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Department of Geography and Economic History
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Author: Emma Nyman
Supervisor: Kerstin Westin



TOURISM TRAVEL FOR FAMILIES WITH WHEELCHAIR CARRIED CHILDREN

EXPERIENCES OF PARENTS TO CHILDREN WITH
CEREBRAL PALSY

EMMA NYMAN

ABSTRACT

People with disabilities tend to face more difficulties and constraints when they are travelling for tourism purposes, compared to non-disabled people. This is problematic because mobility in general (and tourism in particular) is, more or less, seen as a 'human right' and has the potential to contribute to peoples' well-being. Tourism travel should, therefore, be available for everyone. This thesis aims to contribute to the understanding of tourism travel for people with mobility-disabilities by studying the experiences of parents to wheelchair carried children with cerebral palsy. The main study objectives are threefold, namely: (1) which constraints these families face throughout the tourism travel chain; (2) how the child's disability affect these families' destination decision processes; and (3) which improvements that can be made in order to make it easier for these families to participate in tourism travel. An interview study was made including 13 parents to wheelchair children with cerebral palsy and these interviews were analysed by using thematic analysis. The findings show that different constraints and barriers (intrinsic, interactive and environmental) are evident during all different phases of the tourism travel chain and affect these families' choices regarding type of tourism trip, which destination they travel to, which transport modes that they can use, which requirements they have in terms of accommodation and which limitations they face when participating in different activities. Some suggestions regarding improvements are also provided, based on what the parents require in order to make tourism travel easier for them.

Keywords: tourism travel for disabled people; destination choice set model; travelling constraints; families with a disabled child; coping strategies

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TABLE OF CONTENTS

ABSTRACT	1
ACKNOWLEDGEMENTS	2
1. INTRODUCTION	5
2. STUDY OBJECTIVES	6
2.1 Aim and research questions	6
2.2 Significance	7
3. THEORETICAL BACKGROUND	7
3.1 The destination choice set model.....	8
3.2 People with disabilities	10
3.2.1 What is a ‘disability’?	10
3.2.2 The social and medical perspectives of disability.....	11
3.3 The main barriers to tourism travel for people with disabilities.....	12
4. PREVIOUS RESEARCH	13
4.1 Tourism travel constraints	13
4.1.1 The pre-travel phase.....	14
4.1.2 The transit phase	14
4.1.3 The destination phase.....	15
4.2 How can tourism travel become easier for people with mobility-disabilities?	16
5. METHODOLOGY	18
5.1 Methods	18
5.1.1 Sampling method	19
5.1.2 Data collection	20
5.1.3 Data analysis	20
5.1.4 Quality and trustworthiness	21
5.2 Ethical considerations.....	21
5.3 Definitions	22
6. RESULTS	23
6.1 Family trips with a disabled child.....	23
6.1.1 Travelling with wheelchair carried children	24
6.1.2 How tourism can contribute to the children’s well-being.....	25
6.2 Constraints throughout the tourism travel chain.....	26
6.2.1 The pre-travel phase.....	26

6.2.2 The transit phase	29
6.2.3 The destination phase.....	32
6.3 How can tourism travel become easier?	35
6.3.1 The pre-travel phase.....	36
6.3.2 The transit phase	37
6.3.3 The destination phase.....	37
7. ANALYSIS OF THE RESULTS.....	39
7.1 How the three main barriers are apparent throughout the tourism travel chain	40
7.2 The destination choice set model and the three main barriers.....	42
7.2.1 The awareness and unawareness set	43
7.2.2 The consideration and excluded set	44
7.2.3 The available, unavailable and dream set	44
7.2.4 The final tourism destination decision	45
8. DISCUSSION	45
8.1 Suggestions for further research	47
9. CONCLUSIONS.....	48
REFERENCES.....	50
APPENDIX 1 – Interview template	58
APPENDIX 2 – Presentation of the respondents	60

1. INTRODUCTION

Tourism travel is, more or less, seen as a ‘human right’ in the Western world today (Eichhorn *et al.*, 2008) and it is stated by the European Union that no one should be discriminated based on their physical or psychological disabilities. A constitution made by the European Union in 2006 provides regulations regarding the rights people with disabilities should have when they are travelling within and between countries in the EU (European Union, 2006). However, tourism travel is still experienced as more difficult among people with disabilities than for non-disabled people, and the regulations and guidelines that do exist are not always followed (Wang & Cole, 2014). People with disabilities can feel restricted in their travel patterns and sometimes even excluded from tourism travel, because of difficulties they face due to their impairments (Yau *et al.*, 2004). People with disabilities, therefore, tend to travel less than non-disabled people in general (Card *et al.*, 2006; Huh & Singh, 2007). About one-third of the disabled population do not participate in tourism travel (Freeman & Selmi, 2010) and studies have shown that people with disabilities want to travel more in the future (Dominguez *et al.*, 2013). If some of the existing barriers to tourism travel that exist for people with disabilities would be reduced, it could encourage these people to travel more and they can get the positive contributions that tourism can provide, for instance in terms of increased physical and psychological well-being and an improved quality of life (Bergier *et al.*, 2010; Pagán, 2015; Stumbo *et al.*, 2011).

Finding appropriate ways to provide tourism travel opportunities in a barrier-free environment should be of great interest among the different actors in the tourism industry (Kim *et al.*, 2012) and perhaps more now than ever, since projections have shown that the number of people with disabilities is likely to increase (World Health Organization & World Bank, 2011). It is important to highlight the tourism travel constraints that people with disabilities experience, since it can help the tourism industry to understand and meet the needs of their disabled customers (Miller & Kirk, 2002).

It is increasingly considered as fundamental in Western countries that no one should be discriminated or feel excluded from the society (Poria *et al.*, 2009) and people with disabilities have, therefore, received increased attention in different research fields recently, for example in geography (Gleeson, 2001) and tourism (Dominguez *et al.*, 2015). However, among the studies that have been made regarding tourism travel for people with disabilities, there is a tendency to include several different disabilities, such as both vision impairments and mobility-disabilities (e.g. Eichhorn *et al.*, 2013; Freeman & Selmi, 2010; Packer *et al.*, 2007; Yau *et al.*, 2004). To include several disabilities in the same study is problematic because these studies become too general and fail to provide an understanding of how people with different disabilities can have different needs. Different impairments and diagnoses can cause different barriers for people who are travelling for tourism purposes (Freeman & Selmi, 2010). Furthermore, many aspects of tourism travel for people with mobility-disabilities remain unexplored (Dominguez *et al.*, 2015). By way of example, there is a lack of research which focus upon travelling constraints for families who have a disabled family member. There is, to the best of the author’s knowledge, no current study that takes into account how parents to wheelchair carried children experience tourism travel. That is where this current study takes its departure.

2. STUDY OBJECTIVES

As well as people with disabilities can find it more difficult than non-disabled people to travel (Huh & Singh, 2007), parents to children with disabilities will probably face other constraints than parents with non-disabled children. This study will, therefore, explore and deepen the understanding of these parents' experiences and how they cope with different constraints throughout the tourism travel chain. The study will only include parents to children with cerebral palsy, which is one of the most common diagnosis among children in the developed world (Magill-Evans *et al.*, 2003; Uvebrant, 2010). The limitation in terms of only including one diagnosis reduces the risk of making a study that becomes too generalized, where all people with disabilities are considered to be a homogenous group. A further limitation regarding the disability has also been made. Cerebral palsy is a diagnosis that can cause different levels of spasticity, leading to various mobility restrictions (Colver *et al.*, 2014; Palisano *et al.*, 2011). This study will only include parents to children who acquire a high level of cerebral palsy and are carried by wheelchairs since these, probably, will have other needs and face other constraints with the physical environment compared to parents whose children have a lower degree of cerebral palsy.

While it could be useful to include the children themselves in the study (Baily *et al.*, 2015) and provide them with the opportunity to share their own experiences of travelling, the aim of this research is to study these issues from the parents' perspective. The whole family is usually affected by the existence of a disability, but family members to people with disabilities are often neglected in research (Green, 2007; Whitaker, 2015), even though a few exceptions do exist (e.g. Mactavish *et al.*, 2002 upon tourism from the perspective of family members to people with intellectual disabilities). Another justification for studying these issues from the parents' perspective is that even if children can have influence upon the tourism decision-making, the parents are often the ones who make the main and final decisions (Bronner & de Hoog, 2008; Seongseop *et al.*, 2010; Wang *et al.*, 2004). Nevertheless, even though this study will be from the parents' perspective and focus upon their experience of tourism travel with a disabled child it can also, indirectly, touch upon how the parents perceive their children's experience of tourism travel.

In this study, the whole tourism travel chain will be included. For people with mobility-disabilities, the accessibility is of utmost importance during the whole travel chain, because "...if any link is inaccessible, the whole trip becomes difficult" (World Health Organization & World Bank, 2011, p. 179). This study, therefore, includes the pre-travel phase, the transit phase, and the destination phase. The purpose of the tourism trips should be to travel for leisure or recreational purposes to an area outside of the home region. Tourism trips within Sweden and abroad are considered in this study, but the trips should include at least one overnight stay at some kind of commercial accommodation (see Hall, 2005).

2.1 Aim and research questions

The aim of this study is to investigate and get an understanding of the difficulties, constraints and opportunities that exist for parents to wheelchair carried children possessing cerebral palsy when they are travelling for tourism purposes.

The following research questions are to be answered:

- Which constraints do parents to wheelchair carried children with cerebral palsy experience during the different phases of the tourism travel chain?
- How does the child's disability affect these families' destination decision choice processes?
- How can tourism travel become easier for families with wheelchair carried children?

2.2 Significance

The main contribution of this research is to give voice to a marginalized group in the society, namely parents to children with cerebral palsy, whose tourism travel experiences have been neglected in previous tourism research. Furthermore, the importance of this study can be considered as fourfold. First, since cerebral palsy is one of the most common disabilities among children and young adults in Sweden (Uvebrant, 2010), many families are, probably, affected by similar constraints and barriers. Also, the constraints will not affect only the person with the disability, but the whole family (Whitaker, 2015) and their travel patterns. Second, the number of people with disabilities is likely to increase in the future due to an ageing population (World Health Organization & World Bank, 2011). Even if these may not necessarily have cerebral palsy, the results of this study could be applied to get an understanding about travelling constraints for people with mobility-disabilities in general and people who are carried by wheelchairs in particular. Third, this study will also contribute to advances in science by starting to fill the gap that exists in the current tourism research field, where studies upon tourism for people with disabilities tend to be very general and include several different kinds of disabilities instead of focusing on one specific disability. Thereby, this study will help to deepen the understanding regarding the heterogeneity that exist among people with impairments and disabilities. Forth, this study is from a Swedish perspective. To this point, there is a lack of research focusing on tourism travel constraints for Swedish people with disabilities. This study has, therefore, the potential to contribute to the existing research upon tourism travel for people with disabilities by providing new geographical and socio-cultural perspectives.

Furthermore, this research also has the potential to contribute to valuable insights for the tourism industry. The findings from this study can help travel agencies, air transport personnel, and other actors in the tourism industry to understand the needs that these families can have. Understanding the needs of the customers is essential in order to be able to fulfil them. This can, in turn, make it easier for families with children with cerebral palsy (or other impairments and disabilities) to travel and encourage more people with mobility-disabilities to become travel active. This study will, therefore, contribute both at a scientific and a societal level.

3. THEORETICAL BACKGROUND

This chapter aims to provide a background to the theories, models and concepts that are used throughout the paper. To begin with, 'the destination choice set model' is presented, which is a model that can be applied to understand tourism destination choice processes. This model will be used when analysing the study results. The following sections in this chapter present ideas

upon what a disability is and explain the three main barriers to tourism travel that usually exist for people with disabilities in general, with a focus upon people with mobility-disabilities.

3.1 The destination choice set model

To choose a tourism travel destination can be a complex process (Karl et al., 2015) and there are several different models and theories which strive to explain why and how people are choosing specific routes or destinations when they are travelling (see Sirakaya & Woodside, 2005). The destination choice can, for example, be affected by our own preferences and capacities (Hägerstrand 1970), or by previous travel experiences (Crouch et al., 2016). It can also be a result of familiarity, which can mean that some tourists choose countries or destinations in which they know the language or culture. However, familiarity can also exist in terms of the popularity of the destination. Then the tourist does not necessary has to be familiar with the language or culture, but is aware that it is a popular destination and that puts the destination closer at their cognitive map (Lee & Tussyadiah, 2012). For families who travel together, the sub-decisions, as well as the final destination decision, are usually made as joint decisions by the parents in the household. However, the children often influence the decisions that are being made, both directly in terms of expressing their own interests, and indirectly in the sense that families who travel with children seek for destinations which are child-friendly (Bronner & de Hoog, 2008).

The decision-making process can be explained by using the ‘choice set model’, which consists of different steps, ranging from all the existing alternatives to the alternative that is actually chosen. Along the way, the set of alternatives becomes increasingly narrow in order to suit the traveller’s needs and preferences. The alternatives that are not considered as available enough due to different constraints (both internal and external) are eliminated throughout this process (Bovy & Stern, 1990; Sirakaya & Woodside, 2005). The concept of choice sets was first applied in a marketing context, where marketers tried to understand on which criteria their consumers based their purchase choice. If they understood this, it was assumed to be easier to affect the consumers and make them buy their products (Decrop, 2010). In tourism, the ‘destination choice set model’ aims to explain how tourists choose which destination to travel to (Mutinda & Mayaka, 2012). An example of the different stages in the destination choice set model is presented in Figure 1.

