicolaisen, et al., 2012).

There has been a fair bit of research on people with *physical* disabilities and how to improve their leisure and tourism experiences (e.g. Stilling Blichfeldt &Nicolaisen, 2011; Burns et al., 2013; Kwai-sang Yau et al., 2004). This often results in taking away physical barriers and improving accessibility for, for example, blind people, people with walking difficulties or who are in a wheelchair. It is harder to find out what the barriers are or might be for people with MID and ASD, because these barriers cannot be seen directly or easily explained by this group. There is, therefore, still a gap in the research. The fact that MID and ASD come in many different forms also makes it hard, or even impossible, to tailor to all people with these kinds of disabilities or disorders. Even the same kind of disability or disorder can express itself differently per person. However, by exploring more what it is that individuals with MID and ASD want and need, small steps can be undertaken to improve their tourism leisure activities.

Over the last few years more research has been done on people with intellectual disabilities in relation to leisure activities, but very little is known yet on the views and experiences of outdoor activities of people with intellectual disabilities (Burns, et al., 2009). Also the body of literature about recreational participation for those with ASD is meager (Potvin, et al., 2013). And this while McGill (1996) states that leisure helps to describe how people view themselves (in Patterson & Peg, 2009). Fullagar & Owler argue that narratives of leisure are a powerful social medium with the potential to produce change in an individual's life and immediate social relationships. Through constructing a narrative we create our identity (Sacks, 1984, in Fullagar & Owler, 1998). An understanding of this narrative leads to getting to know the person's wants and needs, and is crucial for the development of alternative leisure support services, challenging the social positioning of people with an intellectual disability (Fullagar & Owler, 1998). It has been noted that people with learning disabilities tend to be the 'excluded voices' in contemporary research. Their stories have often been ignored, and thus their experience of service provision is silenced (Booth & Booth, 1996).

As an answer to this exclusion, more researchers are attempting to justify the living environment and way of 'world-making' by people with intellectual disabilities. These researchers focus on, for example, the way people with disabilities experience the physical and social environment and how they then perceive reality based on the results of that experience (Devlieger, van Hove & Renders, 2006) (Renders & Meininger, 2011). In all three disability paradigms (defect, development and citizenship paradigm) this 'world-making' of people with MID and ASD is mostly neglected and they are still expected to adapt to the standard that is set for the most dominant group in society, the 'normal' people. Renders & Meininger (2011) call for more attention to develop methods that give better insights into the living environment of people with intellectual disabilities.

And this where my research comes into play. When I initially started this study, I thought my research would take place in the citizenship paradigm, because I find it important that people with MID and ASD are treated the same way as others in society and maybe even more importantly, that society learns that these people are there and play an important part in our society. But at the same time I had my doubts about whether it can be expected of people with MID and ASD to fully live up to the standards of our participatory society, which expects them to fully participate in daily life. The citizenship paradigm was introduced to help with the inclusion of people with intellectual disabilities. However, the paradigm leans too much on the theories and discourses of citizenship which means that even the citizenship paradigm reflects a certain image of a perfect citizen and these ideals of good citizenship do not correspond with the way people with a disability or disorder view or experience their living environment (Beckett, 2005). Often decisions are still made for them instead of with or by them, and this does not lead to the inclusion intended by the citizenship paradigm. I really wanted to hear the story of people with MID and ASD on how they experience certain things, in this case their holiday, and how this helps them feel about themselves. Therefore, I place this study more in the 'world-making' perspective and am going to answer to the call of Renders & Meininger (2011) with the following research objective:

> ***To study how Dutch people with a mild intellectual disability or autism spectrum disorder themselves, instead of experts, professionals or parents telling it on their behalf, experience specialized guided holidays in Europe, and identify how the different elements of their holiday contribute to - and whether elements can be improved to enhance - their sense of empowerment, which will contribute to their equal participation in society.***

To shine light on this untouched field of research, this thesis wishes to look into the major benefits and challenges that Dutch people with MID and ASD encounter when they take part in specialized guided holidays. What do they experience, find important, and what do they need from themselves, their guides and surroundings to get the desired benefit from their holiday experience? By letting people with disabilities speak out and express themselves on planned and recently executed leisure activities in a holiday setting I hope to contribute to a better understanding of feelings of empowerment of this group and how this can contribute to them being able to participate more in Dutch society and become more accepted by our society.

1.3 Thesis structure

I have offered some background information and the problem statement for this thesis research. In the following chapter the theoretical framework for this thesis is presented, explaining the three main concepts for this study: MID and ASD and the dominant paradigms in disability studies, empowerment and tourism leisure experience. Chapter 3 explains the methodology used for this research, describing the ways the project was designed and how data was collected and analyzed. Chapter 4 explains the setting for this research, giving details about the holidays and the participants of this research. Chapters 5 to 7 then present the results of the fieldwork and its analysis. The conclusions that can be drawn from this research will be provided in Chapter 8. In Chapter 9 I give a thorough reflection on this thesis experience. The final chapter contains the recommendations I have drawn from this research.

2. Theoretical framework

To achieve the goal of this thesis as described in the previous chapter it is important to gain a better insight into the concepts that play an important role in this thesis. As the main part in this thesis is played by people with MID and ASD I will start with a subchapter on the historical context around people with MID and ASD and the different paradigms connected to these developments. I will then look at the different definitions of disabilities and developmental disorders before narrowing down to the description of MID and ASD used in this research. In the second subchapter I will elaborate on the concept of empowerment by first looking at several definitions of empowerment before coming to the definition of empowerment used for this research. As this research takes place during the holiday of people with MID and ASD, the last subchapter will look more closely at the tourism leisure experience, in particular for people with MID and ASD.

2.1 Mild intellectual disabilities and Autism Spectrum Disorder

The way people with disabilities and developmental disorders are treated is closely related to the prevailing societal ideologies and scientific theories on handicaps (van Leeuwen & Limpens, 2007). Prehistoric finds point out that tribe members with physical disabilities were looked after by their stronger tribe members. Over the centuries that followed people with both physical and intellectual disabilities have been treated in many different ways, from being worshipped as people standing close to the gods (Greek and Roman times) to being locked away and chained up like animals (Middle Ages, Early Modern Times) (Wuyts, 2010).

2.1.1 Scientific theories

The first recorded scientific research into *intellectual* disabilities started around 1800, during the Enlightenment (Van Gennep, 1997). Before this time there had been no real distinction between intellectual and physical disabilities. The word ‘autism’ has been in use for about 100 years and comes from the Greek word ‘autos’, meaning ‘self’. Eugen Bleuler, a Swiss psychiatrist, was the first who started using this term around 1911. He used it to refer to one group of symptoms of schizophrenia (Weintraub, 2013). In the United States, researchers starter to use the term ‘autism’ in the 1940s, to describe children with emotional or social problems. Leo Kanner, a doctor from Johns Hopkins University, used it in his description of several children that showed withdrawn behavior. Around the same time, Hans Asperger, a scientist in Germany, identified a similar condition, which is now known as Asperger’s syndrome. The link between autism and schizophrenia remained until the 1960s. From that moment on medical professionals began to have a separate understanding of autism in children (Weintraub, 2013).

Since 1900 there have been three main paradigms with regards to disability studies: the defect, development and citizenship paradigm. These paradigms are used to look at what constitutes a disability, but also how people with a disability are treated by society and the way they are cared for. The three paradigms succeed one another, but the arrival of a new paradigm does not mean that the previous paradigm ceases to exist. All three paradigms are still visible in society today and have influence on the daily lives of people with disabilities and society in general (Wuyts, 2010); (Verdonk, 2011). Examples of this are the special facilities where people with disabilities or developmental disorders work or live. The paradigms are situated between two models. Both models are used for research into physical as well as intellectual disabilities. Much attention has been paid to the solving of barriers for people with physical disabilities, but there is still a gap in the research concerning people with MID and ASD.

The first model is the medical model of disability (see figure 1), in which a disability is seen as a biomedical disorder for an individual, and this individual is the problem.

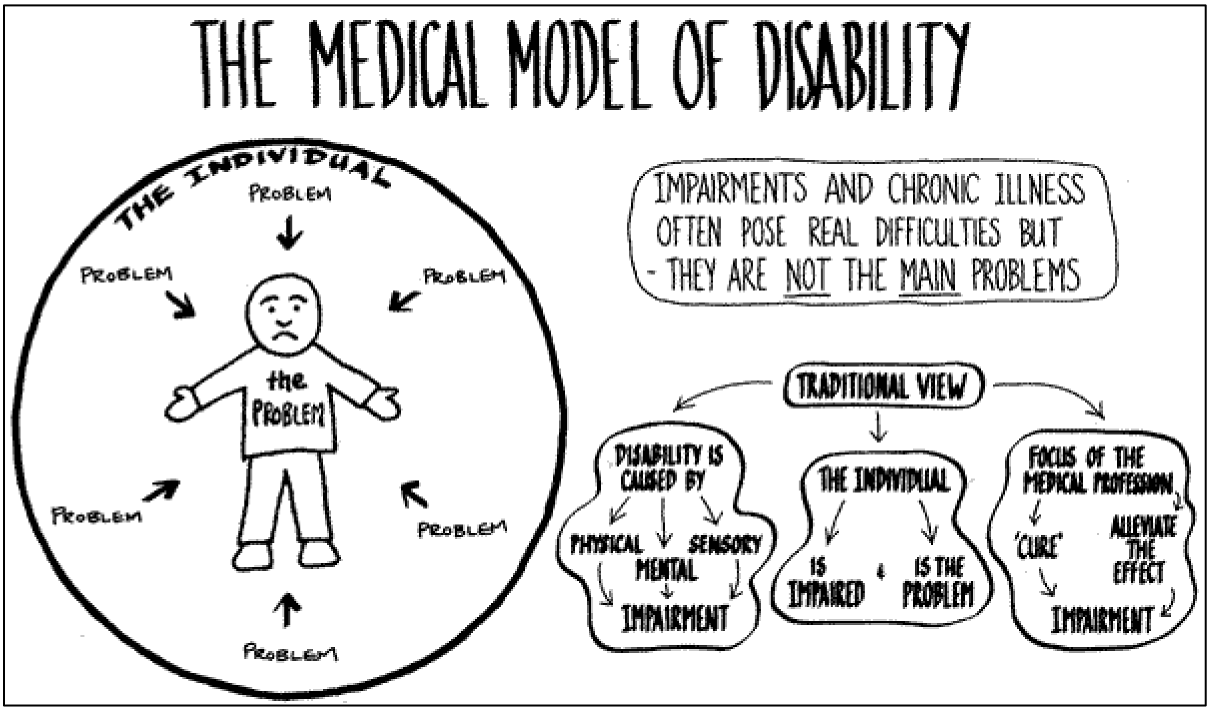


Figure 1. The medical model of disability (Dupree, 2011)

The second one is the social model of disability (see figure 2). In this model it is society causing the disability for people with a disability because of the barriers they create due to high standards in society, which are biased towards whiteness, maleness, wealth, able-bodies and a conception of rationality free of emotion.

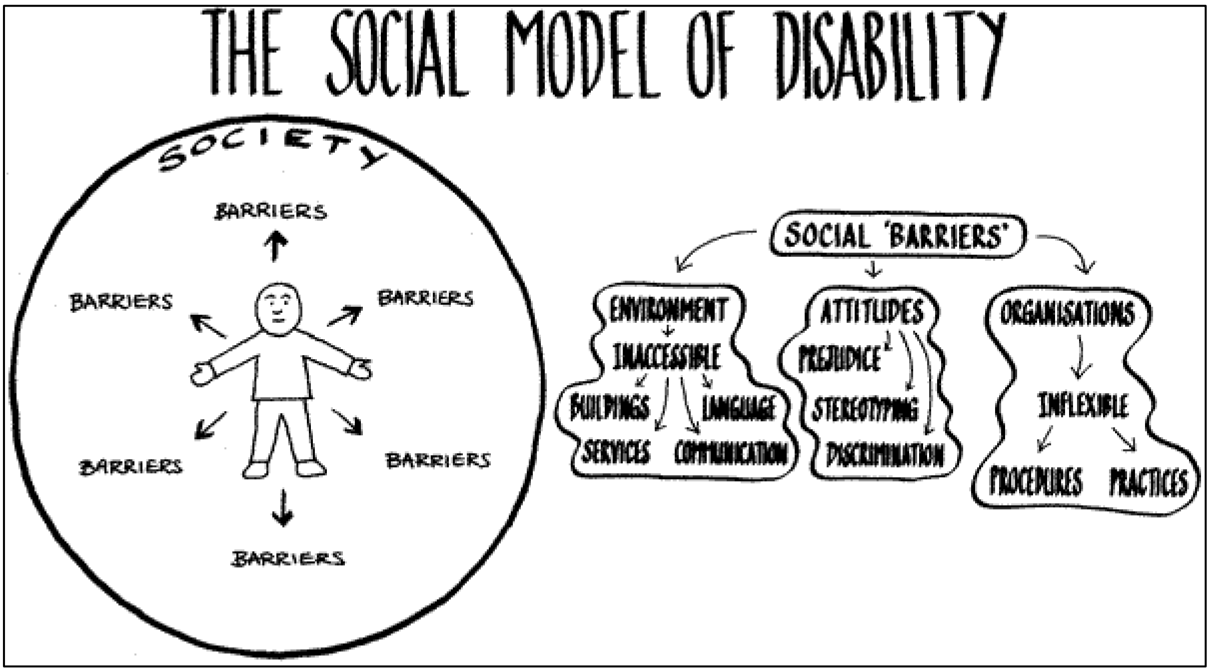


Figure 2. The social model of disability (Dupree, 2011)

The medical model is closely related to the defect paradigm and the social model plays a bigger part in both the development and citizenship paradigm.

Defect paradigm and segregation

The defect paradigm was dominant in The Netherlands between 1900 and 1970. The central point of this paradigm is the individual with his/her disabilities. It focuses on the differences between people with and without disabilities. These differences are the result of the disability, which is caused by neurological or genetic defects and seen as a disease or disorder within the individual. This makes them function less or differently and this diagnosis is thought to be definite, because they will not change. The person with a disability is seen as a patient who needs care in a specialized facility or should be locked away to protect society. The connected aid model uses the doctor-patients relationship (medical model) and providing care is at the centre of this model. This paradigm caused the transfer of people with disabilities to separate institutions, away from society. This segregation was considered necessary to provide good care and to protect society (van Leeuwen & Limpens, 2007). Bruno Bettelheim, a Hungarian psychotherapist claimed, after WWII had ended, that autism was caused by distant, heartless parents who forced their children into mental isolation. He compared these children with prisoners released from concentration camps (Boelsma-Hulsman, n.d.). His theory was accepted for 20 years, which resulted in autism being seen as a mental illness instead of a developmental disorder and limited treatment for children with autism. Persons with an intellectual disability received, besides physiotherapy and occupational therapy, behavior modification training in which they were taught desirable behavior and had to unlearn their deviant behavior. Also people with autism were treated with medications such as LSD, shock therapy or behavioral change techniques, relying on pain and punishment (Weintraub, 2013). The defect paradigm can be summarized as: patient role, isolated from community, and institutional driven supports (Schuurman, 2002).

Development paradigm and normalization

The roots of the development paradigm lie in Sweden and Denmark where they included pensions for people with disabilities, who could not work, in the set up for their Welfare State during the 1940s and 50s, after World War II had finished. The development paradigm puts emphasis on the differences and similarities of people with and without disabilities. Laws were put in place to make sure people with disabilities could lead their lives as normally as possible. This normalization process was meant to lead to normalized housing arrangements, and education and employment opportunities as this could have a positive influence on people with disabilities. In 1964, Bernard Rimland, psychologist and father to a son with autism, wrote a book in which he acknowledges autism as a biological disorder instead of an emotional disease. From this moment on autism became the topic of a lot of research and slowly it became clear that autistic behavior is the result of a developmental disorder (Boelsma-Hulsman, n.d.). Around the same time, researchers also started to become more critical towards the institutionalized way of living for people with disabilities and started asking questions about the usefulness of these practices. They no longer consider disabilities as biomedical defects that need to be treated and fixed, but as damage to cognitive processes that can be trained and developed. The development paradigm's basic assumption is that every person develops over time. People with MID and ASD also develop themselves, but often not at the same pace as others and often they do not reach the same end level. But it is not only knowledge and skills that play a part in daily life. Therefore the development paradigm also puts emphasis on socioemotional factors such as motivation and emotion. People with disabilities were no longer considered as patients, but as normal people with special needs and with their own development abilities (van Leeuwen & Limpens, 2007). The connected aid-model is teacher-student, in which stimulating own potential and development possibilities is key. This needs to be done in a 'normal' environment and therefore institutional care is replaced by community care. Small-scale facilities, such as daycare facilities for children and adults, were set up in neighborhoods to maximize the development opportunities for people with disabilities. Bit by bit, the barriers between institutions and society were removed. The focus on development was also noticeable in the treatment of people with autism during the 1980s and 90s, albeit that this behavioral therapy took place in highly controlled learning environments. Society became more careful about the denomination of people with disabilities. During the last quarter of the 20th century, the humiliating and patronizing names for people with disabilities started to slowly disappear from the official vocabulary for professionals and policymakers in both the USA and The Netherlands. Prejudices in society, however, still remain. The development paradigm can be summarized as: client role, present in community, and community agency driven supports (Schuurman, 2002).

It took a while for the development paradigm to reach The Netherlands. It was not until the early 1970s that the defect paradigm started to receive more and more criticism and that the development paradigm got introduced. Unlike other countries, however, The Netherlands translated the normalization process into normalization within the institute. Small-scale facilities appeared on the grounds of the already existing facilities away from society. It was much later that the transition of institutional care to community care occurred in The Netherlands (van Leeuwen & Limpens, 2007).

But after a while the development paradigm also started to receive criticism by people involved in the care for people with disabilities and also by researchers involved in disability studies . The way the normalization process was carried out in an inconsistent manner received most criticism. The normalization process consists of two dimensions: the physical-structural dimension and the perspective dimension. The physical-structural dimension deals with the de-institutionalization of the facilities, which seemed to only result in mini-institutes where people with intellectual disabilities were trained to develop themselves in a routine manner. What the wishes were of the people themselves was hardly taken into consideration, and they were still apart from society. The perspective dimension sees people with disabilities not as people with limitations because of their disability, but as people who should get the chance to fully participate in society with the right support. This should not only be in the ways they are cared for, but also in education, employment opportunities and being part of society. Normalization was hardly noticeable in these latter three areas, which caused critics to doubt the success of the development paradigm. Another point of criticism was that the Welfare State in The Netherlands had also created a constructed society in which facilities were created according to set standards and people were put into fixed categories. These categories emphasized the difference between 'normal' people and people who needed extra care. In this system the latter group still needed to adapt and live up to the standards that were set for the 'normal' people in society, again reason for critics to question the development paradigm, as this paradigm expects people with MID and ASD to live life as normally as possible.

Citizenship paradigm and integration/inclusion

In the mid 1990s, the perspective dimension of the normalization process starts to receive more and more attention and with this the citizenship paradigm appears. Since the 90s this is the most dominant paradigm in The Netherlands. Changes in government policy, also related to emancipation movements of women and other minority groups in society, played an important role in this too (Van Gennep, 1997). Within this paradigm people with disabilities are no longer judged by what they cannot do, but by what they can do and how they can reach their full potential. They should have input in how they can become and feel like equal citizens in society. Someone with a disability is above all a member of society, just like everyone else born in that society. It can be, however, that because this person has a disability he or she needs some extra support to be able to participate in society the same way as other members do. This support should take place in their daily environment and be aimed at the individual's wants and needs. This paradigm can be summarized as: citizen role, inclusive communities, and individualized and community driven supports (Schuurman, 2002).

The main difference between this and the previous paradigms lies in the fact that, in the citizenship paradigm, a disability is no longer seen as a characteristic of the individual, but as the expression of the interaction between the person with the disability on the one hand and the social environment on the other (van Leeuwen & Limpens, 2007). Because of this strong connection to the social environment, the disability is of a dynamic character, which means that in different situations the disability can be expressed in different ways. Society can play an important role in reducing the limitations caused by a disability. It is not the problem of an individual, but one of society. This connection to society is of great importance in the citizenship paradigm and integration in this society is therefore seen as the solution. This integration comes in three different dimensions: physical, functional and social integration. Physical integration is about people with disabilities living amongst people without disabilities. Functional integration means that people with a disability make use of the same facilities as the rest of society. And social integration means that people with a disability are seen as socially equal and respected partners in social relationships (van Leeuwen & Limpens, 2007). Over the last few years the term integration is also being replaced by the term inclusion. The difference here is that in segregation, normalization and integration, society is taken as the norm and the people with a disability will have to adapt to these norms. Inclusion considers everyone to be unique or different and there are no norms. People should be able to develop their own talents and society needs to support them in this. Accepting diversity and anticipating on this diversity is also important in inclusion. In many different fields, people are searching for the right way to implement 'living in society'. Schuurman (2002) defines 'living in society' as: living as a citizen, in an inclusive society with individual support that is provided by the (local) community. 'Living in society' is often seen as the opposite of the institutionalization from the defect paradigm, but these are two different things. Whether you live in an institute or a certain neighborhood is a *form* of living, whereas 'living in society' is a principle of life. People can live in a nice neighborhood without being part of or belonging to it and it is this belonging that makes people feel part of society (Schuurman, 2002). Closely linked to the 'living in society' is the concept of 'quality of life'. Being part of society is seen as a positive influence on someone's quality of life (Schuurman, 2002). Quality of life is characterized by the following characteristics:

:

a) freedom of choice;
b) participation;
c) development;
d) respect, privacy and safety;
e) family, friends and social contacts; and
f) personal support.

All of these six are needed to reach the three requisites of ‘living in society’.

As a result of the paradigm shift the American Association on Mental Retardation (since 2006, American Association on Intellectual and Developmental Disabilities, AAIDD) drastically changed their definition of what constitutes an intellectual disability in 1992. In their new definition (see paragraph 2.1.2) a disability is the result of societal values; it is the result of the capacities of the individual and his/her environment. Also the General Assembly of the United Nations drew up standard rules for the creation of equal opportunities for people with disabilities in 1993. This was the result of civil right movements for minorities in society that was particularly strong in the United States. Social emancipation, in which people with a disability themselves decide, instead of others deciding for them, plays an important role in the citizenship paradigm. People with disabilities themselves should decide who they want to live and work with etc. This gives them some control over their lives and gives them the opportunity to make their own choices. In the citizenship paradigm, ‘care’ is replaced by ‘support’, because it is about helping people making their own decisions. It is not up to others to decide for them. When talking about this, the term ‘empowerment’ is often used. Empowerment here means making people in marginal situations stronger so they get control over their own lives. Empowerment will play an important role in this research and will therefore be explained in more detail in subchapter 2.2 .

What next ‘world-making’ and inclusion?

As mentioned before, all three paradigms are still present within our society. Even though people say they see people with MID and ASD as full citizens and accept them, their actions do not always seem to match this. Old ideas and images are still prevalent in society, and it will be hard to change this, but not impossible if people are open for it. My personal experiences match with Wuyts (2010), who argues that people are idealists and want to take care of the 'unlucky' ones by means of charity, but prefer to keep direct contact with the 'unlucky' ones to a minimum or not at all (Wuyts, 2010). Somehow, Dutch social care work is less influenced by scientific insights than other Northwestern European countries and the United States. Where the defect paradigm plays an almost insignificant role internationally, within The Netherlands there are still several care workers whose thinking and performance is based on the defect paradigm (van Leeuwen & Limpens, 2007). Also the medical model, of people with disabilities being weak and in need of professional support, continues to exist in special education, day care and separate work facilities, where people with disabilities are still kept away from society. The cooperation with existing, regular services remains limited and this perception leads to people with disabilities still being made to feel disabled. But not only the occurrence of previous paradigms is an issue, the citizenship paradigm has also started to receive criticism. According to Renders & Meininger (2011) the citizenship paradigm leans too much on the theories and discourses of citizenship which means that even the citizenship paradigm reflects a certain image of a perfect citizen with corresponding values, which is often based on the most dominant group within society and therefore leaves values of minority groups unacknowledged (Renders & Meininger, 2011). The latter is confirmed by Beckett (2005) whose research shows that the ideals of good citizenship do not correspond with the way people with disabilities view or experience their living environment. Often decisions are still made for them instead of with or by them, which does not correspond with the social emancipation that should be a big part of the citizenship paradigm. Renders & Meininger (2011) ask the question whether we might miss essential knowledge when we only use the citizenship paradigm to get information on the life and living circumstances of people with intellectual disabilities. They do not dismiss the citizenship paradigm as a whole but, just as with the defect and development paradigm, the citizenship paradigm is subject to changes and perhaps even succession by another paradigm as time and research go on. No such new paradigm has come into existence yet, but Renders & Meininger (2011) do notice that in the last couple of decades more researchers attempt to justify the living environment and own way of 'world-making' by people with intellectual disabilities. These researchers step away from both the medical and the social model of disability and focus on for example the way people with disabilities experience the physical and social environment and how they then perceive reality based on the developments of that experience (Devlieger, van Hove & Renders, 2006) (Renders & Meininger, 2011). In all three paradigms this 'world-making' of people with MID and ASD is mostly neglected and they are still expected to adapt to what is said to be normal.

Table 1 provides a summary of the different disability paradigms discussed in this subchapter.

	Defect paradigm *(1900-1970s)*	*Development paradigm* *(1970s-mid 1990s)*	*Citizenship paradigm* *(mid 1990s-current..)*	*'World-making'* *(upcoming)*
Human vision	Person with limitations	Person with possibilities	Person with rights and duties	Ask them how they see themselves
Status	Patient	Student	Citizen	Ask them how they feel in society
Type of care	To tend to and treat	Train and develop	Support	Ask them what they need
Place	Institutions in society	Special facilities in society	Regular housing facilities	Ask them where they would like to live
Societal	Segregation	Normalization	Integration/Inclusion	Ask them how they would like to be treated by society

Table 1. Summary of the three disability paradigms- adapted from A. van Gennep (in van Leeuwen & Limpens, 2007)

Now that we know more about the context of disabilities studies and the three paradigms connected to this field of study, I will move on to describing the definitions of MID and ASD in general, and for this research.

2.1.2 Definitions and constructions of MID and ASD

The World Health Organization (WHO) gives the following definition of disability in their instruction manual International Statistical Classification of Diseases and Related Health Problems (ICD-10):

> *"Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)."* (WHO, 2011)

Generally speaking, physical or intellectual disability represents losses in terms of functionality and capability to perform certain tasks and to enroll in certain activities, consequently constituting a limitation or restriction that frequently leads to exclusion from certain activities and contexts, such as tourism activities (Figueiredo, et al., 2012). But of course, not all people with disabilities face the same constraints and difficulties. These depend on the nature and level of disability. Therefore, to define people with a disability as a single segment is a simplification since they are a diverse and heterogeneous category (Burns, et al., 2009) regarding their participation in social life and socio-economic profile. Part of this diversity is also recognized by the WHO, which defines four main types of disability: intellectual, motor or physical, hearing and visual (Figueiredo, et al., 2012). For this research I will focus on the first type: people with an intellectual disability, which on its own is again a diverse and heterogeneous group. So let us have a closer look at what the definition of an intellectual disability is and at the mild intellectual disabilities of the holiday participants for this research.

In their book ' Verstandelijke beperking: definitie en context' (*'Intellectual disability: definition and context'*) De Bruijn et al. (2014) try to give an extensive answer to the question what we mean by an intellectual disability and its context in The Netherlands. However, already in the foreword it is noted that science and practice still have a long way to go, hand-in-hand, to provide an all-embracing answer to the question of what actually constitutes an intellectual disability (De Bruijn, et al., 2014). In their book they take the first steps in providing an answer. They start by providing a few definitions of intellectual disability, all of which are from American organizations. The USA has always been a frontrunner (together with some Scandinavian countries) when it comes to disability rights and studies, so that these definitions all have their origin in the USA is a logical consequence. The American Association on Intellectual and Developmental Disabilities (AAID) provides the following definition of intellectual disability:

> "*Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18.*" (AAID, 2010)

The American Psychiatric Association (APA) defines intellectual disability (intellectual development disorder) as follows:

> "*A disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains."* (APA, 2013)

Because The Netherlands is only small, we tend to look at developments in other countries. The Netherlands is, however, becoming much more a knowledge generating country with many experts in the field of MID and ASD and provides high levels of care in the field of disability (Riswick, 2015).

The way we define and 'measure' MID has changed over the years. Instead of only looking at IQ, like we used to do, we now also look at a broader context of the person's life. We now use the following measurements: people with MID have an IQ between 50 – 70, have limited social adaptability and are in continuing need of support. There are no exact numbers of people with a MID living in The Netherlands, but according to the Sociaal en Cultureel Planbureau (The Netherlands institute for Social Research) The Netherlands probably has around 110,000 people with MID. However, estimates of the number of people with MID differ significantly in international literature, from 3 per mille to over 20 per mille. Within The Netherlands this would mean the number of people with MID lies between 50,000 and 330,000 (SCP, n.d.). The difference between the numbers can be explained by the fact that sometimes people with MID are not easy to record, as not everyone makes use of support.

Besides people with MID, this research also involves people with ASD. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published by the APA, gives the following description of people with ASD:

> *"People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later."* (APA, 2013)

The Trimbos Institute (2014) describes ASD as being characterized by:

- A reduced ability to make social contact
- A reduced ability to communicate
- A reduced usage of fantasy
- A rigid pattern of constant recurring stereotype actions

Until 2001 professionals used many different terms for the developmental disorders related to the autistic spectrum, such as autism, Asperger's syndrome, pervasive developmental disorder (PDD), PDD-Not Otherwise Specified (PDD-NOS), high functioning autism and low functioning autism. From 2001, these are all placed under the collective term: Autism Spectrum Disorders (ASD).

The term 'ASD' refers to a group of people that is particularly heterogeneous and for each individual the social and other problems differ in type and severity, which leads to all kinds and combinations of limitations. Some of these combinations have been put into diagnostic categories, while others have not (yet) received a name and are placed under the category PDD-NOS. Often people with ASD also suffer from some kind of MID.

Depending on the severity of their disability or disorder, people with MID and ASD in The Netherlands can live with their parents or other family members, independently, in small-scale living facilities or in large institutions for people with disabilities. The current policy aims at de-institutionalization of these large facilities, which should result in living in local society, however, this process is slow and remains behind of initial expectations and objectives (Schuurman, 2003). When it comes to leisure activities, only few people with MID partake in 'regular' leisure activities. Most of them are a member of a club specifically for people with disabilities (de Klerk, 2002). People that live independently hardly ever participate in public social activities. Not having someone to undertake activities with is the main reason for people with MID to not get out of the house more often, while one third admits they would like to (de Klerk, 2002). Looking at education, all children between the ages of 5 to 16 are obliged to attend school. Children with MID or ASD are encouraged to go to ‘regular’ primary and high schools, to enhance integration in society. Special education exist for the children that cannot keep up at ‘regular’ schools. With regards to higher education, the accessibility policy of the education provider is responsible for people with MID and ASD being able to participate or not. Having work and being able to work is seen as an important way of being part of society and in The Netherlands a shift has occurred from ‘compensation in loss of income’ to ‘stimulating labor participation’. This has as a result that many people with MID and ASD have work, but many of them work at a facility that is set up for people with MID or ASD. We still have not reached the goal of fully including people with MID and ASD in our Dutch society.

2.1.3 Description of people with MID and ASD for this research

As can be concluded from the information above, it is important to recognize that the group of people with MID and ASD is not a homogenous group, as MID and ASD come in many different forms. It is therefore hard to come up with a clear description of the people with MID and ASD for this research. However, there are some factors that influence the type of people that will be encountered in this research. The biggest influence is caused by the fact that this research makes use of a case study. The organization used in this case study is Flow Reizen and they target a certain group of people with MID and ASD. Characteristics of this group of people are that they are relatively independent, mobile, and sporty. They usually live independently, with or without support from care-workers or family. They need just a little bit of help with matters such as money, medication, behavior and/or social contacts. Examples of the types of disabilities are different kinds of ASD, such as classical autism, Asperger’s, PDD-NOS etc, but also people with epilepsy, acquired brain injury, developmental disabilities or Down Syndrome. Their ages range from 18 to about 50 years old.

The literature defines people with MID as having an IQ between 50 – 70, have limited social adaptability and are in continuing need of support. For this research I will not be using IQ as a measurement. The reason for this is twofold. First of all, I am not in the position nor have the instruments to measure someone’s IQ; and secondly, people with ASD can have a very high IQ, but still encounter difficulties in their daily lives. Having limited social adaptability and in need of support do also apply to most people with ASD. I have chosen to include people with ASD in this research, because people with ASD are becoming more prominent within society and therefore also make up a large part of participants traveling with Flow Reizen. Because of this, it would be interesting to know how they experience their holiday and how this empowers them.

The description of the people with MID and ASD involved in this research is as follows: ***People between the age of 18 and 60, who participate in a specialized guided holiday and are in need of support during their holiday experience. This support can be on a daily basis, such as help in money matters or looking after the medication. But it can also be that support is only needed in specific situations, for example making social contact or when unexpected situations arise. Besides this support they are relatively independent when it comes to daily activities, both at home and during their holiday. The kind of disabilities differ and can be MID or different kinds of ASD.***

Now that we know who this study is about, the next subchapter will explain an important concept used in this study.

2.2 Empowerment

Early in my thoughts about this research I thought about using the concept 'empowerment' in my research. At that point I did not realize that empowerment was such a strong and often used concept in research on mental health and disabilities studies already. For me it was the idea that people with MID and ASD would feel stronger within society by being able to do certain things. Which is at the heart of most explanations of empowerment by other researchers, but let us have a look at some of these definitions, before defining how I will use empowerment in this research.

2.2.1 Defining empowerment

Empowerment is a difficult concept as it tends to mean different things to different people (Quinn & Spreitzer, 1997). According to Renblad (2003) empowerment is a form of power that can be defined as the ability to decide on one's own. It also means that one has the opportunity to exert influence and to participate. The concept is based on a philosophy grounded on the idea of equality – that everyone is of equal value – and stems from individual strengths and resources (Renblad, 2003). In her article about how people with intellectual disabilities think about empowerment and ICT, Renblad states that the empowerment process is a life-long development process and more difficult for people with disabilities because of the stereotypes that exist, such as the idea that people with disabilities neither can nor should practice self-determination. She emphasizes that it is through interaction with our surroundings that we learn and develop, and this process affects how we see our opportunities and ourselves (Renblad, 2003). The possibility of having influence, of being included and of having control over your own life – in other words to be empowered in everyday life – are important for quality of life. And yet, previous research has shown that people with intellectual disabilities have little or no influence on this (Renblad, 2003). She continues by saying that historically, professionals and social services have made people with disabilities and their families passive, giving them few opportunities to express their needs and make choices or decisions about their future. Through a raise of interest, policy and paradigm changes, and education, many people with disabilities and their families are now able to feel empowerment and self-determination.

Koren et al. (1992) measure empowerment in families whose children have mental health problems or suffer from multiple disabilities. In the literature review for their study, they state a few of the major themes of the definitions of empowerment: the reduction of powerlessness; gaining, developing, seizing, enabling or giving power; attaining control over one's life; and democratic participation in the life of one's community (Koren, et al., 1992). These definitions show that empowerment can be both a process as well as a state of being and that it can be linked to the individual as well as the community.

In 1991, Emener examined the construct of empowerment, defining it as a guiding philosophy underlying rehabilitation practice that emphasizes the rights of individuals with disabilities to make informed choices, take risks, and assume control of rehabilitation planning (Niesz, et al., 2008). Emener identified both internal and external factors associated with empowerment, such as high self-esteem and supporting social networks. Later, Kosciulek (1999) introduced the consumer-directed theory of empowerment (CDTE). This theoretical framework was specifically designed for the development and evaluation of disability policy and rehabilitation service delivery and relates to community integration, empowerment and improved quality of life of people with disabilities. It conceptualizes empowerment as including both internal-psychological factors and situational-social factors. The internal-psychological factors include: sense of control, competence, responsibility, participation, and future orientation. The situational-social aspects include: control over resources, interpersonal skills, work, organizational skills, and social skills (Kosciulek & Merz, 2001). The CDTE suggests that greater consumer direction in disability policy formulation and service delivery will lead to increased community integration, empowerment and quality of life among people with disabilities. Empowerment was operationally defined in the CDTE by the 28-item Empowerment Scale from Rogers et al. (1997). This scale was developed specifically to measure empowerment amongst people who made use of mental health services. Rogers et al. (1997) state that *"despite the burgeoning use of the term 'empowerment' in the lexicon of mental health programs, few researchers or service providers have attempted to define, operationalize, or measure it"* and that *"it has been referred to as a 'buzzword' with little meaning"* (Rogers, et al., 1997). Part of the purpose of their study was therefore to further define and operationalize the construct of personal empowerment from the perspective of consumers. Because they felt that there was no existing instrument that captured the dimensions of empowerment in relation to people with mental illnesses they set up a board of ten individuals to create a list of attributes they thought to be connected to empowerment. This resulted in a list of 15 attributes:

1.) Having decision-making power;
2.) Having access to information and resources;
3.) Having a range of options from which to make choices;
4.) Assertiveness;
5.) A feeling that one can make a difference (being hopeful);
6.) Learning to think critically (unlearning the conditioning and seeing things differently);
7.) Learning about and expressing anger;
8.) Not feeling alone/feeling part of a group;
9.) Understanding that a person has rights;
10.) Effecting change in one's life and one's community;
11.) Learning skills that one defines as important;
12.) Changing others' perceptions of one's competency and capacity to act;
13.) Coming out of the closet;
14.) Growth and change that is never-ending and self-initiated; and
15.) Increasing one's positive self-image and overcoming stigma

The results of their study suggests that:

> '*an empowered person is one who has a sense of self-worth, self-efficacy, and power. The empowered person recognizes the use of anger as a motivating force to instigate social change and is optimistic about the ability to exert control over his or her life. He or she recognizes the importance of the group or community to effect change, but the empowered person also values autonomy'* (Rogers, et al., 1997).

Their study further suggests that programs wishing to promote empowerment among their participants should focus on increasing self-esteem and self-efficacy, decreasing feelings of powerlessness, and increasing feelings of power especially by increasing financial resources. Going on a holiday can help in the first two, but will not help in increasing financial resources.

Connelly et al. (1993) carried out a qualitative inquiry examining empowerment from the consumer's perspective. These consumers suffered from severe mental illnesses such as schizophrenia or manic depression. The analysis identified that empowerment had four domains: participating, choosing, supporting and negotiating. For the clients, empowerment meant they participated more in the community, their choices were increased, they provided support for each other and they negotiated on a more equal basis with staff (Connelly, et al., 1993). Miller et al. (2002) show by means of field observations and focus groups of people with intellectual disabilities, that benefits from volunteering work include pride, skill development and generalization, empowerment, and increase in social interaction and verbal communication (Miller, et al., 2002). Also Patterson & Peg (2009) demonstrate, by making use of semi-structured interviews with people with intellectual disabilities, that involvement in serious leisure activities increases levels of confidence, skills and self-esteem, which are all closely related to empowerment.

2.2.2 Definition of empowerment for this study

As other researchers have already pointed out: empowerment is not an easy concept to define. My initial idea of empowerment making people with MID and ASD feel stronger within society by being able to do certain things, certainly makes up a large part of empowerment, but this definition can be extended and more detailed. The different researchers mentioned above have pointed out several elements that can lead to empowerment. For the definition of empowerment for this research I have clustered these different elements of empowerment into a more concise list, more suited to measuring empowerment during the tourism leisure experience. It improved the clarity of the tool for this research. For example, '*having decision-making power*', *'having access to information and resources'*, and *'having a range of options from which to make choices'* (Rogers et al., 1997) were combined with *'the rights of individuals with disabilities to make informed choices'* (Niesz, et al., 2008) into the characteristic *'making one's own, informed choices*'. The empowerment process can be studied by gathering information from people with MID and ASD on the following ten characteristics:

1. Making one's own, informed choices;
2. Feeling part of the holiday group;
3. Participation in all elements of the holiday;
4. Feeling of having equal rights as other people at home and at the destination;
5. Having a sense of control/taking control;
6. Bringing about change in one's life and one's community;
7. Learning skills that one defines as important and can be used in the future;
8. Changing one's own and others' perceptions of one's competency and capacity to act;
9. Increasing one's positive self-image and overcoming stigma;
10. Coming out of the closet

When during the research participants indicate other characteristics for empowerment or when there seems to be other important factors that contribute to empowerment, these will be included in the findings.

The definition of empowerment for this research is as follows:

> ***Empowerment is the process of people with MID and ASD becoming more secure about themselves and their capabilities by experiencing different elements of a specialized guided holiday. Through a greater sense of empowerment the position of people with MID and ASD within society will improve, with as desired result having equal opportunities to other members of society.***

Now that we know about two important concepts of this study, it is time to move on to the last one.

2.3 Tourism leisure experience

The sense of becoming more empowered can occur during all kinds of situations and activities, but for this research I will focus on how a specialized guided holiday can contribute to the feeling of empowerment. I will therefore look in more detail at the tourism leisure experience and what the importance of this is to people with MID and ASD.

2.3.1 General tourism leisure experience

Tourism and holidays are part of the larger leisure experience. So I will first have a look at what this leisure experience is. The origin of leisure studies can be traced back to the 1960s/1970s. Prior to this, researchers viewed leisure as either time after work or engagement in particular types of activities (Lee et al. 1994). During the 1970s researchers started to see leisure more as a state of mind, causing a shift from leisure as an objective paradigm to a subjective one. This shift created more opportunities for leisure research, in which the term 'leisure experience' got introduced, also indicating the paradigm shift. The term 'leisure experience' is used widely within the field of leisure research and it is therefore important to understand the concept and how existing literature explains the concept. Lee et al. (1994) point out that 'leisure experience' is:

a) multi-dimensional: leisure is characterized by a variety of experiences, including positive experiences, as well as stressful or unpleasant ones;
b) transitory: leisure experience takes place in short, interrupted episodes, not for extended periods of time; and
c) multi-phased: leisure experience takes place in 5 distinct and interacting phases: anticipation, travel to the site, the on-site activity, return travel, and recollection, and each phase entails different kinds of leisure experiences (Lee, et al., 1994).

All of these characteristics of leisure experience are also present in tourism leisure experiences. A holiday consists of both positive as well negative experiences, it takes place over a short period of time and the five phases are particularly clear when it comes to preparing for a holiday (anticipation), traveling to and from a destination (travel to the site and return travel), being on location (on-site activity) and later thinking about this holiday (recollection).

When people participate in leisure to the fullest, they express talents, demonstrate capabilities, and experience a variety of positive emotions. Perceived freedom to choose to participate or discontinue participation is an important element of leisure and a feeling of perceived control over the activity (as opposed to being controlled or being restricted in the activity) is important to the leisure experience (Dattilo, 2002). Leisure also affects our sense of identity. Engaging in leisure should positively influence our perceptions of ourselves. In addition, leisure is important to the well-being of people, as it provides the opportunity to make personal choices, the opportunity to interact with others, and the emotional value of enjoyment. Satisfying leisure experiences can contribute to a sense of self-worth, contribution, and belonging to the community that may be otherwise be missing (Dattilo, 2002). Aitchison (2003) believes that leisure can contribute significantly to the enhancement of well-being and summarizes the effects of leisure as follows:

a) playing an important role in increasing self-esteem, confidence and psychological well-being;
b) enhancing physical health and fitness;
c) reducing the risk of illness; and
d) contributing towards positive social interaction and relationships. (Aitchison, 2003).

It has become clear from all of the above that leisure adds to the well-being of people and should have a positive influence on our lives. This is of course no different for people with MID and ASD. The following paragraph dives more into the importance of leisure activities for people with MID and ASD.

2.3.2 Leisure experience for people with MID and ASD

The quality of a person's 'leisure life' is an important indicator of that person's overall quality of life (Fullagar & Owler, 1998). According to Patterson & Pegg (2009) leisure and sporting experiences contribute particularly to the quality of life of people with disabilities, as it makes their lives more bearable. It relieves tension, and helps build and maintain relationships with family and friends (Patterson & Pegg, 2009). However, for people with an intellectual disability, leisure has traditionally been seen as 'filling in' of time, or through discourses of 'therapy'. That leisure experiences can also be an important site for the formation of identity, is overlooked. These conventional approaches of leisure tend to produce people with limited leisure planning skills or desire to even initiate their own plans (Fullagar & Owler, 1998). Participation in these conventional programs reinforces feelings of safety within groups and discourages people from taking risks to do things for themselves, and as a result of this, people with intellectual disabilities lack the confidence to expand themselves within the wider community (Fullagar & Owler, 1998). When recreation is provided exclusively within a group context, there is a discourse of sameness produced which hides the diversity and difference that exists between people with MID and ASD. This causes people outside of the group not to see and recognize the individual differences of the people with MID or ASD. The effect of this often results in a sense of exclusion for the person, because his/her specific wants and needs are not met, producing a negative attitude towards oneself. People with MID and ASD are often aware of their 'difference' within the community and often explain this 'difference' as something negative. This feeling of low self-worth often results in a variety of negative behaviors. The cause of this behavior is often looked at as a problem of the individual, rather than being a social issue.

Butler (1987) suggests that individuals be encouraged to recognize their own uniqueness, through acting on their own desires (in Fullagar & Owler, 1998). It is the act of attempting something different which starts the process of opening up new opportunities and when our motivation to live fully is increased, this leads to a more positive sense of identity. Leisure, being free from other constraints, can offer the opportunity to create the feeling of 'I can' (Fullagar & Owler, 1998), resulting in a positive sense of self-respect. Participating in leisure activities will also lead to meeting people with a common interest and these friendships are very important to find out what we like to do and how we do it:

> *"Leisure offers us an opportunity to experience something different or challenging, or simply, pleasurable. However, it also provides the chance for a person to change their relation to themselves. That is to develop a more positive narrative, which is to exercise power over oneself in a pleasurable rather than destructive or inhibiting way"* (Fullagar & Owler, 1998)

People with intellectual disabilities have the ability to participate in both casual as well as serious leisure activities. Casual leisure activities are often short and do not require any special training. Whereas serious leisure activities require a large investment of time and energy. People with intellectual disabilities successfully engage at such a level so as to enable them to develop increased levels of confidence, skills and self-esteem (Patterson & Pegg, 2009).

Research carried out by Cowert et al. (2004), concerning the activity participation of individuals with disabilities, suggests that they do not have the same opportunity as their typically developing peers, although they may have similar desires (in Solish et al., 2010). Also children with ASD take part in fewer social and recreational activities than their typically developing peers. Some of the identified barriers to their participation in activities include: few friends with whom to participate in the activities, deficits in skill and independence, and impaired cognitive abilities and social skills (Solish, et al., 2010). When participating in leisure activities, people with disabilities often do this alone, with members of their immediate or extended family, or with classmates (Buttimer & Tierney, 2005).

A challenge for people in the leisure service sector is to motivate people with MID or ASD to explore their possibilities instead of being constrained by what they (or have been made to) believe they cannot do. This can be achieved by providing support only where the person believes they need it. Even if the desired outcome is not entirely successful there is a sense of achievement, because they have been able to follow through their own idea (Fullagar & Owler, 1998). This can help in gaining confidence to try other new things. Research participants [with intellectual disabilities] commented that they loved the public acknowledgement of their successful involvement in serious leisure and that they enjoy winning, standing on the podium and getting a medal (Patterson & Pegg, 2009). Events, such as the Special Olympics, contribute to these success stories.