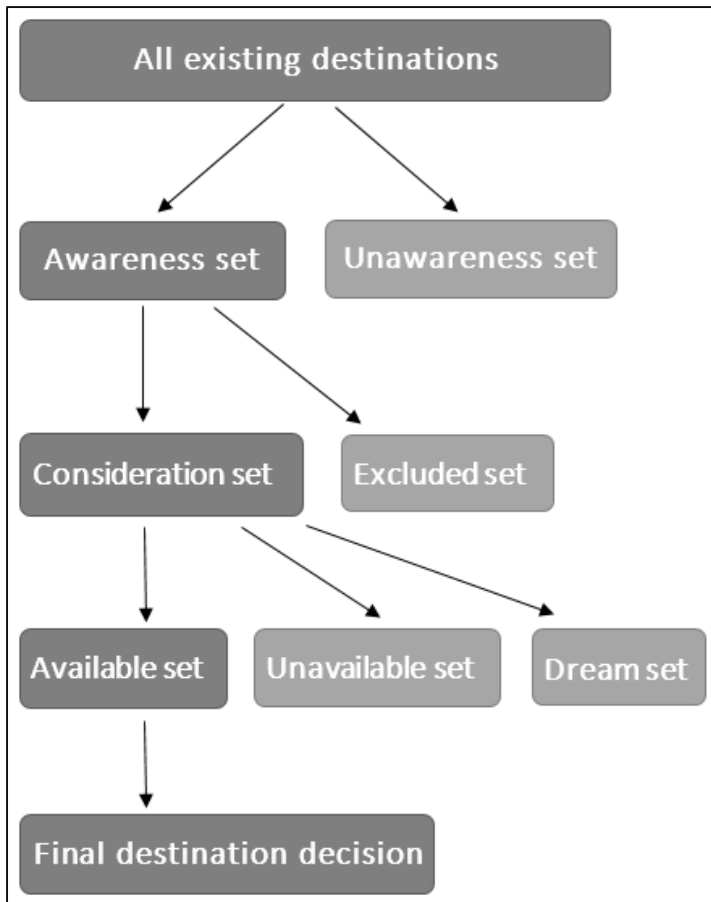


Figure 1: The destination choice set model. Source: Adapted from Bovy & Stern (1990).

First of all, there is a set which consist of all the destinations that actually exist. However, tourists are only aware of a smaller set of all destinations, which is called the ‘awareness set’ (Decrop, 2010), while the rest are put into an ‘unawareness set’ (Karl et al., 2015). The tourist then evaluates the destinations in the awareness set and comes up with a ‘consideration set’, which consists of destinations which the tourist can consider travelling to (Decrop, 2010). Some destinations can be excluded rather unconsciously by the tourist (Karl et al., 2015). The different destinations that remain in the consideration set are then compared based on their attributes. In this stage, the tourist search for information about the different destinations in the choice set. Some destinations are rejected because they are considered to be unavailable due to different constraints and circumstances. Some destinations that are rejected are put into an ‘unavailable set’. This set consists of temporarily unavailable destinations, due to for example financial constraints, which can change over time. Other destinations are put into a ‘dream set’, which are the destinations that the tourist wants to travel to, but which are considered to be permanently unavailable (Decrop, 2010), for instance due to permanent health constraints (Karl et al., 2015). The destinations that remain are put into a so called ‘available set’, which is usually quite small and consists of a few destinations among which the consumer make the final destination decision choice (Decrop, 2010).

The final destination decision choice is usually affected by both the individual’s own experiences and other people’s suggestions (Mutinda & Mayaka, 2012), as well as destination attributes and motivation to travel to a specific place (Decrop, 2010). For people who find many

destinations unavailable due to factors such as ill-health, the destination choice can go from the ideal destination choice to an accepted destination, and sometimes even to an even lower level of satisfaction, where the final destination is tolerated, but far from the ideal choice (Karl et al., 2015).

3.2 People with disabilities

The exact number of people with disabilities in the world today can only be estimated due to three main reasons (Patterson et al. 2012). First, there is a lack of data regarding disabilities in many countries since they do not have a tradition of collecting census information. Second, the term ‘disability’ is defined and measured differently in different countries. Some countries only consider medical and mobility impairments, while others include socially constructed disabilities as well. Third, in some cultures and contexts, people do not want to be defined as ‘disabled’, which also affects the statistics. Due to these factors, no one can know exactly how many individuals in the world who have a disability (ibid.). However, an estimation tells that around ten percent of the world’s population can be considered as having some kind of disability and the number of people with disabilities is likely to increase in the future. This is due to the fact that people live longer today and many elderly tend to acquire impairments and disabilities as they become older (World Health Organization & World Bank, 2011).

3.2.1 What is a ‘disability’?

There are different definitions that are used to explain what a ‘disability’ is, and Gröschl (2007) argues that there is no single definition that is able to cover all disabilities since these are highly diverse (see also Darcy, 2012; Dominguez et al., 2013). A disability can, for example, be either physical or psychological (or both) and these can be divided into numerous sub-categories depending on the characteristics of the disability. For instance, physical disabilities include mobility-disabilities, hearing- and vision impairments, and so forth. (Darcy et al., 2010).

The term ‘disability’ is sometimes used as an umbrella term for different disabilities, as well as for other terms such as ‘impairment’ and ‘handicap’ (Harris, 2008), but there are some differences between different concepts. ‘Impairment’ refers to the individual’s functional limitations (Shaw & Coles, 2004), while a ‘disability’ is when the impairment causes limitations and restrictions when it comes to performing *activities* that are considered as ‘normal’ (Burnett & Baker, 2011). A person with an impairment does not have to be considered as disabled “...if he or she can find ways to compensate for the impairment” (Mann, 2005, p. 2). It can also depend on the specific situation. Something that can be experienced as a small impairment in the everyday life can become a disability when participating in outdoor recreation (Lovelock, 2010) or other leisure activities (Nicolaisen et al., 2012). A study made upon children with different impairments showed that the children themselves feel disabled when they are not able to enjoy the same activities as their non-disabled peers (Singh & Ghai, 2009). Furthermore, the difference between ‘disability’ and ‘handicap’ can be described as follows:

“...the person using a wheelchair may not be handicapped in his/her everyday life if he/she is not limited to, or prevented from, fulfilling his/her roles as, e.g. an employee, a parent and/or an active person in the local community. Yet, if the mobility-

disability prevents the fulfilment of such roles, the disability will qualify as a handicap.” (Blichfeldt & Nicolaisen, 2011, p. 81, italics in original).

Whether a person with an impairment is considered as disabled or handicapped can, therefore, depend on the specific context. What might not be considered as a handicap at home can be a handicap when the person is travelling, due to other restrictions in mobility, accessibility, and so forth, which can appear when a person is trying to take on the role as a tourist (Blichfeldt & Nicolaisen, 2011). A further implication with these definitions was mentioned by Lindqvist (2012), who asks what ‘normality’ is. The fact that the aforementioned concepts are defined in relation to what is considered as ‘normal’ makes the definitions somewhat vague since what is normal depends on the social and cultural context (ibid.) and disabled people are often objectified by non-disabled people and their preferences of what ‘normality’ is (Valentine, 2001). The same can be said about the idea of ‘difference’, where the person with a disability is seen as different in comparison to non-disabled people (Connors & Stalker, 2007).

3.2.2 The social and medical perspectives of disability

There are different perspectives that can be used to describe a disability. These are usually divided into so-called ‘social’ and ‘medical’ perspectives. The medical perspective of disabilities considers the disability as something abnormal, which is a problem that needs to be fixed (Grue, 2015). With this perspective, people with disabilities are seen as a minority group and people are defined by their impairments (Bromley et al., 2007; Nicolaisen et al., 2012). This perspective can reinforce feelings of social exclusion and discrimination among people with disabilities. With the social perspective of disability, on the other hand, the disability is seen as something created by the society (Lee et al., 2012; Lindqvist, 2012; Valentine, 2001). Disabilities is considered as socially constructed (Darcy, 2012; Daruwalla & Darcy, 2005) and whether a person is disabled or not depends on the existence of barriers in the person’s surroundings (Darcy et al., 2016; Martin, 2012; Shaw & Coles, 2004). It may not necessarily be intended barriers which the society sets up towards people with disabilities. Instead, it is often a matter of shortcomings in knowledge and understanding about these peoples’ needs (Bromley et al., 2007).

In a case study made by Bromley with colleagues (2007), people carried by wheelchairs were asked about how they experienced their own disability and difficulties in their surroundings. The results showed that 39 percent of the respondents thought that it was their mobility-disability that led to disadvantages and challenges regarding accessibility, while 61 percent thought that it was the geographical places that were planned in an inaccessible way. Furthermore, 53 percent thought that the biggest problem was how they were treated by the society. 67 percent of the wheelchair users agreed with the statement: “I am disabled by society not by my impairment” (Bromley et al., 2007, p. 236), which indicates that the social perspective to disability can be seen as more important and attuned to disabled peoples’ own perceptions of it, than the medical perspective (also supported by Darcy, 2002; Dominguez et al., 2013; Freeman & Selmi, 2010). Which perspective that others have to disabilities can have large effects on how the disabled person experience a situation, for example when travelling for tourism purposes. How tourism providers perceive disabilities can affect how they are working with improving the physical accessibility of places, but also how they treat their disabled customers (Nicolaisen

et al., 2012). The same has been seen in leisure studies, where it is considered as easier for people with cerebral palsy to participate in leisure activities if the providers are inclusive and take on the social perspective to disability (Conhar et al., 2016).

Children with disabilities tend to see their disability in medical terms rather than social, but at the same time, they do not experience their disability as a big problem that needs to be cured. This can be a result of being born with a disability and, therefore, not being fully aware of how their life would be if they were not disabled. In line with the social perspective, children focus more upon their similarities with other children, not the differences (Connors & Stalker, 2007) and they want to be treated as everyone else (Singh & Ghai, 2009). If the children are treated differently by people in their surroundings, they can start to feel different, which indicates that the social perspective is important as well (Connors & Stalker, 2007).

3.3 The main barriers to tourism travel for people with disabilities

Different barriers and constraints that disabled people face are apparent in several ways during the different phases of the tourism travel chain, and how large these barriers are is highly determined by the individual's physical functioning (Bi et al., 2007). As mentioned before, tourism can contribute to increased well-being for people with disabilities. However, it can also be the other way around. If tourism is not accessible enough for these people, it can reinforce feelings of social exclusion and widen the gap between disabled and non-disabled people. It is, therefore, important to identify the barriers that people with disabilities face when they are travelling for tourism purposes, and work actively to reduce or even, when possible, eliminate those barriers (Stumbo et al., 2011).

Early studies upon leisure constraints categorized these into 'intrapersonal', 'interpersonal' and 'structural' barriers (Crawford & Godbey, 1987; Crawford et al., 1991). While these constraints applied to the general population, some adjustments were made in order to explain the constraints faced by people with disabilities. It has been suggested that people with disabilities face three main barriers when they are travelling, which they have to overcome in order to fully participate in tourism. These are 'intrinsic barriers', 'interactive barriers' and 'environmental barriers' (Smith, 1987).

To begin with, the 'intrinsic barriers' are the limitations that are associated with each individual's own physical, psychological or cognitive functioning, which are affected by the impairment (Yau et al., 2004). These barriers are usually not visible for other people (Packer et al., 2007) and includes fears or anxiety regarding tourism travel (Lee et al., 2012). Intrinsic barriers can limit disabled peoples' tourism participating, and sometimes even prevent them from travelling (Packer et al., 2007). Second, the 'interactive barriers' can be actual communication problems, negative attitudes from other people (Card et al., 2006; Daniels et al., 2005; Dominguez et al., 2013), or feelings of social exclusion (Preston & Rajé, 2007). Third, the 'environmental barriers' are usually seen as the major barriers once the individual is actually travelling, and refers to the difficulties related to the physical environment (Blichfeldt and Nicolaisen 2011). The three main barriers can be categorized into 'internal' and 'external' barriers as well. The internal barriers are the initial obstacles in terms of, for instance, anxiety about being able to participate in tourism. Once these barriers are dealt with and the person starts to

participate in tourism, he/she face the external barriers, which include both the environmental and interactive barriers (McKercher et al., 2003).

Most efforts in terms of reducing barriers that exist for people with disabilities have been made regarding the environmental barriers. A problem is, however, that the emphasis tends to be on ensuring the lowest required level of accessibility for disabled people, rather than planning and designing places that are fully accessible (Bromely et al., 2007). A further problem with focusing on the environmental barriers is that some tourists with disabilities experience negative attitudes from the surroundings as a larger barrier than the physical environment, and it is perceived as more difficult to overcome negative experiences in terms of interactive barriers compared to environmental barriers (Bi et al., 2007).

Usually, people with disabilities do not simply accept that different barriers exist and do not allow for these to prevent them from travelling, but are rather dealing with these proactively (Lee et al., 2012). This indicates that if the motivation to travel is strong, some of the barriers can be negotiated. However it is not considered possible to travel if the constraints are perceived as too difficult to overcome (Gladwell & Bedini, 2004; Kazeminia et al., 2015; Nyaupane & Andereck, 2008). Different people are dealing with travelling constraints in different ways, and a barrier that can be negotiated and easy to overcome by some, may not be experienced as such by another person (Bi et al., 2007; Daniels et al., 2005). Some people can learn the hard way that tourism travel is difficult, by having negative experiences from one trip and thereby feel like it is not possible to participate in tourism travel with their disability or impairment. Others, however, take the negative experience as a lesson to learn from and plan their tourism trip differently the next time they are travelling. It is, therefore, not only the three main barriers that need to be reduced, but it is also important that people with disabilities are encouraged to travel. Their attitudes towards travelling constraints might have to change if they are desiring to participate in tourism travel. However, this can be made more easily if the barriers are reduced, which indicates that there is a relationship between travelling constraints and attitudes regarding the possibility to travel among people with disabilities (Lee et al., 2012).

4. PREVIOUS RESEARCH

This chapter aims to provide an overview of the research that exist regarding tourism travel for people with disabilities. The chapter is divided into two sections. The first presents different constraints that exist for disabled people during the different phases of the tourism travel chain, while the second presents previous studies' suggestions regarding how it can become easier for people with disabilities to participate in tourism travel. The findings from previous research that are provided in this section relate to people with mobility-disabilities in general but is mostly focused on people who are carried by wheelchairs. This generalization is due to the lack of research upon tourism travel for families with disabled children.

4.1 Tourism travel constraints

Travelling as a family is usually seen as something important. Family holidays can strengthen the family relationship since they can get away from the everyday stress (Hazel, 2005). Both the parents and the children tend to increase their happiness and life satisfaction during, and in

close relation to, a tourism trip (Durko & Petrick, 2013). Families who are travelling with a disabled family member usually travel differently than families without disabilities (Huh & Singh, 2007; Jo et al., 2004), due to the adaptations that they have to make in order to make it possible to travel together (Kim & Lehto, 2013).

Different constraints and barriers are evident during different phases of the whole tourism travel chain (Turco et al., 1998; Yau et al., 2004). In this section, three phases of the travel chain are presented, namely the pre-travel phase; the transit phase; and the destination phase.