> *"Through the power of sports, people with intellectual disabilities discover new strengths and abilities, skills and success. Our athletes find joy, confidence and fulfillment - on the playing field and in life. They also inspire people in their communities and elsewhere to open their hearts to a wider world of human talents and potential."* (SpecialOlympics, 2015)

Also in the field of tourism there are some challenges for people with disabilities. Tourism is considered as a basic human right and also as a tool to promote social inclusion (Figueiredo, et al., 2012). However, it is also an activity that many people with disabilities feel must be sacrificed as it requires an orchestrated cooperation of physical, mental and social capabilities, which are often adversely affected or compromised by a disability (Kwai-sang Yau, et al., 2004). The constraints people with disabilities encounter are categorized into three levels: intrapersonal, interpersonal and structural. The latter two constraints refer to attitudinal and social-physical barriers, and are consistent with the social model of disability (Burns, et al., 2009). Intrapersonal constraints influence the motivation and desire to travel, which for many people with a disability, is the same as to people without a disability. To define disabled tourists as one segment is a simplification, because they differ as much as all other tourists in terms of travel motivations, holiday preferences etc. and also because, as has been pointed out earlier in this study, the term 'disability' is an umbrella term, covering a wide variety of impairments, activity limitations and participatory restrictions (WHO, 2008, in Blichfeldt & Nicolaisen, 2011). For tourists with intellectual disabilities, the sense of freedom and being at ease without the norms imposed by society can be a powerful issue when experiencing leisure and recreational activities (Figueiredo, et al., 2012). Figueiredo et al (2012) show that negative attitudes from people with intellectual disabilities towards traveling are: *'I have no company to travel with'*, *'when I travel, I feel more dependant'*, and *' traveling causes me insecurity feelings'*. But on the positive, research participants mention *'to show others that I am a dynamic person'* as an important motivation for them to participate in tourism activities. For many of them, '*traveling is an important aspect of their life'*, and they like to travel because they '*have a lot of spare time to travel'* or '*to forget their problems'*.

Much of these findings of participating in leisure experiences and tourism show a link to the different characteristics of empowerment. For example, the free will to participate or discontinue in a leisure activity can be linked to 'making own, informed choices'. This study further investigates how tourism leisure experiences can contribute to the sense of empowerment for people with MID and ASD.

2.4 Research questions

Combining the research objective and theoretical framework has led to the following main research question and sub questions for this study.

Main research question:

How do Dutch people with MID or ASD, participating in specialized guided holidays in Europe, experience the different elements of an active specialized guided holiday and in what way do they believe that these experiences influence their sense of empowerment?

Sub questions

1. Who are the people participating and how do they characterize their MID or ASD and their position in society?
2. What kind of elements make up the specialized guided holiday experience and how can they be characterized?
3. In what ways do these different elements influence the participants?
4. How can these experiences be characterized relative to the defect, development, and citizenship paradigm?
5. What elements are considered most empowering by participants and what improvements can still be made to enhance this sense of empowerment?

3. Methodology

> *[Benny has just explained that his expectations from guides is to be addressed in the right manner, which according to him is: " just say it as it is.". In the past he has had experience with people not addressing him in the right manner]*
> *Pieternel: "When they address you in the wrong manner, how does that make you feel?"*
> *Benny: "Well, childish, when they talk to me in a funny voice."*
> *P: "Ah okay, like that."*
> *B: "Or when they think; 'he has an intellectual disability, so he must like Frans Bauer'."*
> *(Both laugh)*
> *B: "Yes, we can laugh about it, but there are really people who think like that."*
> *P: "And how does that make you feel when people think like that?"*
> *B: "Well, I think that's a prejudice. Because I think he is a really nice man, but his music….yuk!"*

This is just a small excerpt from an interview that depicts one of the many funny, and at the same time confronting, moments I experienced during my interviews for this research. And this shows exactly the reason why I was so adamant about choosing this thesis topic and finding the right kind of methods that would give people with intellectual disabilities the chance to truly express themselves. This chapter explains the research design and chosen data collection methods. It explains the considerations for this research and how all this data was then analyzed.

3.1 Research design – Qualitative case study

By using qualitative research methods I would like to show how different elements of holiday experiences affect the sense of empowerment of people with MID and ASD. Usually, when the research question and purpose are formulated, the next step is to find a setting – participants, locations, organizations, places – in which to conduct the research (Boeije, 2010). However, for this research it worked the other way around. I used the holidays I guide for Flow Reizen as case studies which allowed me to come up with the more specific research questions for this research. The setting was decided by the fact that I work for this organization, which trips they let me guide and which participants on those trips were willing to participate.

The research makes use of four different holiday trips as case studies and has an exploratory approach. Exploratory studies yield new insights into a topic for research, but they also have a shortcoming. This shortcoming has to do with representativeness. With this research I do not attempt to give any definite answers and I do not want to generalize the population of people with MID and ASD, as I know that this group is too big and diverse to capture in this, or any, study. The sample I use for this research is not representative of all people with MID and ASD. Within the scope of this research a small group of people with MID and ASD share their personal experience, which will hopefully provide better understanding of what empowers some in this group of people, but this will not apply to every individual with MID or ASD. Besides being exploratory, this research also has an interpretivist approach. Interpretivism aims at discovering how the subject of a study understands his or her life (Babbie, 1998). To be more precise, this research has an idiographic, interpretivist approach. This means that a small number of individuals is asked about a certain experience and is given the chance to explain themselves. The idiographic approach yields an in-depth understanding of the subject's experiences and how the subject has interpreted them (Babbie, 1998). The purpose of this research is not just to study something, but to actively engage participants in the research, which in itself can lead to empowerment (Niesz, et al., 2008). As a result of this I cannot draw conclusions about the feelings of all people with MID and ASD, but as discussed before this is not the aim of this research.

Interpretive qualitative research is sometimes called 'emergent design' (Niesz, et al., 2008). This refers to the flexibility of the type of research, allowing researchers to pursue questions that emerge through the ongoing inductive, data analysis. Through the interaction with the people being studied, researchers often come to the conclusion that their ideas about the best way to collect data must be adapted and research plans must be changed.

3.2 Data collection methods

There are many different qualitative research methods, but for this research three of these methods were considered most suitable. These three methods were tested during the first trip which was used as a pilot study and when necessary adaptations to the initial set-up of this research were made after this first trip.

3.2.1 Structured interviews

According to Malik et al. (1991, in Dattilo et al., 1996), few people with intellectual disabilities have the reading or writing skills necessary to complete a research questionnaire. However, many of them have the communication skills needed to answer appropriately stated interview questions (Dattilo, et al., 1996). More valid responses can be obtained, because interviews provide greater potential for correcting misunderstanding and bring forth more in-depth coverage than questionnaires. There have been some studies that document the ability of people with intellectual disabilities to make valid and reliable responses to self-reporting instruments (Dattilo, et al., 1996). These studies support the use of self-reporting measures, such as an interview, to obtain information directly from people with intellectual disabilities. According to Wadsworth & Harper (1991, in Dattilo et al.,1996), questions directed to people with intellectual disabilities rather than to other people who might respond for them (e.g. parents, siblings, care providers) are consistent with fostering more individual choices and decision-making by individuals with disabilities, which can be related to the concept of empowerment and is also in line with my objective for this research. Because these interviews took place during the participants' holiday, it was important that they did not take up too much time (max. 30/45 min per interview). It was also very important that the questions were short and simple to understand and that participants were given enough time to think about them and express themselves clearly.

The interviews took place on-site at the destination at the start of the holiday and at the end of the holiday and followed an interview guide to create structure for both the researcher and the participants. Participants were given the opportunity to elaborate on their answers. Before the interview started, permission was asked, by means of a consent form and information letter(see appendix III + IV), to record the interview by means of a digital voice recorder and all participants agreed to this. Notes were also made during the interview to write down extra information that could be important for the research. The interviews were transcribed after the fieldwork. The two interview guides (see table 2) were based on the five distinct and interacting phases of a leisure experience as described by Lee et al. (1994): anticipation, travel to, on-site, return travel and recollection. This created a clear structure and made it easy to follow for participants and easier to analyze afterwards. The questions for each phase were connected to the ten different empowerment characteristics.

Interview guide 1 (start of holiday)	**Interview guide 2 (end of holiday)**
Introduction: *Age, work, hobbies, living arrangements*	On-site: *Undertaken activities, own choice, opinion on activities, repeat at home, free time, daily activities, unexpected/new activities, attitude from others, feelings after activities, part of the group, meeting new people, guidance during holiday, treatment, positive and negative experiences*
About disability: *Kind of disability, opinion on the term disability, effects of disability, reactions from others, help needed during holiday*	Discussion photo-assignments
Anticipation: *Reason for booking holiday, looking up information, deciding on destination, booking the holiday, expectations*	Return travel: *Getting home, feelings*
Travel to: *Travel to pick-up point, travel to destination, group travel*	Recollection: *Staying in touch, telling people about the holiday, reunion, plans next year*
On-site: *Expectations of activities, new activities, learn new things, expressing own will, attitude from others, differences from home, own input*	Participation in research: *Thoughts on participation, learning new things, effect of participation*
Explanation of photo-assignments	

Table 2. Summary of interview guides (for complete interview guides see appendix I)

3.2.2 Participant observation

Participant observation is a specific form of field research in which the researcher participates as an actor in the events under study (Babbie, 1998). Where participation was at first viewed as a means to observe, nowadays participation is considered essential in detecting meanings, feelings and experiences (Boeije, 2010). Within participant observation, there is a wide range of roles the researcher can take, from complete participant to complete observer. As a complete participant, the researcher lets people see him/her only as a participant and not as a researcher. The complete observer, on the other hand, does not become part of the process at all and might also stay unnoticed by the subjects of study because of this. Both roles have their pros and cons, and many researchers opt for a role in between the two. It is important to note that anything the participant-observer does or does not do will have an effect on what is being observed (Babbie, 1998). Because of my role as a guide during the holidays, it was impossible to not to be participating in the events under study, but I informed participants about my research. By actively participating and using participant observation, I was able to observe the participants during the actual experience and these observations were written down in a notebook at the end of the day.

3.2.3 Photo elicitation

Photo elicitation is a visual research method that makes use of images. Images can be used in many different ways in research. Much research uses found images that already exist as visual materials, but another way of using images in a study is by making them part of the research project (Rose, 2012). These images can be made by the researcher, but in this case they were made by the people that are being researched. Ter Haar (1981) works with photography and adults with intellectual disabilities. He explains that there are different purposes for taking photos. One of them is 'bringing messages across'. Some of the participants find it hard to express themselves in words, and photos are a solution for them to show what they find important during their holiday experience. He also mentions that photography can enhance self-confidence, because participants are 'allowed' to use the camera and can be proud of the photo they have taken. And by walking around with a camera and taking photos of the area or other people, photography can also contribute to integration of this group of people, because of the contact with others that will follow from this activity (Ter Haar, 1981). This method does not emerge from specific theoretical contexts, and can therefore be used to answer a wide variety of research questions. It is the most popular form of visual method currently in use across the social sciences (Rose, 2012). The method is said to have four strengths:

> 1). Photographs carry a lot of information and discussing the photograph with the interviewee can introduce different things than just talking about a certain topic.
>
> 2). The method is particularly helpful in exploring everyday things in life, because participants are asked to reflect on activities in which they are usually immersed and it gives them the opportunity to take a step back and express their thoughts and feelings about it.
>
> 3). Elicitation interviews with participant-generated images are often argued to empower research participants, because it gives them a clear and central role in the research process and also because they are the 'expert' in the interview, explaining their photographs to the researcher.
>
> 4.) Because of this third reason, several researchers also claim that this method demands collaboration between the researcher and the research participants in ways that other methods do not (Liebenberg, 2009; Rasmussen & Smidt, 2003; Mannay, 2010; White et al., 2010, in Rose, 2012).

Photo-elicitation can be seen as a productive method, but also a complex one. It is important that researchers using this method are highly reflexive in their use of the method, discussing their own role in the work and looking carefully at the impact and use of the results. This attentiveness to the role of the image, to the research process and to the researcher's role in the method suggest that photo-elicitation can be a valuable critical visual methodology (Rose, 2012).

Participants were each handed a digital camera with memory card and, by means of four different day assignments (see table 3), all participants were asked to take photographs which were later discussed in their second interview with the researcher. These day assignments were explained to them each morning and they also received a hand-out of the assignment with example images on them. Because time was limited during the holiday to discuss all the photos, participants were asked to take no more than 10 photos per assignment. Some participants made more than 10 per assignment; others found it more difficult or forgot their cameras, resulting in less than 10 photos per assignment. When only a few photos were taken by participants, they were asked whether there had been moments participants had wanted to take a photo, but did not do that for some reason. These answers were written down and used in the data analysis.

Assignment 1: *Take a photo of something that is very important to you during this holiday.*	Assignment 3: *Take a photo of something that is very nice or special to you.*
Assignment 2: *Take a photo of something that bothers you or is difficult for you this holiday.*	Assignment 4: *Take a photo of something you would not (easily) do at home.*

Table 3. Summary photo assignments (for complete photo-elicitation assignments, see appendix II).

Assignment 1 was asked to get a better insight of what participants find important during their holiday. No such question was asked directly during the interview because it can be many different things and therefore overwhelming and even impossible for participants to answer. By giving them time to think about this and making it visual a better insight is gained in what they find important and how this relates to their daily life at home. Outcomes of this assignment can be used to include in future holiday planning and by doing so, increasing the possibilities for empowerment. Assignment 2 was asked to get to know the negativities that participants encounter during their holiday, why this was considered a negative experience, and how this influenced their holiday feeling. By knowing this, actions can be undertaken to do something about it and remove possible obstacles to empowerment. Assignment 3 is purposely quite similar to assignment 1, so that participants once more look at positive things during their holiday. The difference is that assignment 3 is not necessarily connected to the holiday, but more to positive experiences in general and how this influenced the participants during their holiday. The effects of these, more regular, things can again contribute in creating a more empowering holiday environment. Assignment 4 is asked to create visual material of activities that participants would not do at home, but do participate in during their holiday. The reasons for not doing this at home are explored and also why they decide to try this during their holiday. Trying new things and feeling good about doing them is a big contributor to empowerment, so by knowing why participants decide to do these things during their holiday can create more opportunities for empowerment.

3.3 Data analysis

The previously described research methods generate quite a lot of input. The results of the interviews, participant observations, and photo-elicitation provided a lot of detailed, but unstructured information. It was therefore important to get all this raw data ready for analysis. The next step in preparing the data was transcribing the interviews. It is important to know that most non-verbal behavior is lost in the process of transcribing, although notes of the interviews have been included into the transcriptions as much as possible because they could be important for the results. Furthermore it was important in the preparation of the data to take out all information that could identify participants and violate the promise of anonymity. This meant making a pseudonym for all participants. When this preparation had been done, the actual analysis could start.

The two basic activities of analysis are segmenting the data into parts and reassembling the parts again into a coherent whole (Boeije, 2010). The transcript and photographs of photo-elicitation can be interpreted using conventional social science techniques (Rose, 2012). Participant observation notes were used to complement the obtained information. Topics that are of interest for the research results appeared at different places within all the obtained data, sometimes using a slightly different terminology. To segment the data I 'cut up' the obtained data, and pieces that I believed belong together were combined. The transcript of the interview also explained the photo and its representation and therefore the interview and photos were treated as one body of data with a coding system that included both of them. Combining the pieces together resulted into meaningful groups. Part of these groups had deductive codes and other groups inductively emerged from the data and were then named and coded. For the assembly of the data, the different phases of a leisure experience provided a structure for dividing these groups in an organized manner.

Depending on the kind of photos that were taken during the holiday, some of the photos were used in this final report. They could only be used if the anonymity of the photographer and people in the photo could be guaranteed and if it added to the research results, by means of clarifying, emphasizing or clearly making visible what is written in the text. Participants were asked during their second interview to explain what the photos represented for them and this was written on the back once the photos were printed off. Duplicates were taken out and also photos that were considered too personal and irrelevant to the assignment were left out of the analysis. Photos were considered irrelevant when they are not connected to any of the characteristics of empowerment The photos were then spread out on the floor and clustered into themes arising from the photo descriptions. These clusters were later used to complement the results and analyses from the transcripts. Many quotes of these transcripts are used to truly show the perspective and experiences of the participants. All interviews and transcripts were originally in Dutch and all the quotes used in this thesis have been translated by the researcher in the most literal way without losing too much of the original tone and meaning.

3.4 Positioning

Besides the research design and its methods it is also important to be aware of the role of the researcher, the selection of the respondents and other principles that might have an influence on carrying out the research.

3.4.1 Role of the researcher

During the fieldwork period I had two responsibilities; being a guide and at the same time being a researcher. This caused me some anxiety and hesitation at first. As a guide I was obviously connected to Flow Reizen, but as a researcher I wanted to stay as objective as possible. Participants also connected me to Flow Reizen and sometimes it prove to be difficult making them let go of the idea that I was doing research for Flow Reizen to improve its holidays. For the research I could adopt the role of participant-observer, which meant I could get great insight into all that participants did during their holiday. But being with them all the time could also influence my role as a researcher. It was therefore very important to be aware of these two roles and try to leave the guide role behind when I was interviewing and vice versa.

It is mentioned in the paragraph on photo elicitation that researchers have to be highly reflexive in their use of this method. I am extremely happy with using this research method as it proved to be very nice and interesting for participants to make photos by means of the assignments. I did not interfere with participants when they were making photos, although I did have to remind them sometimes to take their camera with them. To not let my view influence the interpretation of the photos too much, I let participants explain what they meant by the photos and wrote this on the back of the photos once they were developed.

3.4.2 Selecting the respondents

Before I could start the fieldwork of this research, I asked permission from Flow Reizen to ask their participants to become part of my research. Together we discussed my ideas and talked through how I could make sure that the research would in no way negatively affect the holiday experience of the participants. Flow Reizen gave me some last pieces of advice, such as keeping questions short and simple and using example photos, and then got their full support and trust in carrying out this research.

During all four trips I was guiding I hoped to find three or four participants willing to participate (out of a group of 15 travelers). I explained to the whole group what I was doing and asked whether there were people interested in participating. People who were interested were then briefed in more detail on what was expected from them and if they were still enthusiastic about participating, a first interview was set up where they also signed a consent form. On this form they agreed they had been well informed about the research, its objective and purpose, and knew they had the right to quit participating at any point in time without any further consequences. During the pilot study, four participants were willing to help out, but one perceived the photo assignments as too stressful and decided to quit his participation in the research. As it turned out three participants was the perfect number to balance out the time between research and guiding work and also offered me enough interesting information on how participants experience their holiday. During the third and fourth trip I first approached the women to ask whether they wanted to participate as I only had male participants during the first and second trip and I wanted to have both genders included in this research. After the women had agreed or not, I explained again to the whole group what I was doing and filled the last spot(s) with participants who volunteered to participate. This way of selecting the respondents for the research led to a total of 10 male participants and 3 female participants in this study. In general, there are more men with intellectual disabilities than women, the official ratio being 1.5:1 (Hofman, 2012). And also within Flow Reizen there are more male participants than female participants, a ratio of around 2:1. And although the numbers of research participants do not match completely with these ratios, I do believe that these respondents, and more importantly their stories, offer the insight I wanted to acquire with this research.

3.4.3 Research principles

Reliability is often a point of discussion in research concerning people with intellectual disabilities (Dattilo, et al., 1996). Interviewing people with intellectual disabilities poses special problems, both practical and ethical (Laws & Radford, 1998). Difficulties in conducting interviews and using self-report questionnaires with this population are widely reported (Finlay & Lyons, 2001). Problems that arise are; acquiescence (the tendency to agree with a proposed statement) and recency effects (the higher probability of choosing the last option offered when closed questions are posed) (Beart, et al., 2001). It should be noted that these difficulties do not apply to all people with intellectual disabilities, as there are many who will have no problem participating in these types of research. However, it is widely acknowledged that vocabulary and meaning should be clear and simple to prevent or minimize these difficulties (Finlay & Lyons, 2001). For the interview questions I tried to make questions short and clear and when needed explained them in more detail. Because of this, I hardly encountered any difficulties concerning participants not understanding the questions they were asked.

This research has purposely left out interviewing caregivers or parents to check the answers provided by the participants, because I wanted to really let them tell their own stories. By using different research techniques that complement each other, reliability should be no issue for the outcomes of this research.

To guarantee the participants privacy pseudonyms are being used in the report.

4. The holidays and its participants

To better understand the findings of this study, I will first provide more information on the setting in which this study takes place. This chapter starts with the different possibilities for people with disabilities to go on holiday and how their surroundings react to the fact they can go on these organized holidays. I will then provide more details on the way Flow Reizen sets up its trips and describe the four different holiday destinations used in this study. The chapter ends with a short introduction of all thirteen participants in this research.

4.1 Disability and going on holiday

As discussed in the theoretical framework of this thesis spending leisure time and going on holidays has not always been an obvious possibility for people with an (intellectual) disability. This has been changing over the last few decades and this has been accompanied by many organizations coming into existence and targeting these groups of people. Some organizations have been offering specialized guided holidays for over 40 years, but until recently there was no monitoring, collaboration or quality control of these different holiday organizations. And therefore also no clear overview of all the different organizations offering these kind of holidays. This changed when the NBAV: Nederlandse Branchevereniging Aangepaste Vakanties (Dutch branch union for customized holidays) was set up and created their own quality certification. The Netherlands is unique in having this quality check on specialized holidays. In their Blauwe Gids (Blue guide) 2015, all 23 tour operators that currently have the NBAV quality certification present themselves. Some offer holidays in The Netherlands only, while other organizations also offer trips (much) further away. Some organizations focus only on people with autism (such as AutiTravel), epilepsy (such as Epilepsiefonds) or physical disabilities (such as Nationale Vereniging de Zonnebloem). Other organizations focus on people with physical and/or intellectual disabilities, but offer different kinds of holidays for the different groups (such as Stichting Wielewaal, TOF vakanties, SET Reizen). And there is also a group of tour operators that focus, like Flow Reizen, on fairly independent travelers with MID and ASD (such as Tracks Travel, Het Buitenhof).

So there is no doubt about the variety of holiday possibilities for people with an intellectual disability and the quality of these holidays, but do people with a disability also feel they have the same right as others to go on a holiday? And is this accepted by their surroundings and society? To gain insight in this, participants were asked how people around them reacted when they told them about the holiday they were going on. Most participants received positive reactions from others when they told them about their holiday plans.

> *"No, no one has said to me that I couldn't do this, on the contrary, they are very enthusiastic about it!" (Sander)*

> *"When I tell my family some say 'Oh, that's great and exciting' and some tell me 'good luck', but I have never heard them say that I couldn't do this." (Thom)*

Some participants experience a more doubtful attitude from their surroundings before they take off on their holiday.

> *"Yes, sometimes they act like I cannot do anything. They tell me beforehand that I should be doing this and that. That makes it seem like I cannot do anything by myself." (Sylvia)*

> *"Yes, there was some doubt from my parents. My father especially thought it would be too complicated with regards to the activities. But in general, I thought it went fine." (Matthijs)*

Parents play an important role in the support of participants going on holiday. Quite a number of participants used to go on (active) holidays with their parents, but now that they have grown older are encouraged by their parents to go on their own.

> *"I used to go on active holidays with them [parents], also hiking with our backpacks on. Just going from hotel to hotel. They have always taken good care of me, yes, that's something I have to give to them. They now see me as much more mature." (Bram)*

"This is my first time travelling with Flow Reizen, I used to always go on holidays with my parents. Now there will be different kinds of activities, it'll be fun!" (Sander, photo assignment 3: 'Take a photo of something you find very nice or special during the holiday')

But this support is not only in the past, it continues throughout the present holiday experience. Of course not only parents play a role in this. As discussed earlier, society plays an important role in this, but also the organizations organizing the holidays and the people working for them. The next subchapter will explain how the organization sets up their holidays and how they make sure the destinations help the participants in making the most of their holidays.

4.2 Destinations of Flow Reizen

Every year Flow Reizen offers a new collection of holiday destinations that is made up of new destinations and previously used destinations. Martijn Riswick, program coordinator at Flow Reizen, explains how they go about setting up their new holiday offer every year:

> *"We start with a brainstorm session in which we take the old brochure and cross out the destinations we won't be using the next season. These can be destinations that have been on offer for a long time and have started to lose interest or destinations that didn't receive the anticipated attention. We then think about where we would like to go and check what kind of holidays we need to balance out the program we offer, making sure that there are enough beach holidays, camping holidays, active outdoor holidays etc. It has to be a complete program we offer. We then check what can be done at that destination and by doing this we come to a more specific location."*

But it is not easy, and it is also not an exact science. Sometimes they think of an activity first, for example a cycling or hiking holiday, and then start looking for a fitting destination to carry out this activity. With choosing this destination they certainly think of the target group.

> *"We find it important to get rid of the stigma that people with an intellectual disability couldn't do a cycling holiday, but at the same time you have to make sure the environment isn't too challenging for them (for example lots of high mountains), so that they can have the opportunity to experience their success stories and feel good about themselves."*

Overall they have a few criteria that their holiday destinations have to match. To keep their prices as low as possible, they are always looking for the best price-quality ratio.

> *"Because these holidays are already a lot more expensive than other, regular holidays, it is important that we find quality destinations that match the high criteria the participants, just like anyone else, have these days and are also affordable."*

The reason that these kind of holidays are more expensive is the fact that every group has three or four guides who are getting paid and whose expenses need to be covered too. Besides this, the organization of these specialized holidays cost more than regular holidays.

Participants also need to somehow know about the destination. It has to be well-known or often travelled to by people in their surroundings. This goes for both the European destinations and city trips as well as the far-away destinations.

> *"We could offer a trip to Guatemala, but I can guarantee you now it won't sell. We need destinations such as Australia or New Zealand. Normally Western destinations, or at least well-travelled countries, such as Thailand. Participants really need to know about the destinations and recognize them, they have to have a certain image in their head already".*

For most destinations, Flow Reizen prefers a small-scale set up because this offers participants a clear overview, which is often comforting for them. But this is different for beach destinations.

> *"We want to overcome the stigma that people with a disability should go to quiet, hidden away destinations, so we also want them to be in the busier, more touristy seaside resorts. Maybe not in the middle of all the clubs, but at least close enough."*

For these beach holidays Flow Reizen works together with other tour operators with whom they thoroughly discuss the options, but for a lot of other destinations they pick their own accommodation providers. It is very important that the participants feel welcome and therefore Flow Reizen is always clear about the target group they provide for. Some accommodation providers never reply to the requests, others back-out and some are happy to welcome the groups.

With all this in mind the holiday program for 2014 was set up. This thesis research was carried out during four different trips in the summer of 2014. What follows now is a short description of these four destinations.

The first trip went to the Black Forest in Germany (10 days) and offered a diverse activity program, with the possibility to take some relaxed hikes as well as more adventurous activities, such as parapenting, water parks or luging. Unfortunately, the weather during the 10 days consisted of a lot of rain and many activities had to be cancelled. This definitely influenced the participants, but all fifteen stuck together to still make the most out of their holiday. Substitute activities were a tropical swimming pool with many slides and an entertainment hall with climbing wall, segwaying and archery. The group stayed at a guest house in a hamlet close to Schluchsee. The guesthouse is run by a Dutch couple who took care of breakfasts, dinners and packed lunches.

The second trip went to Dalarna, Sweden (12 days), and also offered a diverse activity program. The journey to the destination took two full days, which was quite long for some. The weather was around 30 degrees with blue skies most days. This made long trips with the buses not so inviting, but trips to some of the many lakes were most welcome. Sweden's nature offered some nice walks and sightseeing trips too. The highlight for most was the railroad biking and the visit to a moose farm, where participants could get close to alpacas and moose. The group stayed in three holiday homes next to each other at a large holiday park. All meals were self-catering, so participants had to help with cooking and cleaning.

The third trip went to Passau, Germany (12 days), and this was a cycling holiday. The first three days were spent cycling on regular bikes around the Danube and Inn rivers. Another three days were spent exploring the more hilly area around the hotel on e-bikes. The other days were filled with other activities, such as shopping, a walk- and wellness day and visiting a nature-themed entertainment park and luging. The group stayed at a typical German hotel with a wellness area and indoor swimming pool. Breakfasts and dinners were included and picnic lunches were had along the way.

The last trip was to Lax in Switzerland (12 days), where the focus lay on activities such as hiking and exploring natural wonders, such as glaciers and the Matterhorn, but also offered other kind of activities, such as parapenting, swimming and digging for minerals at Binntal. With only 10 participants, this group was smaller than the other three. They stayed at a small hotel run by a Dutch family. Breakfasts and dinners took place at the hotel and packed lunches were also provided by the hotel.

All four trips were hotel/guesthouse trips, which means that the guides drive two mini-vans to the destination and that the group stays at a hotel, guesthouse or holiday park. Overall, these kind of trips are more nature and culture oriented and more active than for example the sun, sea and sand trips, which almost always include a flight to the destination and more relaxed activities. Flow Reizen also offers camping trips, which are a bit more adventurous and requires greater contribution of the participants in daily matters, such as cooking and cleaning, than the other two types of trips, although the holiday park trips also require this. Participants are most of the time very aware of these differences and choose their kind of trip accordingly.

> *"First of all, it is nice and quiet here, with lots of space; nature and space. Fresh air and those sort of things. And that you do not have to do too much, but still be a bit active. Yes, being active, not one of those lazy holidays, I don't like them, those beach holidays. Really doing nothing, that is.. only sunbathing and then burn and having to put sunscreen on constantly. And then just lie lie lie there, that is not my kind of holiday." (Bram)*

> *"That it is a bit more active, I think. For example, a holiday to some sort of beach side resort in Spain that's often lying on the beach during the day and going out at night. That doesn't sound appealing to me." (Max)*

Some of the participants of this research have already given part of their input on holiday matters in this and the previous subchapter, but in the following chapter they will introduce themselves and we will get to know them a bit better before reading more about what they have to say about their holiday experiences and what influence it has on them.

4.3 Introduction of participants

The participants of this research play a crucial role as they will share their personal experience during their holiday. To get to know and maybe understand their stories a bit better what follows now is a brief introduction of them and their daily lives. They will explain something about their disability and how this influences their lives. To guarantee their anonymity their real names have been replaced by pseudonyms.

John is in his late-thirties and works as a volunteer at a nursing home. He lives in a semi-supervised residence, where he has his own apartment. In total there are 9 apartments and a supervisor is available from 7am-1pm and from 3.30-8.30pm. In his free time he goes to the fitness centre and he likes to paint. This is the 3rd time that John joins a holiday from Flow Reizen and his choice fell on Switzerland this year.

When asked about his disability he explains that he was in a car accident when he was nine years old. This resulted in a 6-week coma and after this another 6 weeks of rehabilitation during which he had to start all over again. He now suffers from tremors and needs more time to think before he says something. Also his walking and speech have been affected. He finds it difficult to give an exact description. He has no problem with the fact that people call this a disability. Because of his positive attitude he rarely has negative experiences with people reacting to his disability. When he goes on holiday he needs some help with money matters and sometimes with eating.

Sarah is in her mid-thirties and works at a thrift shop where she sorts out and prices the glassware and works at the register. Next to this she still has time for her hobbies: making 3D-cards, running and cycling. She lives independently and receives help from her parents when she needs it. She cannot remember how many times she has been on holiday with Flow Reizen.

She explains that her disability is an unidentified development disorder with some autistic traits. This means that she can go very quiet and have panic attacks. Sometimes this also results in being angry without a clear cause. She sometimes finds it difficult to deal with this and therefore experiences this as a disability and agrees with using the word disability. Thankfully, most people in her surroundings are very understanding. She finds it difficult to explain the kinds of support she needs when being on holiday, but explains that, because she can go very quiet, she finds it hard to, for example, ask the way. In these kinds of things she needs help.

Thom is in his mid-twenties and works as a gardener. In his spare time he likes to go cycling, swimming and spend as much time outside as possible. He lives in a supervised residence with 10 others and all of them have their own apartment with own facilities. His 3rd Flow Reizen holiday brought him to Switzerland.

Thom has PDD-NOS and finds it hard to deal with certain things, such as calculations. He can get angry when things do not work out the way he wants them to, which will then result in stress. For this he needs someone to fall back on. However, due to his medication, these situations are minimized. He does not care if people call it a disability, because he just accepts the way he is and with this his disability. Most people at home also deal with it in a normal matter. Most people he lives with also have a PDD (*pervasive development disorder*) or another kind of disability. When being on holiday he needs some help with money matters.

Liesbeth is in her late-thirties and works at a factory where she checks boilers four days a week. Besides her work she goes to the gym three times a week and she loves cooking. She lives independently with someone helping her once a week or not all when she thinks she does not need it. This cycling trip to Passau, Germany, is Liesbeth's 11th Flow Reizen holiday. She and her boyfriend (who she met during a Flow Reizen trip) take both summer and winter trips.

She finds it hard to describe her disability, but tries anyway. She describes it as a MID caused by something in her head. It has something to do with chromosomes. Liesbeth explains that a normal person should have 24 or 25 chromosomes [*should be 23 pairs]* and that she has too few of them. At first she says that she does not know the effect of this on her daily life, but after a bit of probing she explains that she can react a bit angry to certain things and that she wants to do everything better than others. It used to bother her when she was younger, but not so much anymore now. She is very happy that the word 'handicap' has been replaced by 'disability', because she thinks that the word 'handicap' really makes you feel less worthy than using 'disability'. However, she knows that she has a disability, but does not really feel disabled. She would hate it if people would feel sorry for her or treat her in a different way. During her holiday she needs some support in controlling her emotions, but other than that she is very capable of looking after herself.

Sylvia is in her late-forties and works at a facility especially for people with a disability. Here she mainly works for a nursery, making cuttings etc. She is very sporty and in her free time likes to go running, swimming, fitness and play badminton. She also enjoys spending time on her computer, but Facebook also causes her a lot of stress, trying to keep up with everyone and all the messages. She lives independently with someone coming to help her once a week. Sylvia has taken 11 Flow Reizen holidays, including this cycling holiday to Passau.

Sylvia has classic autism. She explains that she can be very focused on certain things. Some of these things are temporarily and other things have been fascinating her her whole life already. Her thoughts linger and she can feel miles away from reality. She experiences this as a disability and agrees with using this word, because her lack of focus and short attention span influences her life and the work she can do. She is very aware of her disability and often notices that other people react to something she has done, which makes her very self-conscious and uncertain about her actions. During her travels she needs help with the language (she regrets that she was only taught English at her high school) and with transport and being on time.

Martin is in his early-fifties and also works at a special facility where he works at the packaging department. He really enjoys listening to music, singing (karaoke) and playing computer games. He lives independently with someone helping him for 1/1.5 hours a week. After Portugal and Sweden, he now takes his 3rd trip to Passau with Flow Reizen.

He does not really know what his disability is, but he knows it means he cannot keep a steady job. Reasons for this are because he is not fast enough and tends to get distracted quickly. He really sees this as a disability as he would really like to have another job, but he has had no luck with this. Besides his work issues he experiences no difficulties in his surroundings. During his holiday he needs some help with his financial matters.

Harrie is in his mid-thirties and does packaging work and one day a week he does computer and printing work. In his spare time, he also likes to spend time with his computer. He lives semi-supervised with someone helping him twice a week. Together with his friend Martin, this is his 4th trip with Flow Reizen. This time trying a cycling trip to Passau.

He explains that when he was younger it was discovered that something was not quite right in his brain. Only recently he has been diagnosed with PDD-NOS. It means that he cannot go to a regular school. Other than that he does not know any limitations on his daily life caused by his disability. He does not like the word disability and would like to replace it, but thinks that will not be possible. He would prefer not giving it a name at all. In his surroundings they just accept him as he is. He needs help with money matters during his holiday.

Sander is in his mid-twenties and works five days a week in catering at a Dutch university. His hobbies are cycling, music and watching football on TV. He also likes to cook and this is important as he lives independently. He got invited by a friend to join him on his holiday, so this trip to Sweden is Sander's first experience with Flow Reizen.

He has a slight form of autism. It is not too bad, he says, only in certain situations he can panic and freeze, not being able to react or move. He sometimes sees this as a disability as he can act differently from other people. He much more prefers the term 'disability'[beperking], than 'handicap'[handicap], as the latter has a very negative sound to it. People he meets at home sometimes do not even notice that he has a slight form of autism, which he likes as it confirms for him that it is not too bad. During his holiday he will only need support when unexpected situations arise.

"Swedish Krona. They're very different; different notes and value. It's quite complicated to calculate." (Sander, Photo assignment 4: 'Take a photo of something you would not do at home very often')

Matthijs is in his mid-twenties and works at a social care farm and a computer centre. Besides working five days a week, he also has a lot of hobbies: horse-riding, athletics, hockey, cycling, hiking, gaming, watching movies and listening to music. At the time of the interview, he was still living with his parents, but after the summer he was going to move to a supervised residence. As a kid he travelled often to Scandinavia with his parents, so he is excited to be back in Sweden with his fourth or fifth Flow Reizen holiday.

He has issues with his balance, spasms and a slight developmental delay. The disability has an old-fashioned Greek name, but he can never remember this. He sometimes sees it as a disability, but more often he does not. However, he has no problem with people calling it a disability: *"They can call it whatever they like"*. Most things he can do by himself, only actions involving his fine motor skills can be a challenge for him. This is also what he needs help with during his holiday. At home he has very diverse experiences with how people act around him and his disability. When he encounters groups of youngsters when he is riding his tricycle they often mock him. His strategy is to reply to them in the same manner; *"When they stare at me or say strange things to me, I'll do the same to* *them.”*. This makes them go quiet as they realize he is a lot smarter than he may look. Funnily enough, this has given him more self-confidence as he was able to shut them up.

Benny is in his late-thirties and works as an actor in a theatre group for people with a disability. They rehearse three times a week and perform in November/December. He also collects CD’s and LP’s and likes to read, watch TV and movies. He has his own apartment, but someone comes to help him now and then. This trip to Sweden is his 15th trip with Flow Reizen and he travels together with his girlfriend.

When asked about his disability he acts very indifferent. “*They say I’m autistic”*, is how he explains it. The first time he really heard this was when he was 23 years old. But he can live with it and it did not make him feel any different all of a sudden. He takes everything very literally and can continue talking about a certain thing for a very long time. He does not see this as a disability, as everyone is disabled according to him: *“People wearing glasses are also disabled”*. He has, however, no problem with people using the word ‘disability’. He has very little contact with people in his environment. He would like to have more contact, but thinks that other people are too busy for this. The only thing he needs help with during his holiday are money matters.

Frits is in his early-thirties and works at the packaging department of a special facility. In his free time he plays a lot of sports: korfball, swimming, mountain-biking, hiking and running. Together with six others he lives in a supervised residence. He joins Flow Reizen for both winter and summer trips and therefore this is his 15th or 16th trip in the last ten years. He is actually taking two trips this summer and this first trip is to the Black Forest in Germany.

He has a slight intellectual disability and used to suffer from epilepsy. For this he has had an operation where they cut away a small part of his right eye and he has not had any attacks since, only light epileptic activities now and then. He also suffers from depression and has changing obsessions. He is also insecure about what others think of him, fills in what he thinks they think of him and is afraid to not be accepted in the group. He certainly sees all this as a disability as it really limits him in living his life the way he wants to and it annoys and tires him. Back home people often overestimate him and his capabilities, which he finds difficult, but also makes him act a bit arrogant, which he does not really want to be. He feels that care-workers at home do not give him the help and solutions he needs and is stuck in his own vicious circle, where everyone keeps telling him he is the only one who can make the changes, but he cannot seem to do it. During his holiday he needs a bit of guidance and help in re-assuring him he is part of the group and doing fine.

Bram is in his late-forties and works as a gardener. His work is also his hobby, but he also likes computers, plants, cycling and hiking. He lives in a special facility for people with autism. He says that Flow Reizen has really changed him and his life during the past 1,5 years. This trip to the Black Forest is his fourth trip in such a short period of time.

He is autistic and used to be a real perfectionist and could spend hours on putting everything straight in his room or picking up all the leaves outside. This gave him a feeling of safety. He also used to start packing his suitcase for a trip a month before he would leave, but for this trip it only took half an hour. This change happened gradually, but started during his first Flow Reizen trip 1.5 years ago. He is now much more aware of his autistic traits and can deal with them better. He never saw it as a disability, but now recognizes it undoubtedly is, because it controls his life. When he was younger he certainly noticed people acting different towards him, but these days he has changed a lot and everyone is very understanding. He very much enjoys the company during his holiday and needs guidance to get him to the destination and offer support in unexpected circumstances.

Max is in his late-thirties and works at a special facility where he does various jobs at the school furniture department, from drawing to archiving. At home he likes to make scale models. He lives at a special residence with five others and has only just recently moved there, so he is still settling in. This is his first trip with Flow Reizen and he has chosen the Black Forest as someone he knew had also booked this trip.

He has a form of autism, called Asperger syndrome. He finds it difficult to make contact with others and can feel quite insecure about what is going to happen. He sometimes experiences this as a disability , but would prefer to give it a different name, but he does not know what name. At home he receives different reactions to his autism, some people do not know and act like it is not there, but he prefers it when people do know and act accordingly. This makes it easier for him. When on holiday he needs help with creating structure by means of a set program.

Table 3 on the following page provides a quick overview of the participants in this study.

Now that the participants have been introduced, chapters 5 to 7 will discuss their holiday experiences and will show which factors are important for them in increasing their sense of empowerment. All this has been structured by dividing the holiday experience and processes in the five different phases of a leisure experience: Anticipation and Travel to, On-site experiences and Return travel and Recollection.

Name	Age	Housing	Work	Hobbies	Type of disability
John	Late-30s	Semi-supervised	Volunteer at nursing home	Going to the gym, painting	Acquired brain injury
Sarah	Mid-30s	Independent (help from parents when needed)	Thrift shop	Making 3D-cards, running, cycling	Unidentified developmental disorder with autistic traits
Thom	Mid-20s	Supervised	Gardener	Cycling, swimming, being outside	PDD-NOS
Liesbeth	Late-30s	Independent (help from care-worker when needed)	Factory work	Going to the gym, cooking	MID caused by too few chromosomes
Sylvia	Late-40s	Independent (help 1x a week)	Facility for people with a disability (nursery)	Running, swimming, going to the gym, badminton, computer	Classis autism
Martin	Early-50s	Independent (help 1x a week)	Facility for people with a disability (packaging)	Music, karaoke, computer games	Does not know exactly, not fast enough and easily distracted
Harrie	Mid-30s	Semi-supervised	Computer and printing work	Computer	PDD-NOS
Sander	Mid-20s	Independent	Catering	Cycling, music, watching football	Slight form of autism
Matthijs	Mid-20s	Moving from parents to supervised	Social care farm and computer centre	Horse-riding, athletics, hockey, cycling, hiking, gaming, watching movies, music	Slight developmental delay and balance problems and spasms
Benny	Late-30s	Independent (help now and then)	Actor in special theatre group	Collecting CDs and LPs, reading, watching TV and movies	“They say I’m autistic”
Frits	Early-30s	Supervised	Facility for people with a disability (packaging)	Korfball, swimming, mountain biking, hiking, running	Slight intellectual disability
Bram	Late-40s	Special facility for people with autism	Gardener	Gardening, computers, plants, cycling, hiking	Autism
Max	Late-30s	Special residence	Facility for people with a disability (school furniture department)	Making scale models	Asperger syndrome

Table 4. Overview of participants

5. Anticipation and Travel to

As discussed in the theoretical framework holidays can be divided in five different phases; anticipation, travel to, on-site, return travel, and recollection. All of these phases consist of multiple aspects. Most of this research has taken place during the on-site phase of the holiday, but this is not the only phase in which empowerment can play a role. Therefore all five phases and its aspects have been discussed with the participants and are described in more detail in the following chapters. Not only were they discussed with participants, but participants were also asked to take photos following four different photo assignments. These outcomes are also used in these chapters. This chapter will deal with the first two phases. Chapter 6 will treat the on-site experiences of participants. Chapter 7 then looks at the last two phases.

5.1 Anticipation

The first phase of a holiday is the 'anticipation' phase. This is the period leading up to the actual departure. During the interview participants were asked about several aspects of this anticipation phase. The following aspects play an important role during this period of time:

5.1.1 Choosing for Flow Reizen

Most of the participants in this research have been travelling with Flow Reizen for several years already. Frits and Bennie are both in the lead with 15 trips. For Max and Sander it is their first experience with the organization. Both Max and Sander have decided to partake in this type of holiday with Flow Reizen because someone they knew had told them and was enthusiastic about it.

> *"I actually found out through Geert. He has travelled with Flow more often and he had already booked this trip, that is how I found out." (Max)*

Some participants have taken holidays with other organizations, but seem to prefer the holidays from Flow Reizen. Liesbeth explains:

> *"I have also travelled with other organizations, but there I felt more like I was the guide than being able to enjoy my holiday.... My father then told me about Flow Reizen and I got in touch with the organization. To try and see whether it was something for me and that is how I took my first holiday with them in 2004."*

Bram is also pleased that he has found this organization:

> *"And now I have discovered something...Flow Reizen is not, well it is not cheap, but not overly expensive and the atmosphere is just fantastic and friendly."*

The reasons for choosing for Flow Reizen are diverse, but these reasons have been given considerable thought by the different participants. During the trips I often asked participants why they opt for Flow Reizen instead of other organizations and reasons for this choice are that participants feel that that Flow Reizen gives them much more freedom during their holiday, the guides are often young and active (the result of working with paid guides instead of volunteers) and the atmosphere of the group is almost always very good. For Flow Reizen, being respectful to each other is of great importance. We, as guides, therefore always have a short talk at the start of the holiday about the fact that everyone in the group has his/her own reason for going on a specialized guided holiday and that we expect participants to show respect to others and accept them the way they are. When problems do arise, they can always come to us and we will help in finding a solution.

Besides this initial talk, we try not to put too much emphasis on their disabilities, treat them friendly and with respect and let them go their own way as much as possible. Participants know and appreciate this, which results in the positive atmosphere.

5.1.2 Choosing the destination

The reasons for choosing the specific destination of the holiday are very diverse for the participants. Some have a very practical reason, for example: the dates of the holiday matched with their time off work or because they speak the language of the destination. Some really like the fact that their destination was only a one-day drive. Others joined their friend's decision. Thom and Frits wanted to try a new destination.

> *"..and then mum said you have to try something new." (Thom)*

Some participants liked the fact that the holidays had an active character. Sylvia, who loves to cycle at home, had good reasons for choosing a cycling holiday:

> *"Because I love cycling, I love cycling, I love active holidays." (Sylvia)*

Although Martin's main reason was the fact that his holiday matched with his time off work, he also saw the cycling holiday as a challenge:

> *"It's just a challenge. I am quite corpulent, so it is supposed to be good for me."*

Others try to avoid too big a challenge because of their disability or an injury.

> *" The country and its surroundings may be very beautiful, but if the activities only make my muscles go tense, then it is just not for me." (Matthijs)*

For photo assignment 4 participants were asked to take photos of something they would not do at home very often. In the results of these photos were quite some images of things that participants described as 'typical of this destination' and 'you don't see this at home very often'. This creates a true holiday feeling for participants and these kind of things can therefore also be seen as a reason for choosing a certain destination:

CD from my favourite DJ. At home I download, but now I bought it here because he is from Sweden -– Sander

Village flower festival. You don't see this at home, it's typical for this region - Max

Flower parade, a special afternoon. Typical German village, beautiful weather, a real nice Sunday – Bram

5.1.3 Looking up information and deciding on holiday

Every season there are many different destinations to choose from for all participants. All the information about the different kind of holidays can be found on the website and in a brochure. Both are used by the participants. Some participants look up the information on their own:

> *"No, I decide completely on my own. Before, I used to discuss it with my mother and care-worker. Yeah, sometimes I used to discuss it, but then the decision had already been made." (Sylvia)*

Others have a partner to consider or a friend or even a group of friends who they are travelling with. But most participants discuss their destination choice with a parent and look up information together. In the end almost all participants decide themselves which holiday they will book.

> *"I look it up in the brochure and then discuss it with my parents and together we have a look at it. I then decide what I like the most." (Sarah)*

> *"Together with my mum I then look whether it is feasible for me and we discuss whether the trip I choose is the one for me to do or whether another one would be better. But in the end I have the final say." (Matthijs)*

Only Thom leaves a lot up to his mum:

> "*No, mum does all that for me." ..."But in the end I have decided to do this trip."*

From an empowerment perspective participants play a big part in looking up information about their holiday and deciding which holiday they will join.

5.1.4 Choosing an organized group holiday

The reasons for going on an organized group holiday differ among the participants. One of the reasons for Bram is the transport, because he does not have a driver's license or car. Or in case some kind of emergency happens and he would not know what to do then. Some find comfort in travelling with a group because they do not speak a foreign language or because they like the fact that there is a set program, because they would not know how to organize the activities and are afraid to end up doing nothing. Harrie says he really needs the guides, because he could not do it all by himself. But one element that is mentioned by almost all participants is the company of people, which is interesting as society and also the lives of people with MID and ASD is becoming more and more individual.