4.1.1 The pre-travel phase

People with disabilities have to overcome some internal barriers before they can become travel active (Packer et al., 2007). Something that can be experienced as both a constraint and a motivation to travel among people with disabilities can be negative attitudes in the society where they live their everyday life. For some people, negative attitudes from their surroundings can prevent them from travelling (Darcy & Daruwalla, 1999), while others chose to participate in tourism travel in order to get away from feelings of social exclusion (Blichfeldt & Nicolaisen, 2011). Except for those factors, people with disabilities tend to have similar travel motivations as non-disabled people, such as the need for a change of environment and to see and experience new things (Dominguez et al., 2015). However, there are several issues that need to be considered before the trip, especially for people who have specific needs in terms of physical accessibility (Kim et al., 2012). It takes a lot of planning and preparing before travelling with a disability (Eichhorn et al., 2008; Yau et al., 2004), and it is not perceived as possible to be spontaneous (Blichfeldt & Nicolaisen, 2011).

One of the major constraints in the pre-travel phase is the shortcomings regarding information provided by the tourism industry. If the different actors in tourism industry do not understand which specific needs and requirements disabled people can have, it can lead to misunderstandings and the provision of wrong information (Blichfeldt & Nicolaisen, 2011; Eichhorn et al., 2008; Wang & Cole, 2014). However, it may not always be the information *per se* that is the problem, but rather a lack of communication between tourism personnel and tourists with disabilities (Kim et al., 2012). Nevertheless, because of these shortcomings people with disabilities tend to rely more on word-of-mouth and recommendations from other people with disabilities, than on the different actors in the tourism industry during the pre-travel phase (Darcy, 2010; Ray & Ryder, 2003).

In the pre-travel phase, people with mobility-disabilities have to evaluate the accessibility of places. The physical accessibility has to be of primary consideration, while the destination choice becomes a secondary concern (Blichfeldt & Nicolaisen, 2011). It can also be difficult to base the travel decision upon the price of the accommodation since there tends to be a lack of budget alternatives that can provide the required accessibility (Darcy & Daruwalla, 1999; Yates, 2007).

4.1.2 The transit phase

Transportation is commonly perceived as one of the major physical barriers that can prevent disabled people from travelling or limit their participation in tourism travel (McKercher et al., 2003). Many people with mobility-disabilities prefer to travel with their private owned vehicle

since there are too many troubles with public transportation (Bromley *et al.*, 2007; Huh & Singh, 2007; Var *et al.*, 2011).

Children with disabilities tend to have more difficulties when they are using public transport modes compared to non-disabled children. How difficult transportation is experienced by children with disabilities depend both upon the severity of the disability and the age of the child. The more severe the impairment in terms of mobility is, and the older the child is, the more challenging public transportation becomes (Wheeler *et al.*, 2009). Difficulties related to public transportation can be in terms of inaccessible trains and train stations (Ferrari *et al.*, 2014; Freeman & Selmi, 2010) or a lack of needed equipment (Patterson *et al.*, 2012). Regarding bus transportation, a majority of people who are carried by wheelchairs experience it as too difficult and avoid to travel by bus. This is mainly because of difficulties to board the buses due to high steps and a lack of ramps (Bromley *et al.*, 2007). There can also be problems regarding the safety and security on public buses, such as a lack of equipment to secure the wheelchair (Manary & Schneider, 2011).

When people with disabilities travel by airplane, some troubles can emerge already at the airport. Those people who are carried by wheelchairs have to leave their own wheelchair at the check-in and switch to an airport wheelchair, which is seldom adjusted and suitable for the specific disability. People who cannot use these wheelchairs can be carried into the airplane and placed at their seats by their travel companions or airport personnel (Darcy, 2012; Poria *et al.*, 2010). Furthermore, on-board of the airplane, there is a lack of accessibility to the toilets, which makes it almost impossible for people with severe mobility-disabilities to use these (Chang & Chen, 2011; Darcy, 2012). People cope with this problem by using different strategies. Some dehydrate themselves (Darcy, 2012) while others use a diaper or catheter (Poria *et al.*, 2010).

Moreover, in previous research upon difficulties related to air travel, people with disabilities have explained that the attitudes from the personnel at the airport and the airplane can be experienced to be as much of a constraint as the physical accessibility (Darcy, 2012; Poria *et al.*, 2010). Studies have shown that airline employees want to provide good service, have an appropriate attitude and assist people with disabilities who are travelling with them (Chang & Chen, 2012), but that it can be difficult for the personnel to understand the service needs of their disabled customers (Wang & Cole, 2014; Yates, 2007). Both people with disabilities (Poria *et al.*, 2010) and flight attendants (Wang & Cole, 2014) feel that many improvements can be made regarding both the physical accessibility of airplanes and the knowledge and education among personnel.

4.1.3 The destination phase

Some people with mobility-disabilities find the accommodation at the destination to be the most problematic when they are travelling (Kim & Lehto, 2012). It is quite commonly discovered at the destination that there are shortcomings with the accessibility, which risk leading to less satisfaction with the whole tourism experience (Kim *et al.*, 2012). A respondent in Yates' study (2007, p. 163) said: "...many places say they are wheelchair accessible but in practice are not". What might be accessible enough for some people is not necessarily accessible for others.

Wheelchairs are very different in their design and appearance, and there are several different forms, types and sizes of wheelchairs (Blichfeldt & Nicolaisen, 2011).

Some people who have mobility-disabilities also need additional equipment such as shower seats, adjustable beds (Darcy & Daruwella, 1999) or a hoist (Yates, 2007). The most important factor is usually that the hotel room is accessible, whereas public areas become a secondary concern. The room has to be big enough and should not have any doorsteps, sills to the shower and so forth (Kim *et al.*, 2012). It is also important that the room, as well as other facilities, have wide entrances, in order to make it possible to enter the rooms with a wheelchair (Hua *et al.*, 2013). Another concern can be the location of the room. Some hotels have ‘handicap friendly’ rooms several floors above the ground floor, which is a huge problem in the case of a fire when the elevators do not run (Gladwell & Bedini, 2004).

Except for the accommodation, some people with mobility-disabilities can find it difficult to participate in different activities at the destination (Bi *et al.*, 2007; Israeli, 2002). Several activities can be inaccessible due to a lack of needed equipment. Some people with mobility-disabilities are, for instance, dependent on hoists in order to access a swimming pool – something that non-disabled tourists can see as a fundamental part of the tourism experience when traveling on sunny holidays (Yates, 2007). Other barriers at the destination can be the accessibility of art museums (Poria *et al.*, 2009), restaurants (Freeman & Selmi, 2010) or shopping centres (Bromley *et al.*, 2007). It can also be difficult to participate in sport tourism and other activities where one has to be physically active (Darcy *et al.*, 2016; Hua *et al.*, 2013).

Moreover, people with disabilities can face several environmental barriers when they are in peripheral areas (Bromley *et al.*, 2007). Those with mobility-impairments are likely to be more constrained by natural than built environments, especially in remote and wilderness environments. In some cases, there can be oppositions regarding social and environmental sustainability, for example in national parks. Some developments that are needed to improve the accessibility for mobility-disabled people are thought to destroy the beauty of nature and, hence, the authentic experience of a national park (Lovelock, 2010).

4.2 How can tourism travel become easier for people with mobility-disabilities?

According to existing regulations regarding physical accessibility, the environmental barriers have to be reduced and everyone should have the same possibilities to access different places (Bromley *et al.*, 2007; Dominguez *et al.*, 2013). However, there are still many barriers that people with disabilities have to overcome in order to fully participate in, and enjoy, tourism. McKercher with colleagues (2003) suggest that some of these barriers, in fact, are created by the tourism industry. They argue that instead of reducing the barriers and make it easier for people with disabilities to travel, some actors in the tourism industry tend to make it more difficult due to misunderstandings and a lack of knowledge among tourism personnel. A solution to this problem could be to have people with disabilities as employees in the tourism sector (Gröschl, 2007), and include them in planning processes, which probably will increase the awareness and understanding (Bromley *et al.*, 2007; Nicolaisen *et al.*, 2012). However, there is still a lack of employees with disabilities in the tourism industry. By way of example, a case

study which included 42 hotels in Canada showed that only 0.52 percent of the employees were considered to be disabled (Gröschl, 2007). Another suggestion that can increase the understanding and knowledge among tourism personnel is to provide education about different disabilities (Bizjak et al., 2011; Card et al., 2006; Freeman & Selmi, 2010; Kim et al., 2012). To do this can be a way to reduce interactive barriers, which can make it more attractive for people with disabilities to participate in tourism travel. Furthermore, it is usually perceived as easier for disabled people to cope with shortcomings regarding the physical accessibility if they are treated in an appropriate and understanding way by the tourism personnel (Takeda & Card, 2002).

There is a general agreement that the mainstream tourism industry tend to fail to attract people with disabilities due to shortcomings in information, understanding and accessibility. If some destinations fail to meet the requirements of people with different disabilities, the feelings of marginalization can be reinforced. Another implication can be that destinations which have good accessibility and are able to fulfil the needs of their disabled customers can after a while find themselves catering *only* people with disabilities. This has already happened in some places and leads to another kind of discrimination, where people with disabilities end up at one place and non-disabled people search for other destinations (Shaw & Coles, 2004). Although, it does not necessarily have to be only negative that people with disabilities start to travel to a specific destination or hotel which they find accessible. In fact, there are suggestions regarding serving 'disabled tourists' as a niche market segment (Freeman & Selmi, 2010; Ray & Ryder, 2003). Previous research suggests that hotels which provide facilities that are accessible for people with different disabilities can benefit from this in terms of improving the hotel's image and reputation (Patterson et al., 2012), which, in turn, can lead to economic benefits for the hotel (Bi et al., 2007; Card et al., 2006; Shaw & Coles, 2004; Var et al., 2011).

Among people with disabilities, there are some different opinions regarding this niche market segmentation. Some people are positive and emphasize the fact that it is easier to travel with other disabled people since they are in a similar situation. By travelling in a group with other people with disabilities it can be experienced as easier to feel included in the group (Blichfeldt & Nicolaisen, 2011). The feeling of 'sameness' has also been recognized among children but in contexts outside of tourism. Some children prefer to be in a group where they do not have to feel different (Connors & Stalker, 2007). However, most of the previous studies upon this topic show more negative attitudes about this niche segmentation. Many of those who have disabilities prefer to travel as 'normal' people (Eichhorn et al., 2013). By being put into a category, a 'niche', people can feel more excluded from the society and it can reinforce the feeling of being seen as the 'other' (Martin, 2012; Var et al., 2011).

One important thing to consider when trying to attract people with disabilities is that these people should not be treated as a homogenous group. If they are to be seen as a niche market segment, they have to be divided into subgroups depending on their disabilities and specific needs. A suggestion is to make a division between mild, moderate and severe disabilities (Burnett & Baker, 2001). Tourism businesses also have to remember the basics regarding demographical differences, as well as different interests and motivations (Lee et al., 2012; Var et al., 2011).

Another thing to consider is that it is often more expensive to go on these trips compared to mainstream tourism trips (Yates, 2007). The lack of budget alternatives for disabled tourists is a well-recognized problem (Darcy & Daruwalla, 1999). A majority of people with disabilities are not willing to pay extra in order to customize their tourism trip (Burnett & Baker, 2001; McKercher *et al.*, 2003; Yates, 2007), while a few express that they are ready to pay more if they can be ensured that their needs and requirements will be met (Poria *et al.*, 2010).

5. METHODOLOGY

In order to get an understanding of the travel experiences of parents to wheelchair carried children with cerebral palsy and how these families' tourism travel patterns are affected by the children's disabilities, a qualitative approach is considered as most appropriate. While quantitative methods could be useful for identifying general tourism travel patterns, it is not helpful when it comes to understanding people's feelings and experiences. Hence, if the research questions for this study are to be answered, qualitative methods are required (see Veal, 2011). Moreover, there is also a potential sensitivity in research that includes people with disabilities (Gröschl, 2007; Jeppsson Grassman & Taghizadeh Larsson, 2015). People with disabilities often prefer to share their own experiences in qualitative studies, rather than being seen as 'objects', which is a risk when different quantitative methods are being used (Kitchin, 2000). This can be thought of as power relations between the researcher and the respondent, and it is often preferred among people with disabilities if they can take on the role of an 'informant' and the researcher becomes an active listener (Kitchin & Wilton, 2000; Valentine, 2003). Even though this study is from the parents' perspective and they do not have any disabilities themselves, these issues are still considered to be highly important. Therefore, a qualitative approach was chosen for this study.

5.1 Methods

Among different qualitative data collection techniques, in-depth interviews and focus groups are usually found to be most suitable for studies involving people with disabilities (Blichfeldt & Nicolaisen, 2011; Kitchin, 2000). While focus groups could have been a viable option due to the time efficiency and potential to create group discussions, in-depth interviews were chosen for this current study due to a geographical spread of the respondents. By using in-depth interviews, it is possible to gain knowledge about the respondents' individual experiences, attitudes and opinions. Interviews can also provide the opportunity for the respondents to identify new issues that are of high importance for them (Patterson *et al.*, 2012).

The interview template was made beforehand. The template was standardized and consisted of semi-structured open-ended questions, in order to allow comparisons between the different parents' answers. To have open-ended questions also enables respondents to talk freely about the different topics (Veal, 2011), which was considered as suitable due to the explorative character of the study. The questions in the interview template were formulated based on previous research upon tourism travel for people with disabilities, as well as informal conversations with parents and care attendants to children with cerebral palsy. The original interview template was in Swedish, but a version translated into English is provided in Appendix 1.

Before the interviews were conducted, a pilot interview was made. The pilot interview was in the form of an interactive interview with a couple who has a child with cerebral palsy. Pilot interviews are valuable when it comes to studies related to people with disabilities since it can help the researcher to understand the issues and constraints that are important and need to be considered. These issues can be difficult to understand if the researcher does not have any disabilities herself (e.g. Blichfeldt & Nicolaisen, 2011; Burnett & Baker, 2001; Darcy *et al.*, 2010). The pilot interview for this study was, therefore, seen as an opportunity to test the interview template and allow for these parents to come up with suggestions for improvements. The initial interview template was slightly revised after the pilot interview.