> *"Together with the group, it gives you an extra sense of security when you are with a group" (Max)*

Max is very quiet and shy at the start of the holiday. At home, he has just moved to a new residence where he feels much more at ease and also during the holiday I notice that every day he opens up more. Being on holiday and being together with the group really seems to do him good.

> *"Yes, I really like meeting new people, because I am a pretty social human being." (Sander)*

Sander has no problem with meeting new people at home and also right from the start of the holiday he gets along great with the guides and group he is sharing a holiday home with. Once they get to know each other better, their bond only intensifies and towards the end they undertake many activities together as a small group and seriously plan to meet up after the holiday finishes.

Some of the photos that were taken for photo assignment 1 'Take a photo of what is very important to you on holiday' link to the reasons for choosing an organized group holiday:

Everyone can do their own thing and be themselves -– Liesbeth

Doing fun things together, I don't like sitting still – Frits

Hiking together, at home I am alone - Frits

Participants attach great value to being together with a group of peers. While in daily life the paradigm shifts have caused people with a disability to lead a more individual life, this does not always seem to match with what people with MID and ASD want. Some seem to find comfort, safety or recognition in being together with other people with a MID or ASD, and for others just being together with a group instead of being alone, evokes positive feelings. They enjoy undertaking the holiday activities together, but also more regular activities, such as playing a board game or having dinner together, is very much appreciated by them.

5.1.5 Booking the holiday

When all the decisions have been made it is time to make the actual booking. This can be done online or by making a phone call to the office and asking for a paper form. Some participants fill in the booking form on their own, others fill it in and have it checked by their parent or care-worker and others leave it completely up to their parent to fill this in. Thom is totally okay with his mother filling in the form:

> *"Well, my mom fills it all in and she knows me well enough, so she knows everything and she always tells me what she put down and I often just say 'Yeah, that's fine'."*

John, however, would like to get the chance to do it himself:

> *Pieternel: "Would you like to try?"*
> *John: "I would like to try, but it all happens so fast. Before I know it, it is all taken care of."*
> *Pieternel: "Your mother has finished it all?"*
> *John: "Yes."*

This year Sander filled in the form with his parents because it was his first time, but for next year he has already thought of how to do it:

> *"I would do it like this: First I will fill it in by myself and then ask my parents to check it."*

This part of the anticipation phase shows the least amount of empowerment, as a lot of work is still carried out by parents. For some participants reading and writing can be a challenge, but by completely leaving them out of the process a chance to try and learn something is missed out on.

5.1.6 Holiday preparation

In order to help participants prepare for their holiday and to take away some anxiety of some participants, Flow Reizen organizes a get-together before the summer holidays take place. During this day participants sit together for about 45 minutes with the group they will go on holiday with. They get to meet their fellow travelers and often also their guides. Some practicalities are discussed and they can talk about their expectations and ask any questions they might have. More than half of the participants came to this meeting. For most the reason was to meet their fellow travelers and their guides.

> *"First, I thought it wasn't so important, only fun, but now I have come to realize that it is important. Otherwise I'll get to Utrecht and would have no idea who to go to. Thankfully I now knew some people from the get-together." (Sylvia)*

Max's main reason to go was to get some extra information:

> *"Yes, about this holiday, but mostly about pick-up points and times. I cared most about the practical information. That gave me some more support and then I feel a bit more confident."*

Some participants decided not to go. A couple of them did go when they had their first holiday, but now find the journey to get there too long for the time actually spent together. Benny and John do not really need to know who is coming along with them:

> *"I'll just see then and there who is going with me." (Benny)*

The answers to the question why participants decided to go or not to go to the get-together once again shows how diverse the group of people with MID and ASD is and that they make their own well-informed choices. For some it is unimportant to know who is traveling with them, while for others it makes them feel more secure (and therefore possibly more empowered) to know who they are traveling with or what to expect.

5.2 Summarizing the anticipation phase

The anticipation phase consists of multiple elements in which participants have to make decisions about and take actions for their upcoming holiday. '*Making one's own informed choices*' plays an important role in becoming more empowered (Renblad, 2003). All participants are very much involved in the decision making process about their holiday. They all make a conscious decision to travel with an organized group holiday. And while most participants have different reasons for making this choice, they also have one reason in common: wanting to be with a group. *'Feeling part of a group'* is in line with one of the 15 attributes leading to empowerment (Rogers, et al., 1997). Getting to know the group also plays an important role in the reasons for coming to the get-together before the summer holiday. Participants say to feel more secure about the trip when they know who they are travelling with. Most of the participants know where to find the information and discuss this with others if they think this is necessary or helpful to them. This also links to Rogers et al.'s research (1997) in which *'having access to information and resources'* is also on the list of attributes leading to empowerment. Choosing the destination is for almost all participants a personal choice, which they support with very diverse reasons. 'Being active' and 'challenging yourself' are among these reasons given by participants. These reasons can be linked to yet another attribute identified by Rogers et al. (1997); *'Increasing one's positive self-image and overcoming stigma'*. The stigma is in this case the image that society sometimes still holds that people with an intellectual disability cannot go on a holiday or partake in certain activities whilst on holiday. For some participants it is true that they cannot partake in all activities and this plays a part in their decision making, but does not stop them from going on holiday. When it comes to the more practical part of the anticipation phase, which is the actual booking of the holiday, a lot of participants do this themselves or ask for the help they need. Only two participants leave this completely up to their mothers. One does not have the urge to do this himself and is totally fine with his mother arranging this for him, but another participant would like to try, but does not get the chance to try. *'Learning skills that one defines as important'* is also mentioned by Rogers et al. (1997) and by not giving him the opportunity to try he misses out on an opportunity to empower himself some more.

Overall, the anticipation phase can be very empowering for participants and most of them make the most out of this opportunity by making one's own informed choices, wanting to feeling part of a group, looking up information and increasing their own positive self-image.

5.3 Travel to

The second phase of the holiday is the 'travel to' phase. Participants were asked about how they travelled to the pick-up point in The Netherlands and about the journey to the destination. For two of the researched trips the latter was only one day, for the other two trips a night was spent in a roadside hotel.

5.3.1 Travel to pick-up point

For the trips there are four pick-up points where the guides pick up the travelers. Fixed pick-up points are Utrecht, Nijmegen, Eindhoven and depending on where the group is heading, either Maastricht or Enschede. Just under half of the participants travelled independently to the pick-up points.

> *"Alone by train from Leiden to Utrecht." (Bram)*
>
> *"Yeah, in the end we had to, because our care-worker hadn't charged her public transport card, so she couldn't come. But we knew exactly which train we had to catch." (Benny)*

Sylvia asked for the help she needed to get to the pick-up point:

> *"By train, but my mum did drop me off at the train station, I asked her to do that."*

The other participants were all accompanied by their parents.

> *"I was dropped off by my mother by car." (Sarah)*
>
> *"I took the train together with my father." (Sander)*

Frits reflects on the fact that he was dropped off by his mother:

> *"Actually, I can easily take the train alone, I just get off at Culemborg station. It's pretty simple, but it is rush hour etc. Ah well, it's just laziness. I don't really do anything to become more independent in that."*

It can be argued that traveling to the pick-up point is not necessarily a big part of the holiday experience. Some participants travel around The Netherlands more often, for example for work or visiting friends or relatives, but because going on holiday is often a big thing for participants I did want to include it here. Going on holiday can cause some tension and anxiety and I think that therefore it is interesting to see that still half of the participants feel strong and secure enough to travel to the pick-up point independently. Because going on holiday is often a big thing it also makes perfect sense that the other half of the participants do want their parents to be there or that parents want to be there to wish them safe travels. Frits's comment is interesting as he specifically mentions that he could do it alone, but does not really try. It seems that for him as an individual, traveling independently could mean empowering himself.

5.3.2 Travel to the destination

All four trips involved a one- or two-day ride in two mini-vans driven by the guides. Using this mode of transport has as an advantage that the group is pretty flexible and that breaks can be taken regularly or extra stops can be made at nice spots. It also gives the group more flexibility at the destination itself as they can go when- and wherever they want. But it also takes more time and is more tiring for some.

> *"The trip is fun, but also very tiring because of the long time on the bus. Sitting still in one position for such a long time and you become really lazy after a while of the long bus ride." (Thom)*

> *"Lots of driving, being on the road a lot. I just sit around doing nothing and start to think." (Frits, photo assignment 2: 'Take a photo of something you find annoying or difficult on holiday')*

Some participants consider other modes of transport, but also realize that these may not be viable options.

> *"Well, the trips are already quite long. Perhaps taking the plane would have been more practical and then we could have arranged transport at the destination, but I am not sure whether that would fit in with the prices we paid." (Sander)*

But most participants seem to enjoy the bus rides, or at least agree that it is the best way to travel to their destination.

> *"The second day we stopped at nicer spots and I enjoy seeing those." (Sarah)*

> *"I actually quite enjoy sitting on the bus. I think I find it relaxing and enjoy the surroundings. I think it's a lot more fun on the bus." (John)*

> *"I quite liked it, I always quite enjoy it. I enjoy it and always enjoy the travel to the destination more than the journey back. I don't know, I think because the holiday is still to come, you have something to look forward to." (Sylvia)*

As a guide and driver, I observed the participants during the journey to their destination. What follows now is a general description of a travel day:

> Often I initiate the first conversation by asking everyone what they do at home. Some participants are very talkative about this right from the start and continue talking once I stop asking questions, while others need time to adapt and get to know everyone better before they will open up. After this initial chat the group often goes quiet as many participants fall asleep. They had to get up early to get to the pick-up point or did not sleep very well because of the excitement or anxiety about the upcoming holiday. Some participants listen to their music or stare out of the window. Some hand out sweets. Often, participants know each other from previous holidays and talk to each other about this. Some participants enjoy talking to others, but some also get annoyed when someone talks too much. Every two hours we stop to change drivers and this also offers the possibility to get to know the group in the other van. During the first stop most participants are still quite shy and do their own thing, but during the following stops, participants start talking more and help each other out when necessary. During these stops participants are moved around in the bus when necessary, for example in case of car sickness. Towards the end of the day participants often get fed up with sitting on the bus and start complaining or arguing with others. During the whole trip I ask people how they are doing, but towards the end of the journey it is most important to keep in contact with the participants, so that they do not get irritated too much or end up in unnecessary discussions.

I would also like to describe one particular situation during a travel day:

> *The day before leaving for the cycling holiday I picked up the van for this trip. Because this was a cycling holiday we got one wheelchair-van to be able to transport some bikes. This van is much longer than the ones we normally have and has the mechanism in the back for wheelchairs to get into the van. Also it only has 8 separate seats next to the windows of the bus. I drove the van to Utrecht, where I met the group at the train station. We walked to the van and immediately the group started commenting on the bus: " It is too big", "Where are we going to leave our luggage?", "I cannot even sit next to my partner and have a chat". It was not until we were all seated in the bus that I heard Liesbeth say: "Now I really feel disabled".*

5.4 Summarizing the travel to-phase

The travel to-phase in this research does not consist of many different elements, only the travel to the pick-up point and the travel to the destination. But also during these two elements participants encounter empowerment themes. Half of the participants travel to the pick-up point independently making use of public transport. This shows their independence and participation in daily life, which is often seen as a result of empowerment. Half of the participants are accompanied by their parents, sometimes because they (think they) cannot make the trip alone, but often just for the company. One participant points out he could easily take the trip alone, but does not see the urge in actually doing this and his parents are caring enough to drop him off. Challenging the participants to make the trip independently could lead to more empowerment as they would *learn a new skill, which can be used in the future*, and *improve their self-image* (Rogers, et al., 1997). But also having their parents there when they leave gives participants a sense of support, which can help in their positive self-image, which is also important in feeling empowered. There is not one right way of doing this. In my opinion, whether participants travel independently or not in this case, is therefore not really a way to measure their sense of empowerment. The journey to a destination is often seen as a sort of necessary evil (Ormond, 2013) to get from point A to B and little research has looked into the spaces between ‘home’ and ‘abroad’ (Gatrell, 2011, in Ormond, 2013). But as is shown in the descriptions of the travel days, a lot of interaction takes place among the participants and also between the guides and participants. This can have both a positive as well as a negative influence on how participants feel about themselves, and is therefore important to consider as part of the holiday experience that can lead to sense of empowerment. Participants were asked about other preferred options and some of them do consider other options, but when thinking about it more thoroughly most of them realize that not all options are possible. This shows that they certainly think about these kind of things and although they do not have a lot of other options they make a conscious choice for these kind of holidays.

Overall, the travel to-phase does not offer a lot of empowerment opportunities, but there are a few. Participants show that they think about the way of travel and make informed choices about this. They can also show their independence by travelling to the pick-up point on their own and being part of daily life, which is often seen as a result of empowerment. For some participants this is still a step they can take and for parents to take a step back in the care for their children. But for some participants the support of parents is also a big part of feeling good about themselves, which also leads to empowerment, so both can help in empowering the participants.

6. On-site experiences

The third phase of the holiday experience is the actual 'on-site experience'. As this research has been carried out on-site, this part of the holiday experience will receive most attention in this thesis. There are several parts that make up the on-site experiences of these holidays: the group, the guides, the program and activities, and treatment. Some of these parts can again be subdivided in several aspects.

6.1 The group

Participants have different reasons for booking an organized group holiday as could be read in 5.2.1, but what is exactly the role of the group, what do participants expect from the group and what are their thoughts of the group at the end of the holiday?

6.1.1 Group expectations

Participants have different expectations of the group before the holiday starts. About half of the participants find the conviviality of the group very important.

> *"That they interact with me in a fun and enthusiastic manner and that it is easy for me to make contact with them." (John)*
>
> *"That together we have a pleasant and fun holiday." (Sarah)*
>
> *"That in general I get along with many of the group. And that we have a fun holiday." (Thom)*

There are also a few participants that find comfort in travelling together with other people with a disability, that there is some sort of peer recognition.

> *"Yes, that's… that you are together with the same kind of people. That they have something, some kind of disability."(Max)*
>
> *"Most participants also have autism, but also more or less the same kind as I have." (Bram)*
>
> *"Yeah, I am not the only one who has that and it makes you think… what would that.. and how would he feel?" (Frits)*

Sylvia finds it important to travel together with people of around her age. Flow Reizen does not work with age categories, so it was a coincidence that most people of her group this year were around the same age.

> *"That I am around people of my own age, I find that quite important. Because I don't want to be around youngsters, but I am also not an elderly person." (Sylvia)*

There are also a couple of participants who have no expectations of the group.

> *"Well, I don't really have any expectations. I'll just see, because everybody is different, reacts differently and has other disabilities." (Sander)*

One of the results of photo assignment 1 'Take a photo of what is very important to you on holiday' was also the conviviality of the group, which was captured in the following photo selection:

Cycling together , I like seeing them cycle – Harrie

Having a picnic. At home I eat alone, this is more fun – Martin

Eating and playing together - Bram

Having a BBQ together, getting to know each other better – Sylvia

Having tea and apfelstrudel together – Liesbeth

Having dinner together, at home it's often quick quick - Frits

The current citizenship paradigm makes that people with intellectual disabilities have to become more independent and fit into a society that is becoming more individualistic. It is important to notice that the participants here put so much emphasis on the conviviality of being in a group and that they like being together with the 'same kind of people'. The changes in our Dutch society ask from people with MID and ASD to be more independent and in the midst of society. While I do not say that this is something we should not do, it is important to see that participants often do not mind being together with other people with the same kind of disability and often even find strength in being together with people who go through the same things as they do. Being together with peers can then empower them.

6.1.2 Getting to know the group

Being together on a holiday does not necessarily mean that you easily get to know the other travelers and that you get along with them. Therefore participants were also asked how they go about getting to know the people in their group during the holiday. My experience is that some participants really want to get to know others and make new friends, while others are okay with just a chat now and then and also cherish their time alone. By getting to know others, participants can learn from them or even become more secure in doing certain things, which can contribute to their sense of empowerment. Most participants do not really have a problem with getting to know others and just start chatting to each other.

> *"Talking, cycling next to them, and sitting next to them during dinner and then have a chat with them." (Liesbeth)*

> *"Just ask along the way what their hobbies are and where they work and what kind of work they do. Keep asking those sort of questions. And then you get to know them better bit by bit."(Thom)*

Some get to know the others better by just joining all the activities.

> *"Yeah, you really get to know them better by being with the group. By doing things together. Especially when it lasts several days, then you really get to know each other better." (Max)*
>
> *"By joining everything enthusiastically and not just linger on the side." (John)*

A couple of participants were pleased they already knew some people from the introduction meeting or they had made contact already through social media.

> *"Yes, beforehand I already met a few on Facebook. And some I had already seen at the introduction, so I already knew them. Yeah and just by talking to them and doing things together." (Bram)*

Only Frits has some difficulties with getting to know new people:

> *"That's not really my kind of thing, to get to know people. I'm not very good at that… at getting to know people."*

6.1.3 Feeling part of the group

At the end of the holiday participants were asked whether they felt part of the group they had been travelling with. Some participants were not so sure about whether they felt part of the group.

> *"Very mixed. Well, there were many different handi…I mean disabilities. One has an intellectual disability and the other a physical and they are two very different things. I try to be very open and social, but with some you get along better than with others." (Sander)*

But most participants did feel part of the group.

> *"Up till now, I do. Because of the vibe and the kind of people that share the same interests."(Matthijs)*
>
> *"Yes, because the group is quite close and equal. Also because there are a few that I already knew." (Max)*
>
> *"Because they were always there for me, everyone helped out when I needed a hand. Only I regretted that sometimes I couldn't join in their conversations. I think because I have different interests." (John)*

Frits explains that it is very important for him to be part of the group because otherwise he feels very insecure. He also tells that when he still suffered from epileptic attacks he felt that being part of the group was easier.

> *"Maybe it's strange, but when I used to have epilepsy I was always immediately part of the group. Because with an attack you have something that stands out and then they accept you sooner than they do now. Yes, now I am part of the group, but on other holidays I was left out, but then when I had an attack I was involved in the group more."*

Feeling part of a group is very important when it comes to becoming empowered. Holidays are especially times of positivity and feeling good about yourself and it is therefore important that nobody experiences this negative feeling of being left out. Due to the pressure of society people with MID and ASD are already often made to feel out of place in daily life, because they do not conform to the set standards. Most participants in this research feel part of the group they are traveling with.

6.2 The guides

Participants were asked about their expectations of the guides during the holiday during their first interview and at the end of their holiday they were asked about the way the guides supported them during their time away. In the citizenship paradigm the type of 'caring' has changed to offering support where needed instead of really tending to them and taking care of everything for them. By having enough sense of control and only receiving the support they ask for, participants can feel empowered.

For Bram it is important that guides give him a sense of trust, are relaxed, but also fun and accommodating.

> *"Yes, that you don't have to rush into the bus, suitcases in the bus etc. Yes, that gives parents who are dropping us off also a sense of trust; that it happens in very relaxed manner." (Bram)*

A lot of the other participants also find that guides have to be accommodating and helpful.

> *"That they help me now and then when I run into a problem, like this morning when the shower didn't work properly, that they can then help me solve it."(Sarah)*

> *"That they help now and then, when you have problems… and with things like language, how you can say things. And perhaps also other things." (Sylvia)*

Sander also expects the guides to be informative:

> *"That they are a bit informative during the holiday, about all that we are going to do and what we can expect."*

A few participants also make a comment about guides being respectful to participants and treat them in an equal manner.

> *"That they approach people in the right way. Well, how should I formulate that? That you are very understanding, I guess." (Martin)*

> *"Look, it can happen that the first two days they sit apart because they have to arrange and discuss things, but I do think that the guides should sit with the group and not stick together the whole time." (Frits)*

Liesbeth has high expectations:

> *"That they can make almost everything possible!"*

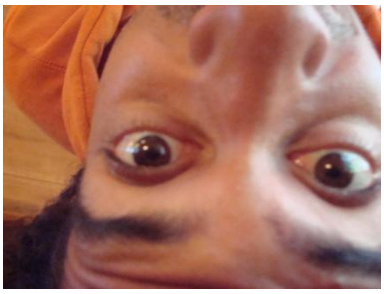
When, at the end of the holiday, participants were asked about how they had been supported by the guides, all were positive.

> *"Good, very good. Yes, they listened to me. When I needed a rest day, that was okay by them." (Martin)*
>
> *"No, that was exactly right. I don't like guides who are constantly on top of everything you do and constantly tell you to…" (Benny)*
>
> *"Well, I don't think I needed that much guidance, but they were good." (Sander)*

Sylvia got a bit annoyed when one of the guides interfered too much with some things she wanted to buy:

> *"I knew for sure that I wanted those postcards. Some people might need that [interference], but I don't. You don't know me that well then. But some people might need that."*

The guides also appeared on the photos taken for photo assignment 1 'Take a photo of what is very important to you on holiday'. A selection of these photos can be seen below:

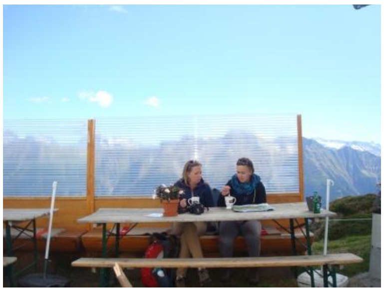


Fun and open guides, makes me daring to say more - Frits

They organize everything and are responsible. On holiday they don't pay that much attention to all that you're doing, that's nice! – John

Make everything positive, like it should be on holiday - Bram

Are there for me when I need them - Martin



Reading the map or an information booklet – John

When reflecting on my job as a guide during these trips, I can only confirm the diversity of expectations mentioned by the participants. Every participant expects something different and it takes a while to figure out what the expectations of the participant are and how to deal with this participant, so as to make sure he/she can make the most out of his/her holiday. Some participants need the guides to encourage them to join activities, while others do not like it when guides interfere too much in their decision-making processes. When guiding it becomes very clear that people with MID and ASD are all individuals that have different wants and needs and cannot be treated as one homogenous group.

6.3 Activities

The holidays do not have a set program of activities, but the descriptions of the holidays in the brochure and on the website do give a number of possibilities. Participants can always add other wishes to this already existing list.

6.3.1 Activities expectations

Participants were asked at the start of the holiday about their expectations of the activities.

Sarah hopes for a bit of a challenge:

> *“That we will encounter beautiful places and some challenges, for example the mountain biking.”*

For Matthijs the challenge lies in pushing the limits of his disability:

> *“That it is doable for me and that I can keep up for as long as possible.”*

There are a few participants who hope that enjoying nature will play a part in the activities.

> *“I like the nature that is here and the mountains, the views and the mountains here.” (Sarah)*

But for almost all participants it is important that the activities have an active character.

Both being active and nature showed up on the photos taken by the participants for photo assignment 1 ‘Take a photo of what is very important to you on holiday’. A small selection can be seen here:

I love hiking and it’s important to exercise – Sander

Gym exercises, fun activities during the holiday – Sylvia

Cycling in a fun group of people - Sylvia

Beautiful nature and great views to have a rest - Harrie

Lots of beautiful views to show people at home – Sarah

True holiday feeling, you won’t see this at home - Max

Having input into the kind of activities they will do on holiday relates to the empowerment characteristic of having a sense of control. So it is great to note here that participants have a lot of different thoughts and ideas about what they would like to during their holiday.

6.3.2 Type of activities

At the end of the holiday participants were asked about what kind of activities they had done. The four destinations offer different possibilities, so the answers to this question differ. But activities such as (mountain)biking and hiking are almost always part of the holiday.

> *"Canoeing, hiking, biking on an old railroad track, moose safari and an entertainment night. And lots of little things in between." (Matthijs)*
>
> *"I biked, I walked. Did I do anything else? I played games, talked, but that's not active. I got to know other people. What else? I think that's it. Oh, and I went swimming, spent time in the sauna and relaxed." (Liesbeth)*
>
> *"We hiked, yesterday we went mountain biking and earlier this week we went to a swimming pool. We went to the lake in Italy for a day and…we looked at a glacier. I cannot remember the rest." (Sarah)*

6.3.3 Opinion on activities

Most participants were positive about the activities they had done during their holiday.