5.1.1 Sampling method

Due to ethical considerations and difficulties in finding parents with children with cerebral palsy, different sampling methods were used. Groups consisting of potential respondents were targeted by using different distribution channels. With help from people working at schools with classes for children with cerebral palsy, care attendant companies and habilitation centres, information about the study was sent home to the parents as letters or distributed via e-mail. Similar strategies have been used in previous research, which involves children with disabilities (see Connor & Stalker, 2007; Poria *et al.*, 2009). A second sampling strategy that was being used was to publish the information letter at different Facebook groups' pages, where potential respondents were members.

The information letter included a short description of the study, the aim, the method and the dissemination. It was also stated that the parents could choose to reply if they were willing to participate in the study, that participation was voluntary and that they could choose to end their participation before, during and after the interview if they felt uncomfortable. They were also promised confidentiality and anonymity (see Kvale & Brinkmann, 2014). In order to find more respondents, the snowball technique was also applied. A similar procedure as in the initial recruitment process was then acquired, meaning that the first respondents contacted new potential respondents in their social networks and these could choose if they wanted to participate or not. A consequence of the fact that the parents have to contact the researcher in order to participate in the study can be that the parents who are willing to talk and have a lot to share regarding tourism travel are more likely to participate than parents who do not travel with their disabled children.

The final sample consisted of 13 respondents. The sample size is quite small due to difficulties in finding respondents, but it is considered as large enough to cover some of the main issues related to travelling with children with cerebral palsy. One of the respondents was a father while 12 were mothers to children with cerebral palsy. The respondents are from different places in Sweden, from Umeå in the North to Kungälv in the South. One of the respondents was temporally settled in another country, but still considered as a Swedish citizen and covered by Swedish regulations. Most of the respondents are living in the Northern part of Sweden, but since this study does not strive to make any comparisons based on the respondents' places of residence, the geographical distribution of the respondents is not considered to be a problem. The opportunities to travel and the set of destinations that they can choose from can vary depending on their closeness to a large airport, but no clear difference was found in tourism travel frequency

or destination choice depending on the respondents' place of living. A further determining factor for not studying differences depending on the respondents' residential location is confidentiality. Some of the respondents live in small places and there is a risk that these parents could be identified if their places of residence were presented.

Among the children, nine were boys and four were girls. The age of the children ranged from four to 16 years old. A short presentation of the respondents and their family constellations is provided in Appendix 2.

5.1.2 Data collection

The interviews were conducted from the 9th to the 24th of February in 2016. Four interviews were made face-to-face and nine were phone interviews. The mix of face-to-face and phone interviews is due to two main reasons. Firstly, the respondents who lived in the counties of Norrbotten and Västerbotten in Northern Sweden could choose if they wanted to meet or not. Some respondents preferred to do phone interviews even though it was geographically possible to meet. Secondly, there was a large geographical distance between the researcher and some of the respondents, which made it necessary to perform these interviews by phone. While face-to-face interviews can make some respondents more comfortable than phone interviews, no clear difference was found regarding how freely different respondents talked during the interviews. However, which respondents who participated in the different interview forms are presented in Appendix 2.

The interviews were held in Swedish since both the researcher and the respondents are Swedish citizens and have Swedish as a mother tongue. All the interviews were recorded with a voice recorder, with permissions from the respondents. The interviews were then transcribed by using a software called 'Listen & Write'. When the interviews had been transcribed, the researcher translated some quotes into English. When quotes are translated, there is a potential risk that the researcher misses out on important underlying meanings. Another implication can be that different people interpret texts and quotes differently and there is a risk that the quotes in this study are a result of the researcher's own interpretation. Even though the quotes are translated as detailed as possible in order to limit these risks, these aspects are important to have in mind.

5.1.3 Data analysis

The analysis method chosen for this study is 'thematic analysis', which is a method that involves thematic coding and finding patterns and themes in the data (Spencer *et al.*, 2014). In a thematic analysis, the data is sorted into different codes which are categorized into different themes. The themes that emerge from the codes usually include codes that are similar to each other. The researcher can either have pre-decided themes, let the themes emerge throughout the analysis process, or both. One of the main strengths of using a thematic analysis method is that it is a flexible method (Braun & Clarke, 2006), which is considered as an important asset due to the explorative character of this current study, since it allows using existing themes regarding tourism travel for people with mobility-disabilities, as well as the possibility for new themes to emerge.

A software tool called MAXQDA was used during the coding process, which is useful when it comes to sorting quotes from interview transcripts into codes and themes. One strength with

this software is that it is easier to get an overview of the codes, compared to manual coding (Godau, 2004; Hatani, 2015). From the interview transcripts for this study, a total of 934 quotes and sentences were sorted into 42 different codes, which were categorized into different themes. Some themes were pre-decided but other themes were allowed to emerge throughout the process. The themes that were pre-decided were those that are related to the different sets in the choice-set model as well as the three main barriers (intrinsic, interactive and environmental) to tourism travel that people with disabilities can face. Except for those themes that were already pre-decided, some other themes emerged. One of the themes that emerged was ‘the disabled child’, which related to the fact that it was a child who had a disability, and not an adult.

5.1.4 Quality and trustworthiness

While validity and reliability are important to consider in quantitative research (Long & Johnson, 2000), the quality and trustworthiness of the study that is undertaken is considered more appropriate and useful in qualitative research (Golafshani, 2003). Trustworthiness in qualitative studies refers to factors such as the credibility of the study (which means that the findings presented should reflect the true results from the study); transferability (meaning that the study findings should be possible to apply to other contexts than the specific study undertaken); dependability (meaning that the findings are consistent and that it is possible for other researchers to repeat the same study); and confirmability (meaning that the findings should reflect the interests of the respondents, and not the personal interests of the researcher) (Lincoln & Guba, 1985).

For this current study, the credibility is perceived as high, since the researcher has worked with detailed and careful transcribing and analysis of the interviews, in order to not miss out on important underlying meanings in the interviews. Furthermore, this study can be applied to other contexts than tourism, such as leisure activities. It can also be useful when it comes to the understanding of other people with mobility-disabilities, and not only wheelchair carried children with cerebral palsy, which indicates that this study has transferability. However, the goal of qualitative research is not to provide generalizations (Morrow, 2005) and while some of the aspects of this study can be applied to other contexts, other findings might be specific for the interviewed respondents. Regarding the dependability of the study, other researchers who interview the same respondents or work with the same data set will, probably, come up with very similar results. The results of this study reflect the experiences of the interviewed parents, and the researcher has worked with taking on an objective role when collecting data, and when analysing and presenting the findings from the interviews. However, all studies are coloured by some level of subjectivity, for instance by choosing certain research questions or interpreting the findings in relation to the researcher’s previous knowledge (Morrow, 2005). In order to truly present the tourism travel experiences of parents to wheelchair carried children with cerebral palsy and provide a high level of confirmability, many quotes are presented in the result section.

5.2 Ethical considerations

Ethical considerations arise in all research that involves other individuals, and especially when the research involves children (Veal, 2011). This study is from the parents’ perspective, but the interview template included questions that were related to their children, since it was the constraints caused by the children’s disabilities that were studied. When studying these kind of

issues, it is important to constantly consider the complexity and potential sensitivity of the topic (Gröschl, 2007). The interview template was therefore constructed with this in mind and did not include questions that the researcher thought could be considered as too personal. This was also tested with the pilot interview, in order to ensure that the interview template was appropriate.

As mentioned earlier, the respondents who were willing to participate had to contact the researcher, which limits the risk that respondents feel like they 'have to' participate. Furthermore, all respondents were guaranteed to be anonymous and pseudonyms were used throughout the whole research process. Regarding the audio recordings from the interviews, it was explained beforehand that no one else but the researcher would have access to the audio files. In the transcriptions, all the names were replaced with explanations such as 'boy with cerebral palsy', 'older sister', 'father', and so forth.

Last but not least, the parents (and their children) who are included in this study are not considered as a homogenous group. Just because the respondents are parents to children with cerebral palsy, they are not considered as a 'problematic group'. They are rather seen as individuals with their own specific needs, just like everybody else. The fact that all people are different and have different needs, requirements and preferences is important to have in mind.

5.3 Definitions

Since some of the terms that are being used in this study can be interpreted in different ways, it is considered as important to clarify them. First, it is, as aforementioned, difficult to distinguish between the terms 'impairment', 'disability' and 'handicap'. This is due to the interchangeable use in previous literature and the fact that different definitions may be suitable for different parts of the tourism trip. The respondents for this study also used different terms to explain their children's physical limitations. On one side, some used words like 'functional disparity/variation', while others used the term 'handicapped' when they talked about their children. Most of the respondents talked about their children's limitations as an 'impairment' or a 'disability'. The differences regarding which terms they used can be due to different reasons. One possible explanation is that they perceive the severity of their child's disability differently. Those who use the term 'handicap' could, perhaps, feel that they are more constrained due to their child's disability than those who use terms such as 'functional disparity'. However, the noticed differences can also be due to different cultures in different parts of the country (or dialectical differences) or due to the respondents' social network. People with more support from others in the same situation might feel that their child's physical limitations are functional disparities or impairments, rather than a handicap. Nevertheless, the sample size is too small to draw any conclusions about this and instead of making an in-qualified guess, the term 'disability' will be used as a convenient middle-way in this paper. However, when quoting the respondents, their own terms will be used.

There are also some different definitions and meanings put into the term 'family'. The definition used in this study is that a family is "...a social group with whom one resides, in other words, the household" (Huh & Singh, 2007, p. 214). Moreover, since this study is about families who are travelling with disabled children, it is also important to clarify who is considered a child. In

this study, only the disabled child's age is considered (the siblings age is not seen as important in this case). The child with cerebral palsy should not be more than 18 years old, since that is the age limit for whom is considered a child in Sweden.

6. RESULTS

The fact that people with different disabilities have different needs can be seen as obvious, but many differences were also found among the parents in this study. While many of the major constraints were found to be similar among all respondents, other constraints were only mentioned by a few.

In this chapter, the results from the interviews are presented. The result chapter is divided into three different parts: 'Family trips with a disabled child'; 'Constraints throughout the tourism travel chain; and 'How can tourism travel become easier?'

6.1 Family trips with a disabled child

Almost all of the parents explained that they used to travel on charter trips with their family. To get a change of climate, get away from the everyday responsibilities, spend time with their family and see new things were the most popular reasons and motivations behind these family trips. Another motivation behind tourism travel was more related to the fact that their children had a disability. This aspect was only mentioned by a few. They said that tourism could be a way for them to feel like a 'normal' family and not being seen as disabled:

"We think that it is important for us and for the kids to develop and see other things and get away from the everyday life... not being seen as disabled, but to be like anyone else." (Respondent 5).

The parents explained that they had to change their travel patterns due to their child's disability. One mother said that they could not do everything in the same way as before they got a child with cerebral palsy, but that they continued to travel with the same frequency and made some adjustment. She said: "I'd rather do something to a level of 80 percent when it comes to travelling than to not do it at all just because we can't do it to a 100 percent." This was mentioned by other parents as well, who explained that the disability could affect *how* they travelled rather than *if* they travelled to participate in tourism. To have a child with cerebral palsy could, according to some of the respondents, have impact upon which type of trip they chose (some parents wanted to go skiing or hiking and deselected those kind of trips), which destination they chose, which transport mode they travelled with, and which kind of accommodation they chose. The most important thing among most of the respondents was that they could still enjoy tourism travel, even if they had additional restrictions due to the disabilities of their children.

Some of the parents explained that tourism travel with a disabled child became easier with time, due to increased travel experience, knowledge and routine. Among those who had travelled a lot with their wheelchair carried children, the barriers to participate in tourism were considered as lower than before they became travel active since they knew what to expect. However, some parents were not worried before they started to participate in tourism travel:

“Maybe it didn’t really matter because he was so small and we thought that... I don’t know how to say it... maybe we hadn’t begun to be worried then. But of course, in one way it’s more difficult now when he’s heavier and bigger and everything, but because we had such a positive first experience, we haven’t been afraid to do it again, so to speak.” (Respondent 9).

Even if tourism is considered as easier than some parents thought before they became travel active, some chose to go to the same destinations and some also use the same accommodation when they are travelling. Others tend to use the same travel company for all their trips. In order to be able to relax, they chose to travel in ways that they know will work and be accessible enough for their children:

“...we have always travelled to Turkey with [travel company] because we think that we both get good treatment and also that they have nice, large hotels which are accessible.” (Respondent 1).

“Now when we have travelled a few times we know what’s working and then we usually chose that. It’s comfortable.” (Respondent 12).

However, even if most of the parents in this study were travel active and chose to participate in tourism with their disabled children regardless of the different difficulties they could face, family tourism travel was not considered as an attractive alternative for everyone. One of the parents explained that they used to travel on family trips but leave their girl with cerebral palsy at home. She said that they chose not to bring their girl with them because they needed a break from the everyday life, all the responsibilities that they had as parents to a child with cerebral palsy and to feel like they were a ‘normal’ family for once. She explained that she had intrinsic barriers that restricted her from even trying to travel with her disabled child, but that she at the same time had bad conscience for leaving her child behind. She reasoned like this:

“It might be something that is upon me... but I think that if you should pay a lot of money and go away and you are on leave from work for a month and you’re going away for two weeks and then you feel like it hasn’t been a vacation at all because you have been worried about her because she has been to warm or she had to throw up or... then I feel like I rather stay at home, where she has everything.” (Respondent 8).

Bad conscience was also mentioned by another mother but in a slightly different context. She explained that it was important for her to spend time with the whole family and that their girl with cerebral palsy should be able to participate in all the tourism trips and activities that the other family members participated in. She felt bad conscience because she felt that she put restrictions upon the other children in the family so that their disabled child would not be jealous and feel left out.

6.1.1 Travelling with wheelchair carried children

One of the themes that emerged throughout the coding process was ‘the disabled child’. Among the respondents, ‘wheelchair accessibility’ was claimed to be for adults, not for children. According to some parents, this was a common problem in public spaces in general, but also when

they were participating in tourism travel. One of the mothers believed that the average man thought about an adult when they thought about a person with a disability and that other people often forgot that people can be born with disabilities as well. Similar thoughts were mentioned by several parents:

“Many times I kind of experience that... that it is adjusted for grown-ups and I guess that isn't so strange, because they are a majority of those who travel, but there are children who are travelling with wheelchairs as well. /.../ We have stayed at specially designed places and they are built in order to be top-accessible, but the problem is that those are also built for adults. It is accessible for adults, not for children. So it's like... it's not that big of a difference to us, even if the place is supposed to be really accessible.” (Respondent 3).