> *"I really enjoyed it, especially the railroad biking and moose safari I thought were very special." (Sander)*
>
> *"Yes, I have to say they were all very enjoyable. They were very, how should I say that, some were very intense or very beautiful." (Thom)*

For most participants their expectations were met, only Sylvia missed a couple of things to make her holiday complete:

> *"I would have liked to go to the disco and to have gone to the Czech Republic, or at least the Czech border. We did go to the Austrian border. Or the tripoint, that I would have liked to see. And I always enjoy kayaking, but that's not necessary on every holiday."*

Some activities were cancelled because of the weather which was disappointing for some participants, but they also understand the weather cannot be controlled.

> *"Yeah, I think it's a shame the climbing got cancelled, but you can't have it all!" (Sander)*
>
> *"Yeah, the weather..you cannot predict the weather of course." (Bram)*

In photo assignment 2 participants were asked to take photos of things they found annoying or difficult on holiday. The weather played a big role the outcome of this assignment. A small selection follows:

Fog and rain. I felt disappointed that the activity couldn't take place - Max

Rain on arrival at the theme park. I felt a bit sad and it didn't seem like much fun like this – Bram

Rainy. I didn't feel like biking, but I feel brave that I did do it! - Harrie

For a couple of participants some of the activities meant a bit of a challenge.

> *"Most of them were quite challenging for me. Because of my disability, with regards to stability." (Matthijs)*
>
> *"Good. Now and then quite heavy with those bikes." (Harrie)*

> *"Rocks, a steep path down. It had rained and it was scary without any help. A fellow participant helped out, which was nice and made me stay calm. Because of this help I was able to go down the path after all." (Sarah, photo assignment 2: 'Take a photo of something you find annoying or difficult on holiday')*

The answers above show that even though some activities were experienced as quite challenging, participants do feel good about themselves after partaking in the activity and push themselves to continue doing them. This can increase their positive self-image, which can lead to feeling empowered.

6.3.4 Participation

Although the holidays are group holidays, the participants are free to choose whether they want to participate in a certain activity or not. When asked whether their participation was their own choice, all participants agreed it was their own choice.

> *"Euh yes, it was just, you didn't HAVE to do it, you COULD do it." (Sylvia)*
>
> *"If I don't feel like doing something I'll just say that I really don't want to do it." (Thom)*
>
> *"I would say it if I really don't want to do something, because then we can look at other options and see whether there is something I do like." (Sarah)*

Others know that they have a choice, but would still join the activities even if they did not really feel like doing them.

> *"I wouldn't say no quick. Because I like to be part of most things and am not on a holiday to just sit here." (John)*

> *"Well, often I'll just join for the fun anyway." (Matthijs)*

And some also opted not to participate in a certain activity.

> *"I didn't bike all days, because the first day had been quite tiring. So I needed a rest day." (Martin)*

> *"I skipped the visit to the old city you guys went to. I just got back from mountain biking and I wanted to have a shower first, because I was quite sweaty and that didn't really fit in the time schedule, so.." (Sander)*

The group also plays a role for participants to express their choice to participate. Both in choosing not to do something as well as in continuing to do something they would rather not do.

> *"Yeah, there were a few others that also stopped halfway, I believe only one continued on. So there is nothing wrong with that." (Bram)*

> *"Yeah, I didn't want to give in…yeah, you want to show off a bit." (Frits)*

Having the choice to participate in a certain activity or not is extremely important in our society these days. And for people with an intellectual disability it is even more important that they can now express their wishes as for many years everything has been decided for them. One of the main characteristics of leisure is that people have the perception that they are free to choose to participate in meaningful, enjoyable, and satisfying experiences (Dattilo, 2002) and also can decide to discontinue their participation whenever they want to. For that reason, it is very positive that participants feel that during their holiday, they have the choice to participate or not. It is interesting to notice again the influence of the group in this matter.

6.3.5 Repeat at home

Participants are encouraged during their holiday to participate in many different and sometimes new activities. This can broaden their horizon and knowledge and views they have about themselves, which leads to empowerment. A way to measure the impact this has on them is to see whether they would continue doing these kind of activities at home. This is in line with the empowerment aspect of *'bringing about change in one's life and one's community'*. The group is divided when asked whether they would repeat these activities at home. Max has just moved and his new environment offers the possibility to continue certain activities:

> *"Yes, for example the walking. Where I now live there is also a forest and all."*

Harrie liked the challenge of going on a cycling holiday, but when asked whether he would repeat it at home his answer was:

> *"I don't think so, because it is too tiring."*

There are also some that just aren't sure.

> *"I wouldn't know, because here you do it in a group and whether that's the same at home I'm not sure." (John)*

A follow-up research would be needed to measure the impact these activities have had on the lives of the participants at home.

6.3.6 New experiences

For Flow Reizen and its guides it is important that participants are pushed a little bit to step outside their comfort zone and do things they did not think they could do or would ever do. Therefore guides try to make new, sometimes challenging, activities part of the program and offer participants the possibility to give it a go. Most participants experienced something like this during their holiday.

> *"Like this afternoon, the treetop climbing, that was quite a challenge for me. I wouldn't have done that by myself." (Bram)*
>
> *"Actually, the cycling. I have never cycled that many kilometers." (Harrie)*
>
> *"Because I have never seen a moose and I never biked on a railroad track and I really enjoyed it. It's different what you do, because you have never done it before, so it is quite interesting and special that you're doing those things." (Sander)*
>
> *"Well, the luging was quite scary the first time I went down, that you almost lose control in the bends. But then you go down a couple of times and you get more...you know how it goes." (Frits)*
>
> *"Parapenting!" (John)*

The following photo selection is a combination of the outcomes of photo assignments 3 '*Take a photo of something you find very nice or special during the holiday*' and 4 *'Take a photo of something you would not do at home very often'.* Both of the assignments contained images of activities participants had never done before. Not all activities have to be very exciting or challenging as can be seen on some of these photos where playing Pictionary and making marshmallows are also embraced as new and fun activities.

Mountain biking. Cycling is one of my hobbies, but I had never mountain biked, that was a new experience – Sander

Pictionary. I never do that at home, but I really enjoyed it – Frits

E-bike. At home I don't have an e-bike and here it is part of the holiday. I liked it! - Sylvia

Gathering dead wood. I really liked it; being active and then light it and make sausages on it. I have never done that before – Frits

Marshmallow from the campfire. We had to gather dead wood ourselves and then light the fire. I had never had one before, it was very tasty and great to experience - Sander

The group played an important role for participants to try new activities.

> *"Well, perhaps wanting to be a bit cool in the group. You are all going down the luge and don't want to let the others down." (Frits)*
>
> *"Well, because you're together with others who have never done that and then you think: 'Yes, I should be able to do that too'." (Bram)*
>
> *"Because we are all together with the group and I think that makes it easier for me to go up [the gondola to the top of the mountain]." (Thom)*

> *"Having an ice-cream. At home I don't often go into town, so also not to an ice-cream shop. Here on holiday I do go, because of the conviviality of the group I participate and I feel at ease." (John, photo assignment 4 'Take a photo of something you would not do at home very often')*

For others being on holiday means getting chances that they do not get at home and therefore they want to make use of them.

> *"Well, because I thought it [railroad biking] would be fun. And I had never done it before and because you cannot do it at home." (Benny)*
>
> *"Because my brother had told me about it; that I could do a tandem flight. And when you get a chance to do it during your holiday you have to take it." (John)*
>
> *"You never do that [e-biking] at home. There you have a normal bike. And here you have a lot more hills than in The Netherlands." (Liesbeth)*

Matthijs is very much aware of his disability and his limitations because of this. But he is also very eager to discover new things he didn't think he could do:

> *Pieternel: "How do you feel now that you've done those things your parents had doubts about?"*
> *Matthijs: "Well, just nice that I tried to do the things that I think I will like and if it doesn't work then there is nothing I can do about it."*
> *Pieternel: "And when you try and you succeed, how does that make you feel?"*
> Matthijs: "*"Well, I feel relieved that I can pull it off after all.*
> *Pieternel: "Relieved? Okay, and nothing else?*
> *Matthijs: "And I also feel good that I can do it, while I thought I couldn't."*

Partaking in these new experiences links to many empowerment themes. Participants can learn new skills that can be used in the future and these skills do not have to be complicated ones. It can also be that participants get to push their limits and learn they can do more they thought they could do. It can change their own perception of their competency and capacity to act. When they succeed in trying new things they will increase their positive self-image and often also overcome stigma as others doubted their abilities to do certain things. When trying these new things is powerful enough it could also bring about change in their daily lives. By offering participants the chance to experience new things and encouraging them to try these, Flow Reizen and its guides contribute to the participants' sense of empowerment,

6.4 The program

As mentioned in 6.3 the holidays do not have set programs. The actual program is decided together with the participants at the destination and therefore differs per holiday. Participants get the opportunity to tell the guides what activities they would really like to do and the guides then put together the program taking into consideration these wishes and time and budget.

6.4.1 Program input

On the first evening at the destination all groups were asked what they wanted to do during their holiday, this took place off the record for this research. But some participants came with new ideas during their interview.

> *"In case it rains, you could go into a cave or something, you have them here in the Black Forest." (Bram)*

> *"Going for a decent hike. Anywhere, even just from the hotel walking up the hill and back again. That you're hiking for let's say 4 to 5 hours. That would be nice. But whether the others would like that?" (Frits)*

Interestingly enough, even though all groups were asked about what they wanted to do, Frits made the following comment, indicating that he did not feel the liberty to share his ideas in the group.

> *"If it wasn't for this interview, I wouldn't have dared to put my idea forward, that's just…"*

These ideas put forward during the interviews can indicate that it might be necessary for some participants to really have a one-on-one conversation with a guide to feel at ease enough to express their own ideas and give their input.

6.4.2 Own program

Participants were asked whether they would prefer that the program was totally up to them to decide, that guides would only be there to get them to the destination and support them in the activities they chose to do. I asked this question because I feel this is what we are trying to achieve for people with MID and ASD in daily life and because I have my doubts whether this is possible for them to live up to. Not because I doubt their capabilities, but because I agree with other researchers that argue that these standards are created for the 'average, normal person' and do not take into consideration other minority groups. We want them to feel more empowered and that is certainly possible, but we need to know what level they feel comfortable at. The answers from participants to this question confirm my feeling that we cannot ask them to make all these (holiday) decisions on their own as none of the participants saw this new type of holiday as a realistic possibility.

> *"No, I wouldn't be able to do that, because I don't know anything about the area and you have a good overview of that. I would like to have some input, but I already have that of course." (Sander)*
>
> *"Because…I find it difficult…to figure out all there is to do here." (Sarah)*
>
> *"No, I quite like the way it is now." (Benny)*

There are, however, a couple of participants who would not mind to try this for part of the holiday. This is great because it can give them a chance to become more empowered and discover what level they are comfortable at.

> *"Well, I would be okay for a couple of days at least. I'll go walking and do some ball sports. I would go to the reception desk to ask in English and otherwise with gestures or by writing it down." (Matthijs)*
>
> *"Perhaps I would like to do more on my own, so maybe I would…" (Sylvia)*

Most participants are happy with the program guides make and the structure it gives to the holiday.

> *"Yeah, I quite like it that there is more or less a fixed program." (Max)*
>
> *"Because I, when there are fun activities planned, already have something to look forward to and be excited about." (Thom)*
>
> *"Guides have to come along, otherwise I wouldn't do it. I'll get bored and go to sleep." (Frits)*
>
> *"Nah, I quite like to know beforehand. Then I can pack my stuff, my backpack or whatever." (Liesbeth)*

6.5 Free time

Besides the fixed program there was also plenty of free time for participants to do what they wanted to do. I was interested to know what participants did with their free time and whether the kind of activities would differ a lot from the activities at home. If there is a difference, then maybe the free time during their holiday could also have an impact on the way they spend their free time at home. Most participants combined some time alone with other easy-going activities with other participants.

> *"Well, for example doing puzzles and we also played some games downstairs." (Max)*

> *"Lying on my bed, listening to music and of course the hotel had a bar, so I just sat there and had a drink. Or just sat downstairs and talked to fellow travelers now and then." (Thom)*

Some participants really used this time to do their own thing.

> *"I read Suske & Wiske and did some Sudoku puzzles. And I wrote in my diary." (Sarah)*

> *"Some coffee drinking, a bit of resting and waiting till it was time. And of course running." (Frits)*

For some the free time during their holiday was pretty similar to their free time at home.

> *"Running I do at home, coffee drinking I do at home, haha!" (Frits)*

> *"Well, at home we also play games in the evening now and then or have a board game afternoon. So yes, it's pretty similar." (Max)*

Other participants clearly notice a difference between their free time on holiday or at home.

> *"Yeah, you have some more free time, so you start reading more and do other recreational activities. At home it's more domestic work I need to do." (Sander)*

> *"Well, at home I sit in front of the computer, for example, but I couldn't do that during the holiday." (Thom)*

Also photo assignment 1 'Take a photo of what is very important to you on holiday' showed some images of what participants like to do during their free time on holiday. This indicates the importance of having this free time and giving participants the opportunity to spend this how they would like:

I like to play games. At home I don't find this important, but on holiday you do a lot more with others – Liesbeth

A nice cold beer. Nice and relaxing on holiday – Frits

Reading a book is an activity for a quiet moment; when you're waiting or before going to sleep. At home I don't have time for this - Matthijs

6.6 Treatment

It is important that participants feel good about the things they do, but also about the way they feel about themselves. The way they are treated and how people react to them is therefore very important. This connects to the empowerment theme of feeling of having the same rights as others. Participants were asked whether they felt they had been treated differently than others. Almost all participants did not feel that they had been treated differently.

> *"No, I don't have the feeling that I am being treated differently than others." (Sylvia)*

> *"No, I think we have all been treated equally, only one needs a bit more attention than the other." (John)*

Only Thom and Harrie felt that they had been treated differently. Not so much treated differently than others, but different from how they are usually treated at home. For Thom this was a slightly negative:

> *"Well, I felt, and I don't want to discriminate, but the group we had, I did notice that because there were some 'weaker' people with us, that I was being treated differently than normal."*

For Harrie it was a positive difference:

> *"I do have that feeling yes. Because there are nice guides here, they understand me a lot better."*

Participants were asked whether someone had told them during the holiday they could not do something, for example a certain activity. All, but one, participants did not experience anyone telling them they doubted whether they could do something, which is also very positive for their self-image.

> *"No, they didn't say that to me." (Liesbeth)*

> *"No, I haven't heard that this holiday." (Thom)*

> *"No, I don't think so. I think I also didn't say it to others, also not among each other I think. That people said that about each other, no, we were all very helpful to another." (Bram)*

Only Martin experienced this during the first day of cycling when the guided doubted whether he could keep up with the fast group and asked him whether he should not be in the slower group:

> *"Yes! Haha! With the fast group that first day. I can't remember who of the guides said it."*

He convinced the guides that he could join the fast group, which made him feel very good about himself:

> *"I was absolutely knackered. But also relieved that I had done it. And proud."*

6.7 Summarizing the On-site experience

The on-site experience consists of many different elements and therefore also many empowerment opportunities. The group plays an important part in this. Participants mention conviviality of the group as very important, but also recognition plays an important part of why participants enjoy these kind of holidays and help them feel good. They share the fact that they all have some sort of intellectual disability, which seems to create a bond between most of them in which they find comfort. Most of them have no trouble getting to know the other group members and get along with them easily. This leads to tight groups and most participants feel part of the group they are travelling with. Feeling part of a group is mentioned by Rogers et al. (1997) as one of the attributes leading to empowerment.

Also the guides play an important part in the holiday experience. Participants expect them to be trustworthy, accommodating and helpful. They also find it important that they treat them equally, which is in line with Renblad's (2003) explanation of the concept of empowerment: *'the concept is based on a philosophy grounded on the idea of equality- that everyone is of equal value'*. This equality counts for both the equal treatment of all participants as well as guides not disassociating themselves from the group too often. According to the participants guides do their job well when they let them be, give them enough freedom and do not interfere too much, but help out when needed. In other words giving them a sense of control and responsibility. Two of the internal-psychological factors mentioned by Kosciulek & Merz (2001) in their consumer directed theory of empowerment.

Activities are of great importance during the holiday and participants all have their own expectations of the activities. For some they have to be challenging and this challenge can be in trying new things or pushing yourself to go a bit further than you are used to. This can be linked to the empowerment theme of *'changing own and others' perceptions of one's competency and capacity to act'*. Most participants find it important that the activities are of an active character. They therefore make the conscious choice of going on the mini-van holidays, which are of a more active character than the beach holidays. Again linking to the empowerment theme of *'making own, informed choices'*. A link can also be made to the Outward Bound programs in which adventure and outdoor based programs lead to development of participants for which the perception of empowerment also plays an important role. Participation in the different kind of activities can also lead to a sense of empowerment and therefore participants were asked about their participation in the different activities and also whether it was their own choice to participate. All participants said that they knew and felt it was completely their own choice to participate and felt comfortable in expressing their decision to participate or not, once again linking to '*making own, informed choices'* and also *'having a sense of control'*. They joined almost all group activities and were very positive about them. Some activities met the expectation of being challenging and meant pushing boundaries for some participants, which they enjoyed. This links to the empowerment theme of *'increasing one's self image and overcoming stigma'*. Many participants also tried or experienced new activities during their holiday, which again meant pushing boundaries for some. The group often plays a role in wanting to try new things, either because participants do not want to show they do not dare to do something or because they feel more at ease with other participants also trying new things. This shows again the importance of the group and feeling part of the group. Also the fact that they get the chance to do things during their holiday that they do not normally get at home makes them wanting to take these chances. When asked whether they would repeat these activities at home most participants were hesitant in this. Part of the empowerment process is that new skills are learned and will be used in the future, but if participants will not continue or repeat the new activities at home this opportunity will be missed. However, it does not have to be the exact same activity that they repeat at home, also smaller things they may have learned during the activity can turn out to be useful at a later point in time. To really measure the influence further studies will be needed.

Deciding on the program together offers participants the possibility to put forward their ideas and most participants make good use of this. This input links to the empowerment theme of '*having a sense of control*'. But when asked whether they would rather be free to make their own program for the entire holiday participants were very hesitant. Most were doubtful about their own abilities to do so. But some would not mind to try for at least a couple of days and see what happens. Having a go at this would link to the empowerment theme of *'changing own and others' perceptions of one's* *competency and capacity to act'*. But in general most participants are very happy with the structure the program gives to the holiday experience.

None of the participants have a problem with entertaining themselves during the free time they have during their holiday. The activities they choose to do are often similar to the activities they undertake at home during their free time. Some participants point out that they have more free time during their holiday and spend them on more recreational activities instead of domestic duties. The empowerment theme here is once again *'making own choices'*,

The *'feeling of having equal rights as others'* is also very important in feeling more empowered. Participants said they did not feel treated differently and felt equal to others. Most experienced no doubt about their abilities from other people and when they did, participants were able to prove them wrong, which made them feel very good about themselves, linking to *'increasing one's positive self-image and overcoming stigma'*.

Overall, the on-site experience offers many possibilities for participants to feel more empowered. They make own, informed choices about the activities they do; they feel part of the group which helps them in many different ways; they choose whether they want to participate or not and in what way; they feel they have the same rights as others and feel treated equally; they have a sense of control when guides do not interfere too much and when they have input in the program; they experience things they never thought they would do and change their own perception of competency and capacity to act; they feel good about them and overcome stigma's by doing things others were doubtful about; and they experienced new things from which they will learn and even though they might not repeat them in the exact same manner in the future, parts of it will be useful.

7. **Return travel and Recollection**

All interviews took place one or two days before the holiday ended, but participants already got asked about their trip back home, how they experienced the holiday and what they thought they would do with these new experiences.

7.1 Return travel

Just like the travel to-phase participants were now asked about how they would travel back home after they had been dropped off by the guides and said their goodbyes to the group. The participants who travelled independently to the pick-up point were also travelling home independently.

> *"Well, in Utrecht I'll just get on the train to Leiden." (Bram)*

> *"On the train together with my girlfriend. Her parents will pick us up in Rotterdam." (Benny)*

And the ones that were dropped off by parents were now also being picked up by their parents.

> *"Mum or dad. Anyhow, it's been arranged that I'll be picked up." (Sarah)*

> *"If all goes to plan, my mum will be there." (John)*

Only for Sander there is a slight change. Where his dad was there for his departure, he will now join Matthijs and his parents for the way back home.

During the return travel, participants are often much more talkative and act more as a group, than during the travel to the destination. The following excerpt from the participant observation is an example of this:

> *On the way back from Switzerland we stopped at a gas station for a toilet break. To make use of the toilet we had to pay and in return we received a voucher that we could use in the shop. When I got back from the toilet, some participants had come up with the idea that if they would collect the vouchers, they could then get a large bar of chocolate for free and share this with everyone in the group. Together they decided on a bar of dark chocolate with 98% cacao. When we got back to the van, everyone got a little piece. Unfortunately, almost nobody liked it because of the high percentage of cacao.*

7.2 Summarizing the return travel-phase

The return travel-phase can be compared to the travel to-phase. The same participants that travelled independently to the pick-up point also travelled back home independently. By doing this they show they are being part of daily life, an important outcome of empowerment. Some participants who were being picked up could think about and discuss with their parents or care-workers whether they could maybe change this for next time, to try become a bit more independent in this and by doing so activating another process of becoming more empowered. But also here, just like the travel to-phase, the fact that someone is there when they arrive at the pick-up point can give participants a sense of trust which can make them feel good and secure about themselves. The journey from the destination back home also offers empowerment opportunities and gives an indication of how the group has formed during the holiday.

7.3 Recollection

To get to know more about the influence of the holiday on the participants it is also important to know how they look back on their holiday. Therefore participants were asked several questions about how they feel at the end of the holiday, what was important for them and what influence this holiday will have once they have returned home.

7.3.1 Learning on holiday

During their first interview participants were asked whether they thought they were going to learn something during the holiday. The answers that were given differ a lot. A couple of participants think they will become a bit more independent again.

> *"Well, perhaps you learn to take care of yourself a bit more. Normally, I'd go away with my parents and now, now you're a bit more on your own and you have to take care of your own...of yourself." (Sander)*
>
> *"Perhaps the independence." (John)*

Others think they will improve their social skills some more.

> *"Well, how to treat other people." (Benny)*
>
> *"Well, that has been a learning goal for me for a while already, but I just thought of it. I have my own strong will, but I also have to learn to adapt." (Frits)*

And some participants hope to learn about and from the destination they are visiting.

> *"Yes, that I'll get to know the surroundings a bit, it's an area I have never been before." (Max)*
>
> *"Euh, perhaps some German words or...I get to know the places of course, where I go, places I may have never been." (Sylvia)*

Photo assignment 3 '*Take a photo of something you find very nice or special during the holiday'* resulted in quite a number of photos from special art and building in the places visited. That so many participants take photos of these things and their explanations indicate that they are very aware of the differences between these kind of things at home and on holiday. Which can link again to learning new things about a destination and expanding their knowledge on these cultural matters:

The Cathedral in Passau, I really liked the towers and colors. I thought it was very special and it made me feel good - Harrie

Special art piece: fish with fish-bones. Very different and beautiful – John

A beautiful restaurant building. Especially the roof is very extraordinary - Sarah

Bram says he learns from everything he does and Thom is not sure whether he will learn something.

All participants were asked the same question again at the end of the holiday; looking back to see whether they had learned anything that holiday. Where Thom was not sure at the start of the holiday whether he was going to learn anything, looking back he has a different view on it:

> *"Well yeah, I have learned that no matter what, you have to show respect to each other. And that, depending on who you have in front of you, you deal with each person in a different manner." (Thom)*

Some other participants have also worked on their social skills.

> *"You learn something new every holiday. Social contacts, that you get to know new people." (John)*
>
> *"That I'll be in contact with others more." (Harrie)*

But Harrie did not only work on his social skills, he also learned something about his own capabilities. He is not the only one.

> *"That I can cycle more kilometers, I have never done that before!" (Harrie)*
>
> *"Euhh.. a bit more self-confidence by doing things I don't do that often, such as hiking in the mountains. And to indicate when something is wrong, but that will always remain difficult for me." (Sarah)*
>
> *"Well, I don't know, that's quite difficult. But that I can relax a bit more now, I think." (Max)*

For Martin learning about his capabilities is a bit of a wake-up call:

> *"Well, I don't really know.. I guess that I really have to start cycling more, because my fitness level is really below all standards, well maybe not that bad, but abominable or something like that." (Martin)*

Learning skills that one defines as important is one of the contributors to a greater sense of empowerment. These skills can be learned on different levels. Some are really practical while others are more about self-knowledge. All of these can be used in the future and can therefore contribute to feeling more empowered.