“I can feel that it's like ‘we have handicap friendly rooms here and there’, well yes, but not for children! /.../ They really don't consider children and that's something that I think is missing in general in the tourism industry, that children... disabled children exist as well.” (Respondent 6).

Furthermore, the fact that it was children who had disabilities could lead to different complications when they grew older. The age factor was mainly seen in relation to weight, where some of the respondents explained that some parts of the tourism trips were easier when the child was younger, and that they needed more adjustments and more wheelchair friendly places when the child grew older and got heavier:

“And now she's so big so you need a hoist to lift her up and you can't find that everywhere. You can't just carry her around nowadays. /.../ She isn't an adult yet, but she's big enough. She's heavy, she really is.” (Respondent 8).

“We managed to carry him and get down there when he was smaller, but we can't do that now. It wouldn't be possible.” (Respondent 9).

“Since his functional disparity is so severe, when he gets older then... then it will require more in terms of the accessibility of places.” (Respondent 3).

The child perspective did not only emerge when the parents were talking about the physical accessibility of places but also in terms of age-related aspects that did not necessarily had to do with the disability. Some respondents mentioned that it would probably be easier to travel a longer distance in the future since the child was thought to become more patient with time.

6.1.2 How tourism can contribute to the children's well-being

Many of the parents said that tourism travel was considered as something important for the whole family and that their child with cerebral palsy enjoyed travelling. The parents thought of tourism as something that could be positive for the psychological well-being for the whole family, both in terms of lessening the everyday stress and because the children enjoyed the activities that they participated in at the tourism trip, such as bathing in a swimming pool. One of the mothers laughed and said that her daughter went crazy every time they watched television and a travel commercial came up, because she really longed to go on new tourism trips. Another

mother explained that her son with cerebral palsy, who loved to travel, had asked her if they could migrate to Spain.

The fact that all children are different even though they have the same diagnosis became clear when the parents talked about how tourism travel affects their children's physical well-being. Since many of the families tend to travel to sunny places and participate in charter tourism, the sun and heat were the main factors that they related to regarding the physical contributions of tourism for their children. For some of the parents, the climate at warm, sunny destinations was considered as extremely important for their children. One mother explained that their son had to use cortisone during the winters, but that he got similar positive contributions from the heat and humidity when they were travelling to warmer countries. Similarly, another mother explained that some tourism trips had a medical aim for them:

“He’s muscles become much better when he gets to the heat, his bronchus becomes good when he gets to the heat, he... yes, well, he feels so much better, he becomes... we travel... I have to think if it was... not last year, I think it was in 2014 when we travelled three times during the summer. /.../ It’s really good and the heat does at least half of the work for most people. [Boy with cerebral palsy] needs Botox, but we noticed that he gets the same good conditions from the heat.” (Respondent 10).

Nevertheless, the warm climate at such destinations was not considered as positive for all children. Some parents explained that their children had troubles with heat and could easily become dehydrated. The heat at sunny destinations can, according to the different answers from the respondents, be favourable for some children while it is considered as a negative thing for other children. Furthermore, the mother who used to travel without her disabled daughter thought that tourism in general was unfavourable for her daughter:

“I haven’t tried to stay away with her for a week or so, but I think that these children want to come home to their own bed during the night. She has her pillows between her legs and behind her back and under her arms and... so that she feels at home, I think that’s important for these children. It’s another thing to go out on the roads, but the thing with travelling far away... I’m not sure if these children gain from it to a 100 percent. But now I’m talking about children with the same limitations as [girl with cerebral palsy].” (Respondent 8).

6.2 Constraints throughout the tourism travel chain

Different constraints can be evident during different phases of the tourism travel chain. This section is divided into three different parts, namely: the pre-travel phase; the transit phase; and the destination phase.

6.2.1 The pre-travel phase

Some of the constraints emerged during the pre-travel phase. For some parents, the barriers to tourism were considered to be too high and they chose to not travel with their child with cerebral palsy. They found it too difficult to travel with their child. Other factors could affect tourism travel participation as well, and these factors were not always related to the child's disability. One respondent talked about how it had become difficult to travel as a family since the siblings

to her disabled child became teenagers and were not interested in travelling with the parents anymore. Other constraints that determined the frequency of tourism trips were related to bad conscience due to the greenhouse gas emissions and the refugees that flee from wars.

Nevertheless, two main topics regarding the pre-travel phase were discussed during the interviews, namely difficulties related to choosing a destination and how to find the information they needed about the destination they wanted to go to.

To choose a destination

The most important determination factor regarding destination choice was usually the climate. The destination itself was usually not of very high importance and it did not seem to matter if they went to Turkey, Mallorca or any other destination with a warm and sunny climate:

“I can’t really say that I have a specific place that I want to go to... No, actually not... we can consider most places, as far as it’s sunny and warm. It’s not like I feel that ‘I want to go here and there’, no.” (Respondent 4).

However, for one of the parents, the destination was of utmost importance. She explained that they usually travelled to visit people they knew, participate in events or to see something specific at the destination. For them, the destination was not exchangeable. Another family went to different ski-destinations in Sweden once a year, which were in a car-travel distance from their hometown.

Nevertheless, among those who most often went on charter trips, they had some criteria to follow. While the destinations close to the Mediterranean Sea were quite exchangeable, some of the respondents wished to go to destinations further away, such as Thailand, the US or New Zealand. Most parents explained that they had to choose destinations located in a few hours’ distance and that longer trips were not possible to do because of their child’s disability. The outcome was that some parents who wished to travel to Thailand or other distant destinations chose to travel to the Mediterranean instead:

“We have mostly travelled to Turkey, which suits us well because it’s not that far... it isn’t a long trip but around four hours or so if you go straight from Umeå and well... we think that it is quite accessible so that you can go with a wheelchair and so on.” (Respondent 1).

“We haven’t flown that much with [boy with cerebral palsy] so we choose destinations that... well, it can’t be a ten-hour flight for example. We have those kinds of restrictions. When we went to Turkey the flight was about four and a half hours and that was okay for [boy with cerebral palsy] and it’s only around two, three hours or something to Belgium. So we kind of started with these shorter trips.” (Respondent 2).

Except for the time-and-space distance to places, the physical geography of the destinations was also considered as a determinant factor. Some destinations were rejected due to too many rocks and stairs. Other destinations could be considered to travel to during some periods of the year, but not always. One mother exemplified this by saying that they did not travel to Greece in the middle of the summer when there was a peak in heat.

Moreover, another constraint during the destination decision process was related to economy. According to the respondents, they had a limited choice of destinations to travel to and they could not book a cheap last-minute-trip. The accessibility of the destination and accommodation had to be prioritized over factors such as price. Some families used to choose handicap friendly rooms, while others thought that regular rooms were fine, as long as the rooms were large enough. All parents said that needed to prioritize the accessibility of the hotel room due to the fact that their children were carried by wheelchairs. Moreover, except for the size of the room, the size of the whole hotel complex was considered as important in terms of accessibility:

"I think that it is... well, we haven't jeopardized anything by choosing small hotels, but we have travelled to [large hotel concept], those big all-inclusive because then we know that there is personnel, there are doctors, there are... yes. It's a totally different concept than the smaller places." (Respondent 10).

"We never chose small hotels. [...] We choose a bigger hotel complex because it is usually wheelchair accessible. Those hotels are often for children and there are a lot of strollers and so on, so they have thought about it." (Respondent 12).

Although, some of the respondents explained that they could make compromises with the accessibility if other features were found to be important:

"It can be something that actually has a good accessibility and a wheelchair friendly toilet, but it's located in the totally wrong place, for example on the wrong side of the island where we want to go. So then you try... we kind of chose the... the option that is the least bad." (Respondent 3).

While the accessibility of the hotel was a primary consideration for most of the respondents, some of them also mentioned other aspects as well. Many parents emphasized the need for a pool. To have a pool was usually more important than closeness to the sea, since it was perceived as too difficult to drive a wheelchair in the sand.

Information

Among the parents, one of the major constraints in the pre-travel phase was to find the right information regarding the accessibility of places. A few of the respondents said that it was possible to find the information that they needed on the Internet:

"Well, if you look for it... you have to know where to look, then you will find it. That's how it is. But it's... the information is available, but you have to know where to find it." (Respondent 5).

However, almost all of the respondents felt like they missed some information. Among those who thought that they could find the information that they needed regarding the accommodation, it was quite common that they wished for more information about another phase of the travel chain or about how the destination looked like outside the hotel, such as the surrounding area. Most of the parents had some complaints regarding the information that different travel companies and booking sites provided. One parent said that you could never really know beforehand how accessible a place was and expressed that every trip to a new place was a wild guess. She continued to explain:

“We have no idea how it really looks like in the country that we are visiting. Well, of course, we have Googled it and we get a clue out of that, but then to... well, like if we are going to stay at a hotel we always have to call the hotel and make sure that we actually get a wheelchair friendly room, for example. [...] And there’s no one who is telling you ‘this is how it will work when you’re flying’, that’s something that you have to learn with time.” (Respondent 2).

The parents dealt with the shortcomings regarding information in different ways. One parent said that she preferred to go to countries where she could understand the language so that it would be easier to get correct information. They also used to travel to visit people they knew in other countries, and then those who lived there could help them to check the accessibility of places in advance. However, the most common way of getting appropriate information was to contact the travel company, the airplane company or the hotel themselves and ask about specifications:

“We start looking for a hotel and try to read about how it is adjusted for wheelchairs, but then you have to have a communication with them and try to get them to explain how it looks like... because the pictures are always lying.” (Respondent 3).

When the parents had difficulties in finding the right information, a common strategy was to ask other people in their surroundings for suggestions and advice. Some of the parents asked other parents who used to travel with children in wheelchairs, while some searched for information in Facebook groups for people with disabilities, or chat rooms at other forums on the Internet:

“Among us who have travelled... we ask each other. That’s the easiest way. If someone has travelled to a place and it turned out to be great, we might travel there ourselves. So that’s how it works.” (Respondent 10).

“We are members of some Facebook groups and things like that, because the information is too poor and... the places that are good... the rumor spreads quickly there.” (Respondent 3).

6.2.2 The transit phase

When the respondents were asked which transport modes they used when they were travelling for tourism purposes, almost everyone answered that they most often used their private owned car when they were travelling inside the country and that they used to fly when they were travelling to other countries, and sometimes for long domestic trips:

“There aren’t so much to choose from. It depends a bit upon what we shall do... If we’re going away for a longer period of time, then he’ll need all his stuff and then we can only go by car. If we’re travelling abroad, then there are the airplanes... and then we have to skip some of his aids, unfortunately. Otherwise we can’t fly and then it’s only possible to... travel within a car distance. And I think that’s a bit boring, I think all of us do.” (Respondent 5).

This section is divided into two different parts, where the first part presents the environmental barriers that the parents experienced during the transit phase. The second part presents interactive barriers.

Environmental barriers during the transit phase

When the respondents were asked about which transport mode that they found most problematic and if they skipped some transport modes because they found it too difficult due to their child's disability, they commonly answered something like this:

“Trains and buses are not easy... because the buses are a constant hassle and that applies to school buses as well, that buses are crappy and the train as well because of ramps that doesn't work and so on. So we skip that. We rather take the car, because then we now that we get to our destination.” (Respondent 5).

“All the trains are not accessible or equipped with a lift and then we can't enter the train. So I wouldn't go with train with [boy with cerebral palsy]. Not as it looks like today at least.” (Respondent 2).

The main difficulties with trains and buses that the respondents mentioned were related to the physical accessibility. Several of the parents also explained that their choice of transport mode was, as mentioned above, restricted due to the aids and luggage that they had to bring when they were travelling. In this sense, air travel was considered easier because the families could leave most of the aids and luggage at the check-in. However, a problem regarding air travel was that they sometimes had to leave the child's wheelchair at the check-in as well. Manual wheelchairs were often allowed to bring all the way to the gate, while electric wheelchairs had to be checked in with the other luggage. One mother explained that they used a sulky as an aid when their disabled son was younger, but that they had to leave the sulky at the check-in, even though it was considered an important aid for them. Those who had to leave their own wheelchair could borrow an airport wheelchair, but these were not adjusted for children with cerebral palsy. One parent argued that those wheelchairs actually only works for people who have troubles with walking and cannot use their legs. Another parent explained that they tried to make it possible for their disabled daughter to use the airport wheelchair by building a headrest out of bags and scarfs, and tie her feet to the wheelchair, which was really uncomfortable for her.

Another barrier faced at the airport was related to the airport toilets. Several of the respondents mentioned that the toilets that were supposed to be wheelchair friendly actually lacked a lot of needed equipment, and they thought that large airports should have at least one wheelchair friendly toilet with equipment such as a large changing table and a hoist:

“Regarding toilets at airports... I don't get that some of those toilets can be called wheelchair accessible... is it only because they have an armrest at the side? It's almost like that. And if the toilet paper is far back on the side, how would it be possible to reach it? It's really strange and it doesn't seem to be any specific standard regarding how it should be.” (Respondent 7).

When boarding the airplane, it was usually possible to borrow a specific airplane wheelchair that was narrow enough to fit in the aisle. However, the respondents said that they experienced

the same problems with the airplane wheelchairs as with those that they could borrow at the airport – they were not at all suitable for their child’s impairment and were only considered as helpful for people who only had troubles with walking. Instead of using those wheelchairs, the parents used to carry their children into the airplane. They explained that the personnel at the airplane could help them with this, but most of the parents preferred to carry their child by themselves.

One of the major constraints during the flight was related to the toilets. Only one of the respondents said that it was possible for their child to use the airplane toilets while the rest of the parents thought that they were way too small and inaccessible. Most parents dealt with this by putting a diaper on their child. Some of the children used to have diapers in their everyday life, but not everyone. However, even if they used diapers during the flight and, therefore, were able to avoid the difficulties with the airplane toilets, new problems aroused - the parents had to change the diapers at the airplane seat. This was seen as a problem both because it was tricky to change a diaper in a such a tight area as a flight seat, but also because it was found very difficult to change a diaper discretely and the parents felt bad about having to compromise their children’s hygiene with their privacy:

“He doesn’t normally use a diaper, but he does on long flights and he think that it’s annoying and we think it’s annoying, but it’s like... that’s how it is and then we might have to change that diaper and that is really difficult. [...] You really have to be discrete with it.” (Respondent 3).

When the airplane had arrived at the destination, a further constraint could emerge, namely transfers from the airport to the accommodation. Transfers were considered as a huge problem at some trips, for some parents, while others did not mention it at all. Nevertheless, the difficulties were mainly related to the physical accessibility of the transfers (usually buses) and some of the parents had chosen to hire a car or take a cab instead of going with the regular transfers.

Interactive barriers during the transit phase

One thing that differed a lot among the respondents was how they experienced the treatment from tourism personnel when they were travelling with different public transport modes or airplanes. Among the parents that were satisfied with how they got treated and received, one mother said:

“It has never been any problems. I rather think that they seem impressed because we are travelling, because it’s a pottering, but we’ve got the routine and experience by now. We have done it very smoothly and so on. No, it hasn’t been... it has been really good and they have been very sweet. It hasn’t been any problems at all.” (Respondent 10).

Among those parents who were less satisfied, one mother explained that they never knew beforehand how they would be received at an airport:

“Sometimes it’s like ‘great that you’re here, of course you can bring the wheelchair to the gate! No problem!’ and the next times it’s like ‘okay... have you called in advance and announced this?’. It’s just so unpredictable.” (Respondent 13).

Some parents said that a lack of flexibility among the personnel was one of the largest barriers when they were travelling with different public transport modes or by air. Regarding trains, one respondent explained that it was possible to book a wheelchair spot at the train, but that the train travel company only provided one package for people who were carried by wheelchairs. According to the parent, it was not possible to book a train trip with more or less help than that one package provided.

Since most of the families used to travel by air, most of the difficulties they faced that were related to interactive barriers were with personnel at the airport or the airplane. Several of the parents mentioned that their children could not sit by themselves and they wanted to have their children in their lap during the take-off and landing, but they were not allowed to do so:

“Everything is possible to fix if you want to. If there is a good will like ‘what is the problem, can we fix this?’, but it’s not like that. It is of course characterized by a plan for safety and it has to be, but some people are almost brain washed by these thoughts about safety so they can’t... they would rather let [boy with cerebral palsy] sit with just one seatbelt, hanging loose like a pile or something, than to let me sit with him in my knee because ‘this is how it is, this is how it has to be’ instead of thinking ‘now we’re in this situation, how can we solve this so that it is both safe and good for the family?’.” (Respondent 13).

Regarding the treatment the families received from other tourists at different transport modes, the parents did not experience any major problems. Some parents said that people could stare at them, but that they were used to that from their everyday life. Otherwise, other tourists were usually perceived as helpful. However, one mother said that they got more help when her disabled son was smaller and sat in a sulky, than when he grew older and had to be carried by a wheelchair. She guessed that other people did not dare to ask if they needed any help, because they would probably not know how to help if the parents actually said yes.

6.2.3 The destination phase

Once the families had arrived at the destination, new constraints emerged. This sections will present the environmental and the interactive barriers that the interviewed parents experience at the destination.

Environmental barriers at the destination

What the respondents needed in terms of accessibility and equipment differed. The parents used to bring a lot of aids for their children when they were travelling. Something that became evident during the interviews was that while some of the aids that the parents needed for their children were quite similar, other aids were more specific to the individual child’s own limitations. They also needed different equipment in the hotel rooms. By way of example, some parents needed a big shower and a shower seat to put in the shower and did not understand how bathrooms with bathtubs could be called ‘handicap friendly’, since it was not possible to get a shower seat into a bathtub. Other respondents required a bathtub, since they did not use a shower seat and if the bathroom only had a shower instead of a bathtub, they had to put their child on the floor. Moreover, some parents said that they needed a shower bed for their children, which was difficult to bring from home, since it was too big to carry as luggage.

The parents found different solutions to difficulties that emerged in the shower situation. One mother explained that the shower was really inaccessible at a hotel where they stayed during a vacation, and they came up with the idea to shower in the changing room to a gym and SPA area at the hotel instead. Another mother explained that they involved the whole family when her son had to shower:

“Several times, the father of [boy with cerebral palsy] has to function as a shower seat in the shower so that I can wash him and then his older sister has been there as well. So I wash [boy with cerebral palsy] while he is sitting at his dad’s knee and then I lift him up to his older sister when he is all slippery.” (Respondent 13).

Among some of the respondents, the lack of an adjustable bed was considered as one of the largest constraints at the hotel. Many of the children needed one, but the parents explained that no hotel that they had visited had provided them with a handicap bed even though they had chosen a handicap room. Parents to children who could fall out of the bed used to rearrange the furniture in the hotel room so that their child’s bed was placed right next to a wall and a parent had to sleep on the other side of the child. Others had more troubles with the fact that the back part of the hotel bed was not adjustable. They explained that their children could not sleep on flat beds because of pain, and they tried to fix the problem by putting several pillows at the upper end of the bed, below the mattress.

Furthermore, one of the respondents explained that even if they chose handicap friendly rooms, the hotels usually forgot about the sills to the balcony. She said that they used to have her daughter’s electric wheelchair when they were at vacations and that it was not possible to drive that one over doorsteps. The problem was not that the wheelchair could not handle it, but that the wheelchair had a weight of 160 kilograms, plus the weight of the girl. If they were to go out on the balcony, the doorsteps made out aluminum would be crushed immediately.

When the parents were asked which activities they used to participate in during their tourism trips, most of those who travelled on charter trips answered that they preferred to go bathing in the pool, and also experience the nature and characteristics of the destination by either walk around or rent a car. It was much less common to participate in organized, guided trips specially made for tourists. Most of the parents deselected those trips because they simply did not have any interest for guided trips. Others, however, felt like they could not participate in such activities because of their child’s disability, since the activities were not wheelchair friendly. Except for such guided trips, there were other activities at the destination that were considered to inaccessible as well. One example that was mentioned by several respondents was natural attractions, which was considered as too difficult among many of the parents. One of the mothers mentioned that her disabled child’s siblings would like to walk in the mountains and, for example, see ruins. Other examples that were mentioned were national parks and the forest, which according to the parents usually were too inaccessible. However, even if there are obstacles along the way, some parents find ways to overcome them. One of the mothers explained:

“We went around Rhodes two times while we were there and, among other things, we went to a cross there, a huge cross, gigantic. There were stairs, but we pulled up the wheelchair there and got up. But it’s like... there aren’t really any limitations.”

You have to... everything is possible. And then we like some challenges, but we're a bit crazy. We've pulled him up in his wheelchair at the sea stacks at Gotland as well, and it's possible. As long as you're not afraid, it's possible. We want him to join us and experience everything that we're experiencing." (Respondent 10).

Except for natural attractions, heritage buildings were also considered to be inaccessible among some of the respondents. Some of the parents accepted that while a mother who had work experience from different museums argued that there has to be a balance between what you are trying to preserve and the benefit of preserving it. What is the value of preserving a place or a building if it is not possible for people to enjoy it? Then the value of preserving it decreases. She did not think that it was a big deal to make it wheelchair accessible as well and she thought that everyone should have access to a natural or cultural heritage. Another respondent mentioned that there was a difference between small and big tourist attractions and that the large attractions usually were more wheelchair friendly:

"These big tourist attractions, they're often... well, they often have some kind of adjustments even if they're not always totally accessible, but there's usually a possibility to see something, and there are usually toilets and... an elevator or something. So the more people, the more accessible it tends to be." (Respondent 9).

Interactive barriers at the destination

Most of the parents said that the treatment they got from tourism personnel at the destination was very good and they did not have any specific complaints. However, regarding the treatment and acceptance among other tourists, the parents' experiences varied more. While some parents explained that they never had a problem with other tourists, others found their treatment towards them and their child to be a major constraint at the tourist destination. One respondent was mostly positive regarding how they were received by other tourists:

"There're people there to help out as soon as we need it. It's never impossible. I think that the average man is very nice too. We always have a helping hand nearby if we need it." (Respondent 5).

However, she could also feel annoyed by other tourists:

"Just because you have CP it doesn't mean that you're stupid. I've heard that several times, that people think that [boy with cerebral palsy] is mentally retarded just because he has CP. And that drives me crazy." (Respondent 5).

Some parents said that other tourists used to stare at them, but that they did not experience the treatment to be different from what they experienced at home. However, for some of the parents, this part was really difficult:

"On the third day, I was standing in the shower crying and thought that 'people must have stared enough now'. [The father] went to the children's pool once with [boy with cerebral palsy] and there were quite many children and mums sitting there, but after five minutes everyone was gone. He and [boy with cerebral palsy] were the only ones left." (Respondent 13).

The parents' experiences regarding interactive barriers did not only vary among the different respondents, it could also vary depending on which country or destination they were visiting. One mother explained it like this:

"How other tourists treat us depends a lot on which place we're visiting. We concluded that it has to be that some societies are more inclusive and that it is not strange to see a little boy in a wheelchair or so. If you see that every now and then, it doesn't become anything strange, but if it's like in Sweden where we fight for getting these children included and integrated... [...] Scandinavians are so careful and afraid to say something wrong, so they rather don't say anything at all." (Respondent 13).

6.3 How can tourism travel become easier?

Some tourism travel companies provide specially designed tourism trips for people with disabilities, but none of the respondents in this study had chosen such a trip and most of them were not interested in doing so in the future either. The main factor behind this decision was that they wanted to travel alone as a family. Other determining factors were the price of the trips (which according to some respondents tended to be higher than for regular charter trips), and the limited destination choice. One of the respondents highlighted the fact that people with disabilities should not be seen as a homogenous group since they are all individuals with different interests:

"I think that the most important part is that it's wheelchair friendly, but not that it is a package like all disabled wants to see the giraffes at the savanna. [...] It's kind of like saying... like 'all the blondes want to go to Thailand and snorkel'. I mean, all people are individuals and they only share physical attributes. [...] Just because you are in a wheelchair... that might be the only thing you have in common." (Respondent 6).

A few of the respondents could consider to go on a trip specially organized for people with disabilities in the future if the price and timing was right. One of the respondents saw these trips as an opportunity for his son to travel without his parents when he grows older, since it would probably be easier for him to go on these organized trips than to travel all by himself.

However, a more attractive solution used among some of the parents, in order to ease tourism participation, was to bring care attendants on their family tourism trips. Many of the children had care attendants at home, but not everyone. The parents who had external care attendants to their children most often brought an attendant when they were travelling as well. To bring a care attendant was considered as necessary for some of the parents, otherwise they would not have relaxing vacations. A care attendant could also be considered as positive in the sense that one extra adult could be a useful resource in terms of muscles. Since the external environment was not always accessible enough and the parents had to carry their children and their wheelchairs every now and then during a trip, a care attendant could be very helpful:

"Then it's like the past years when [boy with cerebral palsy] has become so big, tall and heavy... then we have decided that we kind of have to bring a care attendant,

so the past three, four years we have always travelled with a care attendant.” (Respondent 2).

However, there were some negative aspects of bringing care attendants as well. It was usually considered as more intense to have a care attendant on a tourism trip than at home. This was coped with in different ways. Some choose to travel without care attendants, others used to bring a care attendant on some trips but travelled alone with their children on other trips, and some decided to bring care attendants even though it was not considered as optimal in all situations.

Furthermore, except for the changes that the parents could do themselves, in terms of choosing specially designed tourism trips or bringing care attendants on their trips, they also had concrete suggestions regarding what different actors in the tourism industry could improve in order to make it easier for them to participate in tourism travel. The following parts of this section present the parents’ suggestions regarding changes that the tourism industry can do throughout the different phases of the travel chain.

6.3.1 The pre-travel phase

Many of the respondents thought that the information they received about wheelchair accessibility was poor and they came up with several different suggestions regarding how actors in the tourism industry could work in order to make it easier for them to find the right information. In this phase, the parents usually reasoned that small changes could make a huge difference. Some parents explained that they knew other parents with children with disabilities who did not participate in tourism travel because they found it tricky to find information and was afraid that they would miss something. During the interviews, some parents expressed that they wished for more knowledge among the tourism personnel so that they could pass on the correct information to their disabled customers. The parents realized that it was not possible for everyone to know everything about all different kinds of disabilities, but argued that it could be good to have an expert at wheelchair accessibility whom the parents could be directed to when they had questions or needed more information. Furthermore, one of the mothers gave an example of how these families themselves could help the tourism personnel to understand their needs:

“They could have some kind of system where the customer can explain ‘this is how this child’s or family’s needs looks like’, like some kind of formulary that you can fill in when you book the trip.” (Respondent 13).

Other parents gave concrete examples of what kind of information they would like to have and had suggestions about how this information could be provided to them. One suggestion was to have an app or an internet webpage where all necessary information was provided at the same place, and another suggestion was to provide a compendium, where it should be possible to find accessible destinations depending on which needs you have and what you are interested in. The compendium could present which destinations that were accessible and recommended for families with disabled children who wanted to go on sunny holidays and another chapter about shopping holidays for these families, and so forth. Furthermore, one mother thought that ‘handicap friendly’ meant different things to different people and came up with the solution that there could be three different levels of handicap friendly: level one, level two and level three. The

third level could be the most wheelchair friendly and actors in the tourism industry should be clear with which level of accessibility they provided.

6.3.2 The transit phase

Regarding the transit phase, most of the suggestions from the parents were related to flexibility. They wished that the personnel could be more flexible and that they could come up with solutions that were adjusted and suitable for the specific individual, instead of just following general guidelines regarding how they should treat and help people with disabilities. Some parents also had concrete examples of things that could be improved with the physical accessibility of different transport modes. One of the respondents suggested that trains could have the same safety in terms of locking and strap the wheelchair, as there is in the taxi cars that are used for mobility service.

Regarding airplanes, many respondents' highest wish was that the toilets should be more accessible and that it would be easier to change a diaper. One mother suggested that the airplane could have a foldable changing table at the back of the plane, were the stewardesses used to be during the flight. Otherwise, the parents did not have very clear ideas about how this problem could be solved. Another problem for some of the children was to sit in an airplane seat. One parent suggested that they could be allowed to bring their child's car safety seat into the plane. Another parent thought that it would be a lot easier to fly if it was possible to disassemble one of the airplane seats and be able to put the wheelchair there. A third suggestion was that it could be possible to book a seat where it would be possible to lay down, such as having three seats in a row without armrests.