7.3.2 Feelings about the holiday

Participants were asked about what feelings they had looking back on their holiday. According to Neal et al. (2007), benefits of tourism experiences range from increased levels of happiness, improved health conditions, increased self-esteem and higher level of satisfaction in several dimensions of life to an overall enhanced satisfaction with life (in Figueiredo et al., 2012). This means that positive holiday feelings can contribute to a positive self-image of participants and might have an influence on their daily lives after the holiday finishes. All participants experienced a positive feeling. For most it was just an overall nice feeling they had.

> *"With a nice feeling. With the feeling that I have had a nice holiday, because I thought it was a nice holiday." (Sylvia)*

> *"With a fantastic holiday feeling." (Bram)*

Some participants point out that it was the conviviality of the group that created the nice feeling they had after their holiday.

> *"Just the atmosphere and the people I get along with, that all of that went well." (Matthijs)*

> *"The conviviality of some people." (Benny)*

For others it was the nice feeling was created by rest and relaxing.

> *"I think with a very relaxed feeling, because I've been away from where I work. That I have been able to let that go for a week and a half." (John)*

> *"That I have had a nice and satisfying holiday. That I really needed the holiday to recover and have a rest. That I just had a satisfying and just a nice holiday and also of course another experience in a different country." (Thom)*

For both Benny and Bram the nature at the destination also plays a role in creating the nice post-holiday feeling.

> *"Yes, the beautiful nature." (Benny)*

And for three participants the activities also play a clear role.

> *"Yeah, I just feel that I have cycled a lot, cycled many kilometers." (Harrie)*

> *"And with the swimming, using those tubes from the slide, that will stick with me." (Thom)*

But four participants also experienced some negative feelings. For all four these negative feelings are caused by very different things. Benny got annoyed by the repetitive tantrums of a fellow traveler. And Frits just finds it hard to really enjoy his holiday because of stress factors at work and never really looks back on (positive) things that have happened. Harrie struggled with the high hills he had to bike on. Because he is not used to this it caused him stress and anxiety. And John got irritated by one the guides pushing his limits, which shows that the approach of trying to go that one step further does not always work:

> *Pieternel: "Do you maybe also have things that you don't feel so good about after this holiday?"*
> *John: "Yes, but that's with every holiday."*
> *Pieternel: "And which things have caused that?"*
> *John: "Well…that some things that I know I cannot do, that I have to try them anyways."*

A few participants do not have negative feelings, but sad feelings about the holiday being over.

> *"Perhaps the farewell. That I have to say goodbye to some people that I really like." (Sander)*

> *"A sad feeling. That I have to wait till the 8th of November [reunion]." (Martin)*

“The parking lot at the theme park when we left. I was sad that the day was over, it had been a great day.” (Frits, photo assignment 2: ‘Take a photo of something you find annoying or difficult on holiday’)

7.3.3 Making new friends

That being together with a group of people is important for most participants has been made clear in the previous chapters, but it is also interesting to know whether being together on a holiday can also result in creating new friendships and whether this is important for participants. Participants were therefore asked if they met a lot of new people at home and how going on a holiday contributed to their sense of creating new friendships. To see whether there is a difference between the home situation and the holiday situation participants were first asked whether they made a lot of new friends at home. About half of the participants said they did not meet many new people at home.

> *“No, I am always stuck in the same circle.” (Frits)*
>
> *“No, but that is one of the new goals I set up, we are working on that, to expand my number of contacts.” (Thom)*

The other half does meet quite some new people at home.

> *“Yeah, more these days. Also because there are more people in the new complex. And at the coffee mornings and board game afternoons others also come by.” (Max)*
>
> *“Yes, that too. With working in the woods and all. And recently I also started going to a club for people with autism now and then, once a month, and that’s for people of all ages. Nowadays it’s also easier than before for me to make contact there.” (Bram)*

Participants were then asked whether they thought they had made new friends during their holiday. About a third of the participants does not think they have made new friends:

> *“No, seriously, I don’t!” (Liesbeth)*
>
> *“I haven’t really tried to get to know others. I already have enough friends, but I would like to have some more girlfriends. I somehow get a lot of male friends, but few girlfriends.” (Sylvia)*

Another third of the participants does think they have made new friends during their holiday:

> *“Yes, for sure. We are all the same kind of people.” (Bram)*
>
> *“Yes, I do feel that way.” (Harrie)*

The last third of the group is doubtful whether they made real new friends:

> *“New friends…? Friends during the holiday yes, but I doubt whether it will last after the holiday finishes.” (Sarah)*

> *"Yes, for the time here, but I do think that when we all get home again and everything is over, it will become less, because there are some that live quite far away." (Max)*

And even though some participants do think they have made new friendships, most participants doubt how they will keep in touch after the holiday and whether they will visit each other. Distance plays an important role in this.

> *"Maybe, I don't know yet, perhaps it's too far." (Harrie)*
>
> *"The others? No, I believe they live too far away for my liking if I heard and understood it all correctly." (Thom)*
>
> *"Yes, I think I will keep in contact with the people that live close by and relive the holiday memories again." (Max)*

Some participants did try to keep in touch when they first started travelling with Flow Reizen, but have experienced the difficulties in staying in touch with the others.

> *"I would like to, but I know from experience that not a lot will happen with it." (Frits)*

But there is a small group that will try to keep in touch with the others and social media plays an important role for them in achieving this.

> *" Yes, we exchanged contact details for Facebook and WhatsApp and that's how we will stay in touch." (Matthijs)*
>
> *" Well, there was a plan to go out with a group of people, so we will stay in touch through social media." (Sander)*
>
> *"Yes, maybe I will add a few people on Facebook." (Harrie)*

But even social media will not help Frits in keeping friendships is his experience:

> *"I don't really try anymore, I know it will disintegrate. Via Facebook you make friends and the first 2 to 3 weeks are a lot of fun, but eventually…." (Frits)*

"This is a friendship plant. It has a lot of shoots that you can hand out to all your friends as a souvenir." (Sylvia, Photo assignment 1: Take a photo of what is very important to you on holiday')

7.3.4 Telling people about it

To check the impact the holiday has on participants after they come back home, participants were asked whether they would tell people about their holiday. All participants said they would tell people about it. Most of them would tell family, friends, colleagues and their flat mates.

> *"Immediately! My mum, my brother, my sister, my aunt and where I work of course and where I live." (John)*

> *"Yes, I will definitely tell people about my holiday, about what I've done and all. Yes, to friends and flat mates and of course my mum and dad." (Thom)*

> *"My parents and flat mates. I have also sent them postcards by the way." (Max)*

Benny also mentions some others he would tell about his holiday:

> *"Definitely the man that I exercise with, and my care-workers and my work."*

Some participants also took their own camera with them or took photos with their mobile phones. They were asked what they did with these photos after they got home. Often they would end up on the computer or CD and would be shown to friends and/or family.

> *"I put them on the computer and some I'll send on to friends and family." (Liesbeth)*

> *"I put them on the computer and show them to my parents." (Sarah)*

Some participants put some extra effort into it.

> *"I do make a photo album, so I can look back on the holiday and see who all went with me." (Sylvia)*

> *"I often make a photo album of them. I used to do that with printed pictures, but now I make one of those instant albums on the computer. That's a nice souvenir." (Bram)*

To know that participants will tell people about their holiday and show them photos indicates that the holiday has had a (positive) influence on their life for at least for the period after they get back home. To know whether this impact continues and whether it has permanent impact follow-up research will have to be carried out.

7.3.5 Thoughts on Flow Reizen

To get an overall idea of how the participants felt about their holiday experience and the way Flow Reizen and its guides go about offering their holiday experience, participants were asked whether they would consider Flow Reizen for another holiday and if they had anything else to add with regards to their holiday experience. Liesbeth and Sylvia both had no idea yet.

> *"I don't know yet, that's for next year, I have no idea about that. I don't know what the brochure will be like." (Liesbeth)*

Most participants thought it was likely that they would join another trip next year.

> *"Yes, I probably will. But I don't know which trip yet. But I like the idea that you're together with a group of people." (Max)*

> *"Yes, overall I really like Flow, because this is the third time and up till now I really enjoy it." (Thom)*
>
> *"If it's up to me I will, but you never know what else might cross my path." (John)*

For Frits, Harrie and Bram there is no doubt that they will join another Flow trip in the future.

> *"This summer even. And I have also booked a trip for the winter already." (Frits)*
>
> *"Yes, I know for sure! But not the same trip." (Bram)*

Bram explains in much detail the changes and development he has experienced since his first trip with Flow Reizen 1,5 years ago:

> *"Yes, it happens gradually, but yeah, most likely for a large part thanks to Flow Reizen. I really feel that every trip I make things only get better. I am looking you in the eye now, there is no way I would have done that a couple of years ago. The world seems more spacious, it's really strange, the trees don't look so high anymore, and that's something that has been happening the last couple of years. The distances seem not so far anymore. But a couple of years ago, I could only look to the ground and hardly see anything else. I see the details very differently now. I can tell you all this now, but previously I didn't dare to."*

He has also become more daring in undertaking new activities since he made his first Flow trip.

> *"Perhaps I wouldn't have climbed it at all, I wouldn't have dared to at all. And now I try, I like to see how it goes. Back then I would have immediately thought 'no, I can't do that'."*

He is proud of this change and knows that this is what Flow Reizen is about:

> *"You can pass this on to the office staff, if you want to. It is such a good example."*

The impact Flow Reizen has had on Bram's life is very positive and this is more or less the ultimate goal for Flow Reizen and its guides. But at the same time they also know that the impact of the holidays differ for all participants because they are all different and that even a small step in the 'right' direction can already contribute to participants feeling a bit better about themselves and more confident. It is of course a good sign for both Flow Reizen and the participants that all participants are so positive and most do consider traveling with Flow Reizen again. This shows a certain trust from participants towards Flow Reizen, which hopefully has an impact on the lives of the participants.

7.3.6 Reunion

To give participants the chance to meet up again and talk about their holiday adventures with their fellow travelers and their guides Flow Reizen organizes a reunion every year. This takes place at the start of November and marks the end of the previous summer season holidays, but also the start of the upcoming summer season holidays as the new brochure is handed out and participants can already sign up for their new holiday adventure. It is also the actual start of the winter season holidays, for which participants can also still sign up at this point. They sit together with their group for 45 minutes and talk about the holiday memories, look at photos and discuss future holiday plans. The day ends with a performance of the Flow Band and one big party. Participants were asked whether they were planning on coming to the reunion. About a third of the participants know for sure they will be there. Another third of the participants knows already they are not coming, because they have other commitments or because they think it is too far to travel for such a short time only. The other third is doubtful whether they will be there. Both John and Thom think it is probably too far and will encounter difficulties in getting there. Sarah is very doubtful, because the train trip causes her quite some stress and anxiety. Therefore, it was great to see that she showed up at the reunion, very stressed because of delays, but she was there. Liesbeth was also doubtful about whether she would come because she was afraid not many people of her holiday would be there and that would be a pity. But she was there and almost all of her fellow participants were there too. She announced that her partner and she will not be going on a holiday with Flow Reizen next year, because they are going to try to go on a holiday independently. They will stay close to home and family, in case they need help, but are going to try.

7.4 Summarizing the recollection phase

The on-site activities play an important role in offering empowerment opportunities, but whether this has long-term results can only be checked once participants are home again and back in their daily routines. To really measure this is outside the scope of this research, but to get an idea of this participants were asked about their holiday experience and how they think it will have an impact once they arrive back home again. The recollection phase is therefore an important phase in measuring the sense of empowerment among participants.

Even though participants may be doubtful at the start of a holiday whether they will learn something, when looking back on their holiday most of them realize they did learn something. This can be related to their social skills, but also about their own capabilities. For some this lies in pushing their boundaries and discovering they can do more than they thought. For others it is feeling more relaxed and at ease. And for one it even meant a wake-up call about having to change his lifestyle and start living a healthier life. All of these can be related to the empowerment theme *'learning skills that one defines as important and can be used in the future'*. The wake-up call can also be related to the empowerment theme *'bringing about change in one's life and one's community'*.

Most participants were positive when asked about their overall feelings about the holiday. They related these positive feelings to the conviviality of the group, having time to rest and relax, being in nature and the different activities. Only four situations of negative feelings were mentioned, all had different causes. Two of these were related to pushing boundaries of participants, one experienced the cycling to be heavier than he was used to, which caused stress, and one was pushed by a guide to try something he could not do and got annoyed by this. One of the empowerment themes is *'changing own and others' perceptions of one's competency and capacity to act'*, but guides have to be careful to not push participants too far, because this will only make feel participants bad about something they cannot do, which is the opposite of what the aim of these holidays is.

As participants find the group very important it is interesting to see how they think about their fellow travelers and whether these people will continue to have an impact on their lives after the holiday finishes. Half of the participants say they meet a lot of new people at home and the other half does not. When they were then asked whether they thought they made new friends during the holiday their ideas on this varied. A third thought they had not made new friends, a third thought they certainly did and the other third was doubtful on the kind of friendships they made. The doubt about whether friendships would last after the holiday finishes was something more participants thought about. Main reasons for this doubt was the distance between the hometowns of participants and previous experience that these friendships do not last. However, there were some participants that thought that through social media they could maintain their new friendships. They clearly think about these kind of things and make a decision on how to handle these friendships. This can be related to the empowerment theme of *'having a sense of control/taking control'*. The friendships that do last link more to *'bringing about change in one's life'*.

To check what participants do with their holiday memories after they get home they were asked about this. All participants tell family, friends, flat mates (if applicable) and colleagues their holiday stories. Some tell their stories with the photos they have made and a couple even make an album of their photos to be able to relive their holiday memories. All participants also cherish positive feelings towards Flow Reizen and its guides and think it is likely they will travel with Flow Reizen again. They are, however, realistic about waiting for the new destinations to be announced to see whether there is something they like and are aware of other possibilities that may arise throughout the year. Once again *'making their own, informed choice'*. One participant is very clear and open about the changes he has been through since he started travelling with Flow Reizen two years ago. He has developed his social skills and started seeing the world much clearer. He has also become more daring in the activities he undertakes and is very happy with and proud of these developments. He is a great example of how these kind of holidays can lead to participants feeling better about themselves and becoming more empowered. Two other examples of this are observed during the reunion in November. One participant decided to travel to the reunion independently, even though she had expressed her anxiety about this during the holiday. Another participant tells that she and her partner, after 10 years of Flow Reizen, will travel independently for the first time. As Martijn Riswick points out during his explanation of what Flow Reizen wants to achieve: "Making yourself superfluous, means you're doing a good job". He adds that this will be impossible as there will be new people signing up for their holidays. He also adds that regularly participants decide to travel independently or with 'regular' tour operators, but they often come back to Flow Reizen. Sometimes because it turns out they could not handle it, but often also just because of the conviviality of the groups.

Overall, the recollection phase shows that holidays can certainly have an impact on the sense of empowerment of participants. During this phase it shows that participants have been empowered by means of making own, informed choices, learning new skills, having a sense of control and even by experiencing things that bring about change in their lives. To see whether these effects are long term, a follow-up research will be needed to talk again to participants after they have been home for a while again. However, a few participants already explained or showed by doing certain things that it is very likely that the holiday experiences have empowered them in a way that they now do more things than they did before undertaking their holiday and it that sense have become more empowered.

8. Conclusion

Now, I revisit the main research question of this thesis: ***How do Dutch people with MID and ASD, participating in specialized guided holidays in Europe, experience the different elements of an active specialized guided holiday and in what way do they believe that these experiences influence their sense of empowerment?***

I would like to start by saying that becoming empowered is not the only reason for people (with or without disabilities) to choose for a group holiday. Common reasons to choose this type of holiday can be, for example, convenience and/or safety. However, that group holidays do have the ability to empower has hopefully become clear while reading this thesis. I will start this conclusion by mentioning the ten pre-determined characteristics of empowerment again:

1. Making one's own, informed choices;
2. Feeling part of the holiday group;
3. Participation in all elements of the holiday;
4. Feeling of having equal rights as other people at home and at the destination;
5. Having a sense of control/taking control;
6. Bringing about change in one's life and one's community;
7. Learning skills that one defines as important and can be used in the future;
8. Changing one's own and others' perceptions of one's competency and capacity to act;
9. Increasing one's positive self-image and overcoming stigma;
10. Coming out of the closet

These ten characteristics will be used here to summarize how different elements of the participants' holiday experiences during the five phases of the tourism leisure experience can contribute to empowerment. The five different phases of the tourism leisure experience are: anticipation, travel to, on-site, return travel and recollection.

Making one's own, informed choices

Even though going on a specialized, guided holiday often means that there is less to worry about when it comes to deciding things, the answers in this research show that there is still plenty of own, informed choices to be made by participants. These kind of choices have to be made during all five phases, but are most prominent during the anticipation phase, when there is still a lot to be decided on. The research shows that participants are very much involved in making all these decisions. But also on-site participants have to make choices, mostly about whether they wish to participate in certain activities or not. Their answers show that they give these decisions considerable thought and have no problem in then expressing their choice.

Feeling part of the holiday group

Travelling with a group does not necessarily mean that people feel part of this group. Participants make a conscious choice to join these group holidays and a reason that all participants have for this is wanting to be with a group. This characteristic is most noticeable during the on-site phase, which is logical as this is when the group spends most time together. The fact that all participants have an intellectual disability seems to create a bond between participants which contributes to the sense of belonging to the group. Not all participants have the feeling they are part the group, sometimes caused by the difference in age or type of disability. Most participants do feel part of the group, which, besides it being more fun, makes them feel more secure.

Participation in all elements of the holiday

Participating in leisure activities and going on holiday have not always been obvious possibilities for people with MID and ASD. The amount of organizations now offering all kinds of holidays for this group shows that times have (thankfully) changed. Participants make good use of the possibility to participate in these holidays, sometimes even more than once a year. When looking at the on-site phase the fact that activities are decided upon together with the participants means that most will be able to join in. Sometimes it is not possible for a participant to join, which is often slightly disappointing for them. Even when participants think they cannot participate they are often encouraged to try, which can lead to positive surprises when they can do it after all, but also the feeling of having tried can make participants feel good about themselves. It is always the decision of the participant whether they choose to participate or not, which puts them in control.

Feeling of having the same rights as other people at home and at the destination

On holiday participants are outside of their normal environment and often also outside their comfort zone. The way they are treated can therefore be different than they are used to and this can have an impact on the way they feel about themselves. Answers in this research show that during the on-site phase participants find it important that guides treat them as equals and this is also how they experience the relationship between the guides and them. By participating in activities that other people participate in during their holiday this sense of equality can be increased. None of the participants experienced being treated differently than others and all felt equal to others.

Having a sense of control/taking control (input,

Despite going on a group holiday, participants still have enough opportunities to make their own decisions and do their own things. During the anticipation phase they know where to look for information to decide on their holiday and are in control of making this decision. On-site they are involved in the program planning and decide themselves which activities they would like participate. They all feel comfortable in expressing the decisions they make. Besides the group activities there is also enough free time, which they fill with activities of their own choice. Participants like it when guides let them be and give them enough freedom, stimulating this sense of control.

Learning skills that one defines as important and can be used in the future

Going on holiday might, at first glance, be more connected to relaxing than learning something, but a lot can be learned during a holiday and participants certainly experience this. On-site the type of skills that can be learned during a holiday can be very different. Some participants work on their social skills, which can also help them in their daily lives. There are participants that learn about or from other participants, which can help them in understanding others better, but also in learning about and accepting themselves. Then there are of course also skills that participants obtain during (new) activities, which can be(partly) used at home. In the anticipation and travel to-phase there are still some practical skills that can be improved in the future to become more empowered.

Changing own and others' perceptions of one's competency and capacity to act

Holidays can be a great opportunity to try new things. For some this means going on holiday in the first place, or trying a new destination, but for most participants this means trying new activities. By trying new activities on-site participants often have to push themselves to go a little further than they are used to, which almost always results in discovering they can do more than they thought they could do. Often it also involves doing things that others did not think the participants could do. Even only trying something without fully succeeding in it can make participants change their perception of their competency.

Increasing one’s positive self-image and overcoming stigma

Not too long ago, going on holiday was not self-evident for people with MID or ASD, let alone going on active kind of holidays. For many participants ‘being active’ and ‘challenging yourself’ is now a reason they give during the anticipation phase supporting their choice for a certain holiday. Most participants experience positive reactions when they tell people about their holiday, but some also encounter doubt from others. This is often easily overcome when participants then prove them wrong when they are capable of going on the holiday and do the activities planned for that holiday. This makes participants feel very good about themselves.

Bringing about change in one’s life and one’s community

Holidays are often taken for a short period of time, which means a temporary change for the traveler. However, some experiences during a holiday can have a big influence on participants and affect their daily life even after the holiday has finished. Most participants are not sure whether activities they did during their holiday would affect their life at home, in the sense that they would continue to do them. They often make a clear distinction between home and holiday. But even when it is not the exact same activity that will be continued, parts of it or ideas they got from it often do influence the life of participants after they get back. Not many participants expect the friendships they make on holiday to really last after the holiday finishes, but there are a few participants that do hope the friendships they made will last and who already made arrangements to try and make them last. All participants felt very good after the holiday had finished and looked forward to telling others about it. Some participants make photo albums so that they can look back on their holiday now and then, and see who was there with them and what they did. For one participant the start of going on these kind of holidays has also been the start of many life changing experiences for him, which he is very thankful for and feels really good about.

Coming out of the closet

For participants, signing up for a specialized guided holiday can be a bit of a barrier, but most participants in this research do not have a problem with this, as long as not too much emphasis is put on the fact that they have a MID or ASD. When explaining their disability some participants have no problem with the fact they have a disability and are not afraid to put other people that doubt or mock them, in their place. Often, participants do this by means of self-mockery or exaggerating their disability. Being on a specialized guided holiday with other people with MID or ASD results in recognition and feelings of security, which can also help people come to terms with their disability. All participants love telling about their holiday experiences they have achieved, despite their disability and possible doubt from their surroundings. They are proud of their achievements.

Overall, it can be concluded from the paragraphs above that specialized holidays can have a tremendous impact on the sense of empowerment for people with MID or ASD. Much of these possible impacts have been confirmed by the participants of this research when they shared their personal experiences and feelings about their holiday. What the influences are in the long run are, unfortunately, outside the scope of this research, but some influences of the holidays could still be experienced a few months after the holidays had ended and participants came together at the reunion.

Prevailing paradigm in holiday experience

This study tries to answer a question that is related to the call of ‘world-making’. ‘World-making’ encourages people with MID and ASD to have their say and by doing so influence their way of living. Up till now, this method of obtaining information has been lacking in all three existing disability paradigms (defect, development and citizenship), where the norm was always set by the most dominant group in society and others should adapt to these norms. However, when looking specifically at the different holiday experiences of the participants it becomes clear that influences of all three paradigms are still visible in present-day tourism leisure experiences for people with MID and ASD.

The defect paradigm shows through in the way people sometimes care for the participants. Parents want the best for the participants which often results in doing things for them in the anticipation phase of the holiday. While this is done with the best interest at heart, it shows that people want to tend to and take care of the person with MID or ASD, which is the type of care that is connected to the defect paradigm. During the on-site phase of the holiday experience the capability of participants to do certain things is sometimes doubted, which also hints towards the defect paradigm . It puts emphasis on the limitations of the participant, which is a characteristic of the defect paradigm.

The development paradigm is mostly visible in the way Flow Reizen and its guides try to let participants develop themselves by giving them the opportunity to try new activities during the on-site phase of the holiday. This is related to the type of care of the development paradigm which is to train and develop. Guides encourage participants to push their boundaries and go that one step further than they think they could, improving their self-image and the image that society might still have of people with MID and ASD. This shows that people with MID and ASD are seen as persons with possibilities, which is the vision of the development paradigm. They are encouraged to have a holiday as normal as possible.