Those children who had troubles with sitting could usually not use the airport or airline wheelchairs either, and one of the respondents suggested that airports could provide their customers with different wheelchairs. In her opinion, it would be very valuable if some wheelchairs were more adjusted, for example for people who could not hold up their own head, people who needed extra support for their core, and so forth. She suggested that there could be pictures of the different wheelchairs at the airline's webpage and that it could be possible to book the wheelchair they needed at the same time as they booked the flight.

6.3.3 The destination phase

Regarding the physical accessibility of the accommodation, one of the respondents suggested that it would be valuable if someone at the hotel, or an external consult, could go on an inspection round and write down which things that were accessible enough and which things that needed to be improved:

"I think it's quite simple... someone goes through it and they can get some kind of label or become certified or something. An accessibility consult who can give out certifications, why not? Or they can have these kinds of inspections by themselves, just like when it comes to fire safety and things like that." (Respondent 3).

Except for the accessibility related to the built environment, another suggestion among the parents was that the accommodation could provide them with some aids so that they did not have to bring everything themselves. They realized that the needs in terms of aids differed a lot

among different people and that it would not be possible for the accommodation to provide them with everything they needed, but that it could be good to have some general aids there, which people with different disabilities could use. One example was that shower seats often are adjusted to suit the individual's needs, size and limitations. A shower bed, on the other hand, can be used by almost everyone and would be a better investment for the hotel, according to some of the respondents:

“One simple solution can be to have a shower bed at the hotel... not one of those large shower beds on wheels or so, but one that is foldable so that you can put it next to the wall and take it down and it has two legs... [...] It wouldn't take up too much space and it wouldn't be a large cost for the hotel, but it would make it a lot easier for us who have children with disabilities” (Respondent 13).

Furthermore, many parents said that they needed an adjustable bed with a fence for their children. One of the respondents suggested that hotels could have a handicap bed on wheels and that they could roll it into the room where it was most needed at the moment. In that way, not all handicap rooms would have to be equipped with one of those beds. A further suggestion regarding aids was that it would be valuable to have a portable hoist at the hotel. One mother said that they used to do a lot of heavy lifting during their vacation and that it was tiresome for the parents. She also explained that they used to carry their son into the hotel pool and that they experienced it as dangerous, since it was slippery. To have a hoist would make those movements much safer. Another mother suggested that the county council in their home county could provide them with 'travel-aids' that was lighter and easier to bring on trips than their child's regular aids:

“When it comes to aids, it would have been good if some of them could be foldable. [...] I mean, even if she has a shower seat at home that is steady and stabile, it might work out fine to have a smaller, foldable one during a four-day vacation trip to the mountains. And the same applies to changing tables and so on, those could be available to borrow or hire for a short period of time.” (Respondent 11).

Regarding activities, most of the respondents were happy with the activities that they could participate in during their vacations, but some of them had suggestions about things that could be made better. Among those who used to go on sunny holidays, many choose not to go to the beach with their child with cerebral palsy, since it was not considered as possible to drive a wheelchair in the sand. One of the respondents came up with a possible solution to this:

“When it comes to these sunny vacations, they could do it more accessible... and here in Sweden as well, for example by building an aisle of asphalt or something all the way down to the water, and also a pier so that it would be possible to get all the way down there and then you can be carried from there to the water.” (Respondent 7).

Finally, something that a few respondents mentioned, both regarding the transit phase and the destination phase, was to have some kind of survey that they could fill in after a tourism trip so that they could explain for the transit company or the accommodation how they experienced the service and the physical accessibility. The respondents thought that a survey about customer

satisfaction could be really helpful for the different actors in the tourism industry so that they got to know what their customers needed and what they could do in order to fulfill their needs and meet their requirements.

In the end of the interviews, the parents were asked about which changes and improvements in the tourism industry that would be most important and valuable for them. Most of the respondents answered that the most important thing was to get enough and accurate information about the accessibility. It was considered as more important to get to know beforehand if they could expect any environmental barriers than to actually diminish those barriers. If the parents had knowledge about shortcomings regarding the physical accessibility, they could prepare for it and come up with solutions. Some parents put it like this:

"[When we are on a vacation] we want it to be relaxing and that we can feel that we have talked about everything and got the answers we need. [...] More knowledge feels like the most important change... compared to if there was a very super accessible toilet. Which would be a utopia, of course." (Respondent 6).

"The most important thing is better clarity. Better clarity regarding what is considered as wheelchair friendly, because they don't really seem to know that. I believe that they think that a handicapped person is someone who has troubles with walking, but can stand up. But can this person use a bathtub?" (Respondent 7).

At the same time as many of the respondents had several suggestions regarding what can be made better in order to ease their participation in tourism travel, many of the respondents also showed acceptance and understanding towards the tourism industry. They understood that not everything could be adjusted to suit their preferences and that not everything could be made wheelchair friendly:

"It is difficult to drive in the sand, or it's almost impossible to drive in the sand, you have to pull the wheelchair backwards, but... I can think to myself that 'it is what it is', that you have to be a little innovative yourself and try to come up with solutions. You can't expect that everything should be fixed and done because then you risk to lose the nature of the experience. I know that many people are like 'this must be available, this must be available' and so on." (Respondent 10).

"It will be... and I guess it is... it is unavoidable, but it will always be more difficult for us to do these trips compared to a family who doesn't have a child with a functional disparity. You can't get away from that, but you can do it... try to make it as easy as possible. That's what you can strive for. And if everyone tries to make it as easy as possible, well, then it can become better!" (Respondent 3).

7. ANALYSIS OF THE RESULTS

The results from this study showed that parents to wheelchair carried children with cerebral palsy can experience different barriers and constraints when they are travelling for tourism purposes. This section is divided into two parts where the three main barriers (intrinsic, interactive

and environmental) first are analysed in relation to the different phases of the tourism travel chain and, secondly, in relation to the different steps of the destination choice set model.

7.1 How the three main barriers are apparent throughout the tourism travel chain

Many connections can be found between the parents’ destination choice set process and the different phases of the travel chain. While the destination decision-making is something that is made in the pre-travel phase, the whole trip is considered in the decision process. If the parents perceive and believe that they would have to face too many constraints with, for example, certain transportation modes or destinations, these would probably be excluded throughout the decision process. Since previous tourism travel experiences are considered as important when future tourism travel decisions are being made (see Crouch *et al.*, 2016), it is important that all the phases of the travel chain are experienced as accessible enough if the different actors in the tourism industry want to be in these families future consideration set. Table 1 provides a summary of how the three main barriers (intrinsic, interactive and environmental) are evident during the different phases of the travel chain (the pre-travel phase, transit phase and destination phase).

Table 1: The three main barriers and the different phases of the travel chain.

	The pre-travel phase	The transit phase	The destination phase
Intrinsic barriers	- Willing to travel? - Possible to travel?	- Intrinsic barriers due to the child’s specific impairment	- Intrinsic barriers due to the child’s specific impairment
Interactive barriers	- Information from the tourism industry - Word-of-mouth	- Lack of flexibility among tourism personnel - Negative attitudes among tourism personnel	- Negative attitudes among other tourists
Environmental barriers		- Inaccessible transport modes - Environmental barriers at airports and airplanes	- Inaccessible facilities and activities - Lack of equipment - Natural environment

For the parents in this study, the pre-travel phase seemed to include mainly intrinsic and interactive barriers, while environmental barriers did not appear to be a major constraint during this phase. This is a similar finding as for previous studies (e.g. Blichfeldt & Nicolaisen, 2011; Darcy & Daruwalla, 1999). However, environmental barriers can be evident in the sense that they are considered in the destination decision-making process as something that can become a problem if the families were to choose a certain destination. The intrinsic barriers in the pre-travel phase are related to the parents’ feelings about tourism travel and whether they are willing to travel with their children with cerebral palsy or not. Similar to the findings in previous studies (Lee *et al.*, 2012), most of the parents did not let the barriers prevent them from travelling, but were rather making adjustments and choose to participate in tourism even if they had a child with a disability. However, for one of the mothers, the intrinsic barriers were too high and she decided to travel without her daughter with cerebral palsy.

Some of the intrinsic barriers could, perhaps, be reduced in relation to a reduction of interactive barriers. It might be perceived as easier to travel if they get enough (and accurate) information about the whole travel chain, either by different actors in the tourism industry or by other people in similar situations. Since many parents said that tourism travel was easier than they thought before they started to participate in tourism, those parents who do not dare to travel can probably be encouraged to do so if some of the interactive barriers are reduced. However, this might not always be the solution to reduce all intrinsic barriers since the intrinsic barriers are different in character. It can be difficult for other people to see the intrinsic barriers (Packer *et al.*, 2007) and, therefore, to know how to reduce them.

Regarding the transit phase, all three barriers seem to be apparent. The intrinsic barriers in this phase seem to relate more to the child's individual needs due the specific impairments, than to intrinsic barriers among the parents. The main intrinsic barriers among parents are, probably, dealt with since they have decided to participate in tourism travel. Most focus during the interviews was put upon the interactive and environmental barriers during this phase. The main interactive barriers that the parents faced seemed to be in terms of negative attitudes and a lack of flexibility among the tourism personnel, while other tourists did not appear to be a large constraint during this phase. Some parents suggested that the tourism personnel should listen more to the parents, and try to come up with individualized solutions.

When it comes to environmental barriers during the transit phase, the parents in this study mentioned similar constraints as respondents in previous studies upon this topic (e.g. Bromley *et al.*, 2007; Darcy, 2012; Poria *et al.*, 2010). Some transport modes are perceived as too inaccessible and are, therefore, not even considered. The transport modes that they chose to travel with have some shortcomings as well. Among the parents in this study, there seem to be an acceptance regarding these accessibility problems. Even though this phase of a tourism trip is rather critical and troublesome, some respondents thought that it would be difficult to improve the accessibility of airplanes to the degree they needed. It can, therefore, be argued that the most important change that the tourism industry can work with during the transit phase is to reduce some of the interactive barriers. Some parents in this study explained that the most important factor was to get correct information about how (in)accessible different parts of the tourism trips were. If they got to know this beforehand, it was considered as easier to deal with the environmental barriers.

All three barriers could be found in the destination phase as well. As with the transit phase, the intrinsic barriers seem to be more related to the individual child's disability than barriers among the parents themselves. Something that appeared during the interviews was that all children have different needs in terms of accommodation and equipment, even though they all have cerebral palsy and are carried by wheelchairs. The children's disabilities affected all the parents' accommodation choice to some extent. Information from tourism actors at the destination and a good treatment among tourism personnel can be considered as highly important for parents to children with cerebral palsy and it seems to be quite easy to improve, for example by educating tourism personnel. However, among the parents in this study, the attitudes from other tourists at the destination seemed to be a larger constraint than bad treatment or attitudes among tourism personnel. Negative attitudes from other tourists can, arguably, be more difficult for the actors

in the tourism industry to change improve compared to attitudes among tourism personnel since other tourists behaviour tend to be out of hand for the tourism industry to control.

In the destination phase, some environmental barriers can also be reduced rather easily. The parents in this study mentioned that the provision of some basic aids and equipment would make it a lot easier for them. The main suggestions were that the hotel could provide them with a changing table, an adjustable bed and a hoist. While these suggestions have not been specifically mentioned in previous research upon destination constraints for people with disabilities it would probably be helpful for other mobility-disabled as well to have these kind of aids available, and not only for parents to children with cerebral palsy.

7.2 The destination choice set model and the three main barriers

How the destination choice set model looks like for parents to children with cerebral palsy seems to depend on the different barriers that these families tend to face when they are travelling for tourism purposes. The aim of this part of the analysis is to combine the three main barriers (intrinsic, interactive and environmental) with the different stages in the destination choice set model, in order to get an idea regarding how the parents make their decisions and how their disabled children affect this process. Since the parents in this study experience some barriers in different ways and seem to be affected by the different barriers to various degrees, they are also likely to have different destination choice set processes. However, this analysis is quite general in order to make an overview of the most common constraints and destination choices that were found among the parents in this study.

A study made by Karl (et al., 2015) showed that people who have difficulties related to ill-health might have to deselect their dream destination and instead chose another destination. Some of the parents in this study who had dream destinations that they wanted to visit seemed to accept that those destinations were not possible to travel to, at least not currently. A generalized example of how adjustments related to the children's disabilities can affect the destination choice set process is presented in Figure 2.

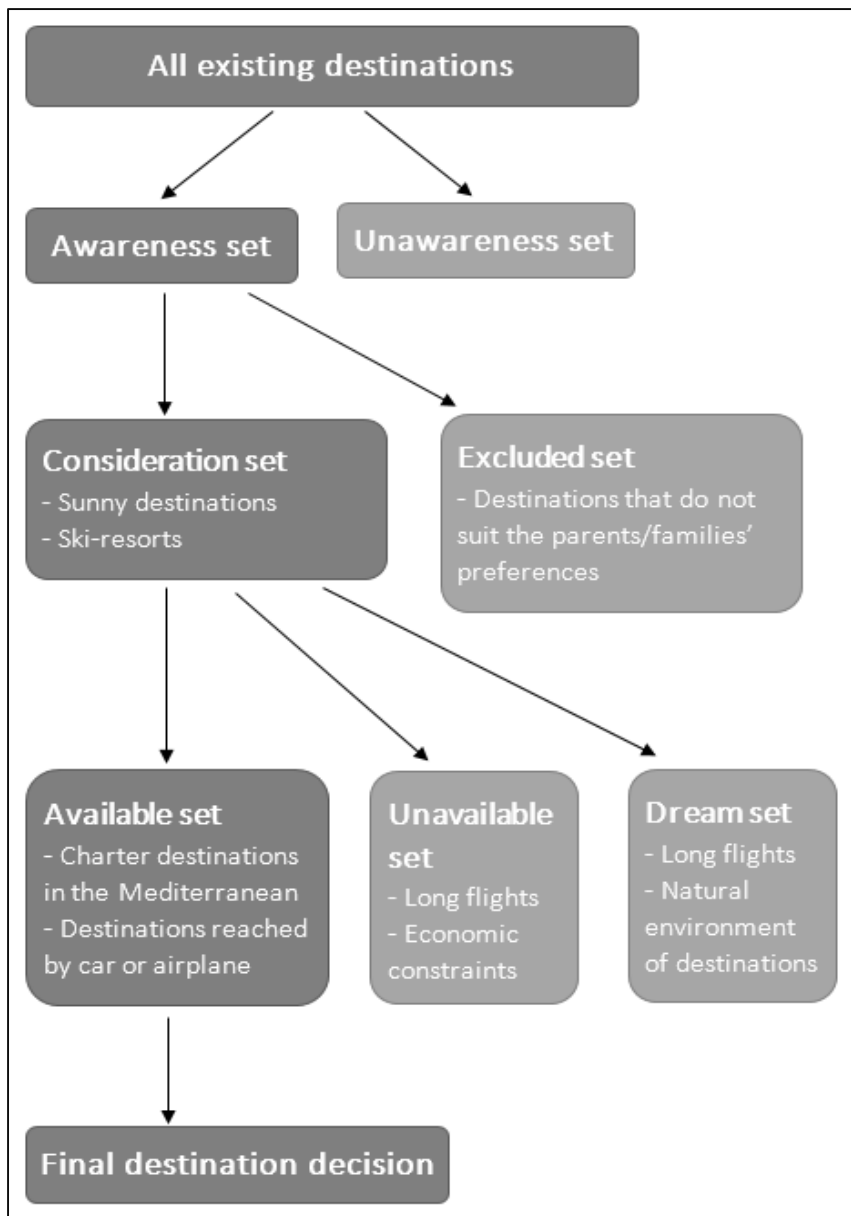


Figure 2: The parents' destination choice set model.