When taking a broader look than just the participants’ holiday experiences, influences of **the citizenship paradigm** are clearly seen in the fact that nowadays so many organizations exist that offer holidays for people with MID or ASD. This indicates that going on holiday is now seen as an obvious right for people with MID and ASD, just like it is for everyone else. This equality carries through in the experiences of participants during their holiday where they feel they are treated equally to others and have the right to say or do what they like. Another influence of the citizenship paradigm is the fact that regular holiday destinations and accommodations are used for the holidays. Where in earlier days special facilities would have been used, now participants are staying in the same kind of spaces as everyone else would and partake in the same kind of activities. They are also free to indicate what they would like to do and receive the necessary support from guides to achieve these wants and needs. This support is the dominant type of caring in the citizenship paradigm.

During tourism leisure experiences all three paradigms are still visible, just as it is in daily life. On the whole, it can be said that the defect paradigm is least visible. The development paradigm still plays an important role in trying to empower people with MID and ASD by trying new things and feeling better about themselves. But the influences of the citizenship paradigm are most prominent, which is in line with the developments in society in general. However, all three paradigms still ask people with MID and ASD to adapt to a certain norm that is most likely not possible for them to achieve. By involving people with MID and ASD more in research that concerns their possibilities of becoming included in society, this inclusion will be much more likely to succeed.

9. Reflection on the research

This thesis research and writing has been quite a journey, with many ups and downs. In this chapter I would like to look back on my experiences during this research and just like I have done in the rest of this thesis I will also give participants the chance to share their experiences looking back on their participation in this research and the impact this may have had on them.

9.1 Personal and participants' experience

My topic search for this thesis was quite extensive. Even though I knew for sure I wanted to have a topic dealing with people with intellectual disabilities, the final topic choice took a while. But once I had chosen I really enjoyed diving into the topic. I got fascinated by the history of how people with disabilities have been treated over the past centuries and the different paradigms that evolved with this, which sometimes got me a little bit lost in all the information about these kind of things and whether they were relevant or not. Partly because of this, it took a long time to write the final proposal, but at the start of the summer of 2014 I was finally ready for my fieldwork to start.

As described in chapter 4 my fieldwork took place on four trips that I guided during the summer. This immediately caused the first difficulty for me in this thesis research as I was going to be both guide and researcher. For the research this was no big problem as I could adopt the role of participant-observer, which only led to more in-depth information for the research. I did have to pay attention of course to the fact that as a researcher I had to try not to let my experiences as a guide influence the way I worked with the participants during interviews and assignments. Most of the times this was no problem, but some participants' behavior gets on your nerves after a week of spending a lot of time together and when you then also have to interview them for an hour this can be a challenge. I only remember one interview where I nearly ran out of patience, but in the end all interviews were carried in a similar manner and fully completed. My main concern about being guide and researcher at the same time was about the amount of time I could spent on the research and on my work as a guide. I knew from experience that being a guide on these holidays is already very time-consuming, so I was hesitant to also add the time for the research to this already high workload. Before the summer started I sent an email to my fellow guides informing them about the research I was going to be carrying out and asked for their help and understanding in creating enough time for me to carry out the research. They have all been so supportive and encouraging that it turned out to be no problem at all combining the two jobs for the summer. I think both roles really complemented each other. During my work as a guide I could observe participants all day long while they were doing all different kind of activities and see what impact this had on them, which I could use as input for my research. And during my work as a researcher I really got to know the participants better and heard so many interesting things from them about what they like and how they feel, which I could use again to be a better guide and provide them with a holiday they thoroughly enjoyed.

My second concern was that participants would not want to participate or that it would influence their holiday too much. I carefully discussed this with the office staff of Flow Reizen and they trusted me in ensuring that participants would not feel obliged to participate or that it would negatively impact their holiday. As it turned out this concern was completely unnecessary as participants were very keen to participate and sometimes even disappointed that they could not participate because I only had time for three participants per trip. During my trip to Passau one participant was so upset that his friend was participating and he was not that it took me two days and a number of conversations to make sure that it would not negatively impact his holiday experience, which in the end meant letting him participate too. Every trip there were enough participants who wanted to partake in the research and most of them took this very seriously, but really enjoyed it at the same time. Why they enjoyed it and what the results of their participation were can be read in the following subchapter. During the final interviews I also noticed that participants were different from the first set of interviews. They were much more at ease, talked more openly etc. I think this has to do with the fact that they got to know me better during the holiday and were more relaxed because of the fact they just had a 10 or 12-days holiday, but I also think that participating in the research really meant something for them. They felt they could share their side of things and were taken seriously.

Most participants took their participation in the research also quite seriously and sometimes even had to remind me that I had to give them a new assignment for that day. I noticed this enthusiasm during my first trip and got interested to find out more about this. Therefore I added an extra question to the final interview guide asking them about what they thought of the research and their participation in it. All participants were positive about their participation and none regretted participating nor felt it had influenced their holiday in a negative manner. On the contrary, it had added something to their holiday:

> *"Nice! Because I had an assignment I had to, no, that I could carry out and because I like to do things for others." (John)*

The photo assignments especially contributed to the enjoyment of participating in the research:

> *"Yes, I have been busy taking photos. I already said to my parents I can't do that, taking photos. But now I have done it and I like that. Yes, I really enjoyed it, because I have learned how to handle a camera. I am even thinking about buying a camera now, because using a phone you have to get it out of your pocket every time and now you do more with the camera, it's faster, so yeah." (Frits)*
>
> *"I enjoyed it. To tell you about the photos, the assignments, to carry out the photo assignments. I just really enjoy taking photographs on holiday." (Sarah)*
>
> *"Great, I enjoyed participating and I thought some assignments were really nice. Because I got the camera in my hands and that I was allowed to carry out the assignments completely on my own. Yeah, I just really enjoyed partaking in the assignments." (Thom)*

For some participants the assignments caused them to pay more attention to certain things during their holiday:

> *"Well, maybe you pay more attention to what you see, because of the photos you're taking." (Sander)*
>
> *"Yes, I'm paying more attention to the details of things." (Max)*
>
> *"I had to participate in the research and that also made me think about things, about what I like and don't like." (Sylvia)*

Not everyone found it very easy to participate in the research, but in the end still thought they learned from it:

> *Pieternel: "What did you think of your participation in the research?"*
> *Liesbeth: "Yeah, okay, it was quite difficult."*
> *Pieternel: "What did you find difficult?"*
> *Liesbeth: "Euh, how to do it and then also explain it, but I did learn from it."*
> *Pieternel: "What did you learn from it?"*
> *Liesbeth: "To take nice photos and how to do it."*
> *Pieternel: "To do what?"*
> *Liesbeth: "To explain the photos and to do something for other people."*

This latter comment stands out as people with disabilities are often seen in the role of recipients of services, and often do not benefit from the possible benefits of being givers of services (Miller, et al., 2002). That their contribution in this research would mean so much to them was something I had not anticipated, but I was thrilled to notice this. They really felt they contributed something, which made them feel good about themselves and hopefully also empowered them some more.

9.2 Limitations

I noticed some limitations early on in the research, which I took into consideration as the research proceeded. Funnily enough, these limitations are also perfectly described by three participants.

The first limitation became clear during the second trip. To clarify the photo assignments I had put example photos on them. I did put down that these were examples and explained that for participants other things might be important or annoying. This was not clear to all participants as some days participants would come up to me telling me that they had not taken a photo of, for example, someone telling them no as was shown on the example photo, because it did not happen to them. Some asked a fellow traveler to stage the situation, so they could take a photo. Benny thought this was quite difficult about the research:

> *"Taking the photos was fun, but also quite difficult. You have to take photos of things you do not like and that people come up to you telling you 'whewhehe'[shaking his head], and when that then doesn't happen... " (Benny)*

The second limitation was that participants sometimes mixed up the assignment of that day with the one of the previous, making it sometimes difficult discussing with participants afterwards why they had taken that photo that day:

> *"I enjoyed taking the photos, but did make some mistakes." (Sylvia)*

Many participants also had the problem that sometimes they forgot to take their camera with them during the day. John also had this problem:

> *"I thought it was annoying that sometimes I forgot to take the camera and didn't get a chance to take a photo." (John)*

When there were no photos I discussed the question during the interview and wrote down what they would have taken a photo of if they would have had the camera.

9.3 Recommendation for further research

What struck me the most was that participating in this kind of research was new for almost all participants:

> *"What I liked about the research? To do things I normally would not do. Taking all those photos.. Yeah, and participating in a research is also something I have never done." (Martin)*
>
> *"I quite enjoyed experiencing something like this. I have never done that before." (Harrie)*

The fact that it was new for almost all participants shows, in my opinion, that we do not ask their opinion often enough and because of this still decide for them too often. I thoroughly enjoyed doing this research with these participants and hearing their view on so many different and interesting things. And I hope that with this thesis I have encouraged others to do the same, and by doing so making a small step towards involving people with MID and ASD more in all kinds of research. This will eventually lead to a society with more equality and better understanding for each other.

10. Recommendations

As a result of this study, I would like to give some recommendations to the people that deal with specialized guided holidays, whether this is helping participants in the anticipation phase or guiding them through the on-site activities. I hope that with these recommendations I contribute to improving the sense of empowerment of people with MID and ASD during their organized holiday experience.

I would like to start with a recommendation for parents that help participants in the process leading up to the holiday:

- Sometimes ignore the urge to care and do everything for your children with MID or ASD. By doing so, you give them the opportunity to develop and improve new skills. For example, filling in paperwork. This can lead to your children feeling more empowered and feeling better about themselves.

The following recommendations are for Flow Reizen and its guides:

- Look into the opportunities of empowering people with MID and ASD during the anticipation phase to see whether there are possibilities that Flow Reizen can undertake to improve the sense of empowerment of people with MID and ASD. For example, making the actual booking process more accessible or inviting for participants to go through this independently. By doing this, another chance is created for them to do things they did not think they could do and this can make them feel more empowered.

- Be aware that the journey to and from the destination is also part of the overall holiday experience. Many social interactions take place and situations occur during this travel time. More research is needed on what these exactly are and what they mean to the participants, but this knowledge could then lead to creating more opportunities for participants to feel empowered during the travel to and return travel phase of their holiday.

- During the on-site activities, do not only focus on new and exciting activities, but also make sure there are plenty of small-scaled, communal activities, such as having dinner together or playing board games. The research shows that participants attach a lot of value to these moments.

- During the on-site experience try to make time for 1-on-1 time. The research shows that many participants need this time to express their wishes and it also gives them the feeling of being valued and taken seriously.

- Create small jobs or tasks for participants during the on-site experience. For example, taking photos by means of a certain assignment. The results could possibly be used for the DVD that participants can buy at the end of their holiday. Participants thoroughly enjoyed participating in this research because they enjoy doing things for others and it challenges them to do things they normally do not get asked to do. It made them feel like they truly contributed something.

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Apendix I - Interview guide

Interview guide 1: At the beginning of the trip

Introductie

1) Hoe heet je en hoe oud ben je?
2) Wat doe je thuis qua werk?
3) Wat doe je thuis qua hobby's?
4) Hoe woon je?
5) Weet je hoeveel keer je al met Flow op reis bent geweest?

Karakterisering MID /ASD(**goed en <u>bewust</u> van persoon voor je inleiden**):

6) Kun en wil je wat over je beperking vertellen?
7) Zie jij het zelf als beperking? Of zou je het liever anders noemen?
8) Hoe uit zich je 'beperking'?
9) Waarin heb je hulp nodig als je op reis gaat? (5)
10) Hoe reageert je omgeving op je 'beperking'?

Voorbereiding & verwachting (anticipation):

11) Hoe kwam je erbij om deze reis te doen? (1,5)
12) Zoek je zelf informatie op de website, facebook of brochure op? (1,5)
13) Wie heeft uiteindelijk besloten dat je deze reis zou doen? (1,5)
14) Wie heeft de reis geboekt? Indien iemand anders, had je dit liever zelf gedaan? Waarom? (1,5)
15) Ben je naar de kennismakingsbijeenkomst geweest? Waarom wel/niet? Met wie? (1,5)
16) Was dat nuttig en waarom? (1,5)
17) Wat verwacht je tijdens deze reis van de groep? (2)
18) Wat verwacht je tijdens deze reis van de begeleiding?
19) Wat verwacht je tijdens deze reis van de activiteiten?

Heenreis (travel to):

20) Hoe ben je naar het beginpunt (E'hoven/Utrecht/Nijmegen/Maastricht/Enschede) gereisd? (5)
21) Had je anders hiernaartoe willen reizen? Hoe dan? (5,7)
22) Vind je het leuk om met een groep te reizen? Of zou je liever alleen reizen? Waarom? (5,7)

Activiteiten (on-site activities):

23) Weet je al welke activiteit(en) je gaat doen en waarom? (1,3,5)
24) Wat verwacht je ervan? Heb je er zin in? Waarom wel/niet?
25) Heb je (deze activiteit) al eerder gedaan? Denk je dat je het kan? Wat moet je nog weten om het te kunnen? (1,3,6,7)
26) Denk je er iets van te leren? (6)

27) Als je niet mee wilt doen aan een gezamenlijke activiteit, zou je dat dan zeggen? Waarom wel of niet? (2,3,5)
28) Hebben mensen gezegd dat je bepaalde dingen op deze reis niet zou kunnen? Welke activiteiten? (6,7,8)
29) Zijn er dagelijkse activiteiten die je moet doen waar je tegenop ziet? (1,5)
30) Zou je liever elke dag helemaal zelf bepalen wat je die dag gaat doen? (2,3,5)

Uitleg foto opdrachten

31) Ik wil je vragen om gedurende deze vakantie een aantal keer foto's te gaan maken. Daarvoor krijg je een fotocamera van mij. Op 4 dagen krijg je een papiertje met daarop de opdracht en aan de hand daarvan probeer je dan foto's te maken. Er zijn geen goede of foute foto's, dus probeer de opdracht in je achterhoofd te hebben als je de foto's maakt, maar het gaat echt om jou en jij beslist dus waar je de foto's van maakt. Maak je er dus niet druk om, het moet voor ons allemaal leuk blijven. Het is ook niet erg als je een keer wat minder of teveel foto's maakt. Heb je nog vragen?

Interview guide 2: At the end of the trip

Activiteiten (on-site activities):

1. Welke activiteit(en) heb je gedaan deze vakantie?
2. Was het je eigen keuze om aan deze activiteiten mee te doen? (1,3,5)
3. Wat vond je ervan? Vond je het leuk/nuttig/leerzaam? (6,7,8,9)
4. Zou je het thuis weer opnieuw doen? (6,9)
5. Heb je alle activiteiten gedaan die je aan het begin van de reis hebt aangegeven? (3,5)

6. Welke dingen heb je gedaan in je vrije tijd? Alleen of met anderen? (1,2,5)
7. Zijn dit andere dingen dan je thuis zou doen? (6,7)

8. Zijn er dagelijkse dingen (zoals douchen, tandenpoetsen, kleding keuze) die je tijdens deze reis anders hebt gedaan dan thuis? Wat is het verschil? Zou je dit thuis ook zo willen? (1,5)

9. Heb je aan een activiteit (indien bekend, benoemen) niet meegedaan? Waarom niet? (1)
10. Heb je een activiteit gedaan waarvan je dacht dat je die nooit/niet gauw zou zullen doen? Waarom heb je die nu wel gedaan? (7,8,9)
11. Heeft iemand anders deze vakantie gezegd dat je iets niet zou kunnen? Zo ja, wat/wanneer? (7,8)
12. Heb je dat toen gedaan? Hoe voelde je je daarna? (7,8)

13. Voel je je deel van deze groep? Waardoor komt dat? Zou je dat willen zijn? Waarom wel/niet? (2,4)
14. Leer je thuis vaak nieuwe mensen kennen? Hoe heb je geprobeerd anderen te leren kennen deze reis? Heb je hierdoor nieuwe vrienden gemaakt? (6,9)
15. Hoe heeft de begeleiding je geholpen deze reis? Te weinig, precies goed, te veel? (2,5)

16. Heb je het gevoel gehad anders te zijn behandeld dan anderen? Waardoor komt dat? (4)
17. Kun je iets (of meerdere dingen) noemen waarover je je beter/fijn voelt na deze vakantie? (7,8,9)

Bespreken van de foto opdrachten:

(1.Maak vandaag een foto /foto's (max. 10) van iets wat voor jouw heel belangrijk is op deze vakantie)

18. Wat staat er precies op deze foto?
19. Waarom is dit zo belangrijk voor je tijdens deze vakantie?
20. Is dit thuis ook zo belangrijk voor je?
21. Is er een verschil tussen dit op vakantie of thuis? Wat is dat verschil dan?

(2. Maak vandaag een foto /foto's (max. 10) van iets wat je vervelend of lastig vindt tijdens deze vakantie)

22. Wat staat er precies op deze foto?
23. Waarom heb je dit gefotografeerd? Wat was er vervelend of lastig aan?
24. Wat was het effect van deze situatie? Weerhield het je ervan iets te doen? Hoe voelde je je?

(3. Maak vandaag een foto/foto's (max.10) van iets wat je heel leuk of bijzonder vindt)

25. Wat staat er precies op deze foto?
26. Waarom heb je dit gefotografeerd? Wat was leuk of bijzonder aan?
27. Wat was het effect van deze situatie? Hielp het je om iets te doen? Hoe voelde je je?

(4. Maak vandaag een foto/foto's (max. 10) van iets wat je thuis niet vaak doet of zal doen)

28. Wat staat er precies op deze foto?
29. Kun je vertellen waarom je dit thuis niet vaak doet of zal doen?
30. Waarom heb je dit nu wel gedaan?

Terugreis:

32) Haalt iemand je op?
33) Met wat voor gevoel ga je terug naar huis?

Thuiskomst/Herinneringen:

34) Ga je mensen opzoeken? (9)
35) Vertel je mensen erover? (9)
36) Maak je een fotoboek? Waarom, wat doe je hiermee?
37) Kom je naar de reunie?
38) Ga je volgend jaar weer mee?

Appendix II – Photo- elicitation assignments

1.Maak vandaag een foto /foto's (max. 10) van iets wat voor jouw heel belangrijk is op deze vakantie

Bijvoorbeeld:

Op tijd zijn

Je favoriete vakantie activiteit

Nieuwe mensen leren kennen / vrienden maken

2. Maak vandaag een foto /foto's (max. 10) van iets wat je vervelend of lastig vindt op deze vakantie

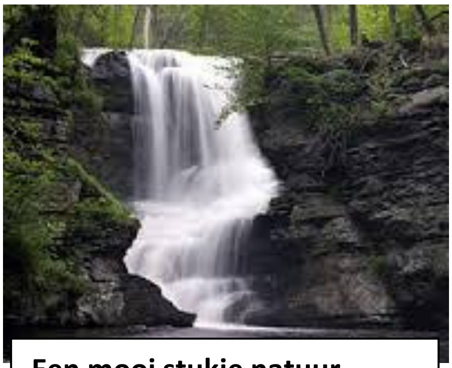
Bijvoorbeeld:

Lang wachten / in de rij staan

Iemand die zegt dat je iets niet mag / kan

3.Maak vandaag een foto/foto's (max.10) van iets wat je heel leuk of bijzonder vindt

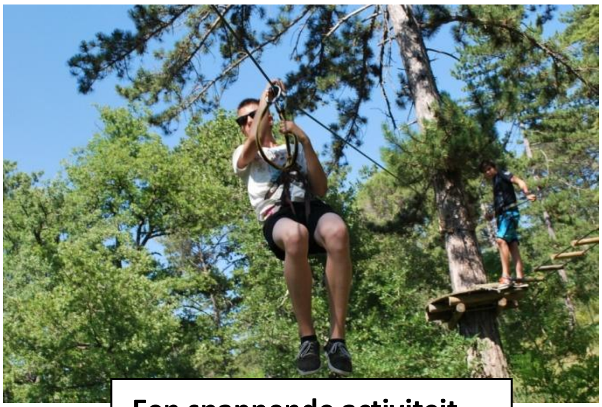
Bijvoorbeeld:



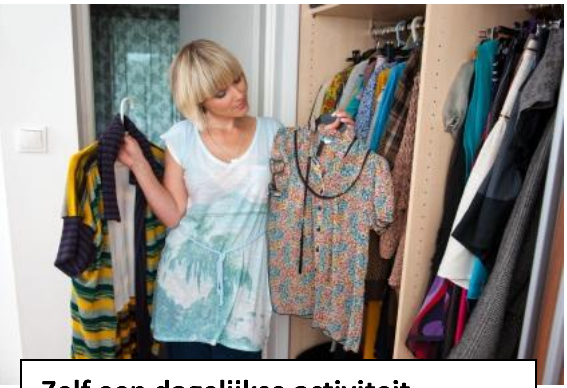
Een mooi stukje natuur

Samen een gezellige tijd hebben

4. Maak vandaag een foto/foto's (max. 10) van iets wat je thuis niet vaak doet of zal doen



Een spannende activiteit



Zelf een dagelijkse activiteit uitvoeren, bijvoorbeeld welke kleren je aantrekt

Appendix III – Consent form

Toestemmingsformulier

Titel onderzoek: *De invloed van activiteiten tijdens begeleide vakanties op het gevoel van empowerment (jezelf sterker voelen) van mensen met een licht verstandelijke beperking.*

Verantwoordelijke onderzoeker: *Pieternel Cremers, Student Master Vrije tijd, toerisme en omgeving, Wageningen Universiteit*

In te vullen door de deelnemer

- Pieternel heeft mij duidelijk verteld waar het onderzoek over gaat en vragen die ik had goed beantwoord

- Ik begrijp dat ik tijdens het onderzoek altijd nog vragen mag stellen aan Pieternel

- Ik begrijp dat alles wat ik vertel tijdens de interviews gebruikt kan worden in het eindverslag dat geschreven zal worden door Pieternel

- Ik begrijp dat mijn eigen naam niet zal voorkomen in het eindverslag. Hiervoor wordt een andere naam verzonnen (anonimiteit garantie)

- Ik begrijp dat de foto's (en video's) die ik maak voor dit onderzoek voor het eindverslag gebruikt zullen worden. Personen zullen niet herkenbaar zijn.

- Ik begrijp dat mijn toestemming eerst zal worden gevraagd voordat deze foto's (en/of video's) eventueel voor een ander doel dan het eindverslag gebruikt zullen worden

- Ik begrijp dat ik geheel vrijwillig meedoe met dit onderzoek

- Ik begrijp dat ik op elk moment tijdens het onderzoek mag besluiten om niet meer mee te werken. Hier zullen geen gevolgen aan zitten.

Naam deelnemer: …………………………………………………………………………………………………….
Datum: ………

Handtekening deelnemer: …...…………………………………………………………………………………

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek zo goed mogelijk beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: Pieternel Cremers
Datum:…………………………………………………

Handtekening onderzoeker: ………………………………………………………………………………….

Appendix IV – Information letter

Informatie over mijn afstudeer onderzoek

Lieve Flower,

Wat ontzettend leuk dat je misschien mee wilt werken aan mijn afstudeer onderzoek. Ik ben daar hartstikke blij mee en we gaan er samen iets leuks en nuttigs van maken!

Mijn onderzoek gaat over hoe jouw vakantie bijdraagt aan jouw gevoel van empowerment, dat wil zeggen dat jij je (nog) beter en sterker gaat voelen.

Voor dit onderzoek zal ik 2x een interview met je doen, eentje aan het begin van de reis en eentje aan het einde. Ook zal ik je 4 dagen vragen om foto’s te maken met een camera die je van mij krijgt. Voor het maken van deze foto’s krijg je een opdracht en extra uitleg.

Ik zorg ervoor dat jouw naam niet in mijn verslag genoemd gaat worden, daarvoor verzin ik (of verzinnen we samen een andere naam). Als er op de foto’s die je maakt mensen staan, dan zal ik die onherkenbaar maken. Dus jij of iemand van je reisgenoten zullen niet herkend kunnen worden. Voor de leuke herkenbare foto’s hebben we natuurlijk de Flow DVD!

Mocht je nog vragen hebben, dan kun je mij die altijd stellen tijdens de reis.

Nogmaals hartstikke bedankt dat je mee wilt werken! Maar vergeet niet dat het je vakantie is en dat dat natuurlijk het allerbelangrijkste is! Mocht je dus merken dat je meewerking aan dit onderzoek je vakantiegevoel beïnvloedt, laat het mij dan alsjeblieft meteen weten en dan zoeken we samen een oplossing. Dit kan betekenen dat je besluit niet meer mee te willen werken, dat mag en zal ik je niet kwalijk nemen. Jouw vakantie is het allerbelangrijkst natuurlijk!

Groetjes,

Pieternel