7.2.1 The awareness and unawareness set

The parents who had been able to overcome their intrinsic barriers could start with the first stage of the destination choice set model – the set with all existing destinations. This set is divided into an ‘awareness set’ and an ‘unawareness set’. The awareness set among the parents seemed to be possible to expand by their own search for new destinations and by getting tips from others. Interaction both directly and indirectly with actors in the tourism industry as well as with other parents to wheelchair carried children or other people with mobility-disabilities seem, therefore, to be important during this stage of the destination choice set process. If the interaction is restricted in some way, the awareness set would probably be smaller, which indicates that interactive barriers can be evident during this phase.

7.2.2 The consideration and excluded set

Among the destinations that the parents were aware of, they came up with a ‘consideration set’ with destinations they could consider travelling to. For most of the respondents, this consideration set consisted of different sunny charter destinations (or non-charter trips for sun and bath purposes), while others preferred to travel to different ski-resorts. The parents need to have some information about the different destinations in the awareness set in order to put them in the consideration set. The destinations in the awareness set that are not put into the consideration set, are instead put into the ‘excluded set’, which can exist of destinations that are excluded since they do not fit the purpose of the trip or suit the families’ preferences. Some parents explained that they used to go to certain destinations with their wheelchair carried child, but travel alone on other trips. This can indicate that some of the destinations in the awareness set can be put into the consideration set by the parents if they travel without their disabled child, but the same destinations could be placed in the excluded set for vacations with the whole family.

During this stage of the destination decision process, all three barriers can be important in different ways. To begin with, the intrinsic barriers among the parents can affect whether they chose to bring their wheelchair carried child or not to a destination in the awareness set and whether they deselect some destinations due to negative previous experiences. The interactive barriers can, for example, be a lack of information which can make the parents put a destination in the excluded set, even though it could have been considered as an alternative if they had got enough information about it. The physical environment can also be important in this phase since it has to suit the preferences of the parents, the disabled children, and other family members.

7.2.3 The available, unavailable and dream set

The destinations in the consideration set are further divided into three different sets, namely the ‘available set’, the ‘unavailable set’ and the ‘dream set’. The results from the interviews indicate that both intrinsic and environmental barriers can affect which of these sets that the different destinations are put into. The unavailable set and the dream set consist of destinations that are considered too unavailable, either temporarily or permanently. The destinations that are permanently unavailable can be so due to environmental barriers, such as an inaccessible physical geography. Destinations which are more temporarily unavailable can be so due to economic constraints, and other things that can change over time (see Decrop, 2010). Some respondents mentioned that they would like to travel to specific destination, but that it was considered as too expensive at the moment. While economic constraints are not necessarily an outcome of the child’s disability, it can be so due to the lack of budget alternatives that provides the accessibility that these families need. These destinations were, therefore, put into the ‘unavailable set’.

One factor that could make some respondents put some destinations into a dream set, while others put these into a temporarily unavailable set was the fact that some destinations were located far away. For parents to children with difficulties with sitting for several hours due to pain, the destinations that were located far away were to a larger extent permanently unavailable (meaning that they were put into a dream set). Nevertheless, some parents guessed that it would be easier to go on long flights with their children once the children grew older and became more patient. These parents categorized distant destinations as temporarily unavailable. Whether some destinations were put into a dream set or an unavailable set seem, therefore, to depend on

intrinsic and environmental barriers. The intrinsic barriers are not related to the parents themselves during this phase, but rather to their children and the specific physical limitations of their disabilities.

During this stage of the decision-making process, there are usually only a few destinations remaining and these are put into the so called 'available set'. Among most of the respondents in this study, the available set consisted of sunny charter destinations close to the Mediterranean Sea. These destinations were considered to be in an appropriate distance and provided them with what they looked for during a vacation, such as a change of climate and to get away from their everyday life. Destinations by the Mediterranean seemed to be an accepted, by not ideal, choice among some respondents who in reality wanted to go to destinations such as Thailand. Furthermore, another restriction among these families was that they had to choose destinations which could be reached by car or airplane, since other transport modes were considered too inaccessible.

7.2.4 The final tourism destination decision

In the last stage of the destination choice set process, the parents make their final destination decision. This destination is usually a destination from the available set, but not necessarily always. The final tourism destination decision can also be made quite easily and be based on familiarity and loyalty. Some of the parents in this study chose to travel to the same place several times. In those cases, some of the steps in the destination choice process might be entirely skipped. This indicates that the final destination decision can be affected by intrinsic barriers among the parents, in terms of not being willing to challenge themselves more than necessary.

8. DISCUSSION

This study has shown that parents to wheelchair carried children with cerebral palsy face several constraints throughout the whole travel chain and that these can affect their tourism travel decisions, such as destination choice. The constraints have been categorized and analysed as three main barriers, namely intrinsic, interactive and environmental barriers. Many of the difficulties that parents to wheelchair carried children with cerebral palsy face when they are participating in tourism travel seem, according to the results of this study, to be similar to what other studies upon tourism travel for people with mobility-disabilities have shown. It is, for instance, considered as troublesome to find enough information before a tourism trip. There can also be some difficulties regarding interaction with other tourists and tourism personnel, due to bad attitudes or treatment. The environmental barriers were also similar to what other wheelchair carried people usually experience when they are participating in tourism travel. Nevertheless, some differences were also found, which related to the fact that it was children who were carried by wheelchairs and the adjustments that were made in order to make places wheelchair friendly were mostly considered to be made for adults in wheelchairs. Moreover, this study has also shown that every single family and individual has specific needs and, thereby, strengthened the argument that people with disabilities cannot be seen as a homogenous group (e.g. Darcy, 2012; Gröschl, 2007). The findings of this study showed that families with children with cerebral palsy are very different from each other, even if all the respondents in this study have children with the same diagnosis.

The study findings also suggest that reducing the existing barriers to tourism travel can be valuable if a destination wants to attract families with wheelchair carried children and be put into these families' consideration set when they are planning their tourism trips. To reduce the tourism travel constraints among these families can also be important due to the power of word-of-mouth. Parents to children with disabilities tend to listen to other parents with disabled children and make decisions based on their suggestions and advice. This indicates that a destination, accommodation or travel company that success in meeting the needs of one family with a disabled child (or other people with disabilities) can attract new customers indirectly. Some of the parents in this study also mentioned that they choose to go to the same place several times, or always fly with the same airline or travel with the same travel company. Due to this loyalty and the potential to attract new customers through word-of-mouth, it could be valuable both for different actors in the tourism industry and the disabled tourists if the different barriers to tourism travel could be reduced.

With regards to the destination choice set model, the destinations that families with wheelchair carried children can consider will, probably, change over time. By way of example, whether destinations are put into an available set, unavailable set or dream set can change due to changing internal and external preconditions for these families. Increasing the accessibility of some transport modes or destinations can make it easier to travel to places which currently are considered as too unavailable. It could, for instance, become easier to travel for longer distances if the comfort at airplanes could be improved for these children. According to the parents, this could be made by making it possible for the children to sit in their own wheelchairs in the airplane or to lay down during the flight. What these families need in terms of accessibility can also change as the children grow older. Many of the parents mentioned that some difficulties with tourism travel are possible to overcome currently, but might be more challenging when the child is older and heavier. This indicates that the destinations that currently are in the available set could be unavailable in the future, or maybe even put into a dream set, if the barriers become too difficult to overcome. However, other things related to the environmental barriers might actually become easier with time, since many parents said that places usually were adjusted in order to suit the needs for adults who are carried by wheelchairs, not children. Due to these factors, the destination choice set processes among these families are probably not stable and consistent over time, but might even change from trip to trip. This indicates that destinations and transport modes have the opportunity to go from being seen as unavailable to be available, if they work actively with reducing the barriers that exist for people with different disabilities.

Furthermore, when trying to attract people with disabilities, it is also important to consider the social and medical perspectives of disability (e.g. Grue, 2015). It is, probably, important for these families that the tourism industry does not consider them (or the disability) as a problem. The difficulties that the parents in this study mentioned were mostly related to their surroundings. Limitations and restrictions caused by their children's disabilities were almost never mentioned and the emphasis was put upon the barriers that existed in their social and physical milieu. This indicates that these parents see their children's disabilities with the social perspective rather than the medical. It would, arguably, be valuable if the tourism industry could increase their usage of the social perspective and not focus upon which problems that a family have due

to a disability, but to focus upon which constraints that exist due to the inaccessibility of different transport modes, destinations, accommodations and so forth. While reducing the three main barriers can encourage more people with disabilities to travel, the tourism industry need to have a more flexible and individualistic perspective towards all their customers and not see people with disabilities as only disabled, but try to make it as easy as possible for everyone to participate in tourism travel, regardless of impairments, disabilities and other potential restrictions. Moreover, the suggestion regarding providing specially designed tourism trips, where disabled tourists are seen as a niche market segment (e.g. Bi *et al.*, 2007; Card, *et al.*, 2006; Dominguez, *et al.*, 2013) was not considered as an attractive option among the parents in this study. This can be a result of a mismatch in how the children's' disabilities are perceived by the parents compared to the different actors in the tourism industry. There is a probably a risk that the disability is seen more with a medical than a social perspective if people with disabilities are put into an own niche market segment, which can be problematic if the parents to disabled children (and other people with disabilities) do not want to be considered as disabled, but rather want to live and travel like 'normal' families and have all the options that other families do.

The results from this study can be used by different actors in the tourism industry. Being aware of some of the different barriers, constraints and difficulties that families with wheelchair carried children can face when participating in tourism can be seen as a good starting point. When the tourism industry is working with reducing the barriers that exist for people with disabilities it is, however, important to have in mind that all disabilities are different and that people can have a combination of different disabilities, but also that all people are different due to demographical aspects, interests and other preferences. By succeeding with this, destinations that are currently seen as too inaccessible among these families can be considered to travel to in the future. This is, arguably, positive both for the destinations since they can attract and increasing amount of tourists, and for families with disabled children (and other people with disabilities) since their opportunities to participate in tourism travel increases by having more alternatives.

8.1 Suggestions for further research

Many aspects of tourism travel for families with children with disabilities remain to be studied, since this a new topic in the tourism travel research field. The findings from this study revealed that families with wheelchair carried children had to change their travel patterns in order to make it possible to participate in tourism. The parents seemed to have accepted that their tourism choices were not always the most desired by them and they thought that it was better to make adjustments than to not travel at all. However, other family members are affected by these choices as well and it would be interesting to study tourism travel for the perspective of the disabled children themselves, but also from the siblings' perspective. While this study has contributed to the research field by focusing on the travel experiences of parents, the perspectives of children who are participating in tourism travel with a disabled family member is still missing in tourism research. How they feel about having to prioritize the physical accessibility higher than other, personal preferences and desires is, therefore, suggested as a starting point for future research.

Another suggestion is to focus more upon the travelling constraints that families with wheelchair carried children face when they are using public transport modes. Since almost all of the

parents in this current study explained that buses and trains and considered as too inaccessible, it would probably be valuable for the transportation companies to get to know more about which parts of the trips with these transport modes that need improvements. The limited choices in terms of which transport modes families with wheelchair carried children can use can also, probably, lead to further implications. If taxes for gas increases and it becomes more expensive to travel by car or airplane, the increase will probably hit some groups in the society harder than others. If families with disabled children (or people with mobility-disabilities in general) cannot use other transport modes, their travel patterns and destination choice sets will probably be even more limited in the future. A suggestion for further research is, therefore, to focus upon how social and environmental goals regarding transportation can stand in contrast to each other and sometimes, arguably, even counteract each other.

9. CONCLUSIONS

The main purpose of this study has been to highlight the feelings and experiences of parents to wheelchair carried children with cerebral palsy. This study has shown which constraints these families can have when they are travelling for tourism purposes and how the disability affects these families' destination choice process. It also provides suggestions regarding how tourism travel can be made easier for these families. In this concluding section, the main findings are briefly presented in terms of answers to the three research questions for this study.

The first research question was about which constraints parents to children with cerebral palsy experience during the different phases of the travel chain. This study has shown that different constraints and difficulties are evident throughout the whole travel chain and these can be categorized into three main barriers (intrinsic, interactive and environmental). Different families face different constraints and experience these in different ways. While all children have the same diagnosis and are carried by wheelchairs, the families' requirements in terms of physical accessibility and aids varied a lot. What is considered as accessible enough for some people might be totally inaccessible for others.

Regarding the second research question, how the child's disability affect the family's destination decision choice process, this study has shown that the disability can impact the destination choice in several different ways. The parents explained that they had to make some adjustments due to their child's disability, but that they considered it important for the whole family to participate in tourism travel. The fact that they had wheelchair carried children could affect which kind of tourism destination they choose, how far they could travel, which kind of transport mode they could use, which accommodation they could choose, and which activities they could participate in.

The last research question for this study was about how tourism travel can become easier for families with wheelchair carried children with cerebral palsy. The parents themselves can ease tourism participation by choosing to travel on tourism trips that are specially designed for people with disabilities or by bringing care attendants, which can allow for the parents to relax more during their vacation. However, there are also different things that actors in the tourism industry can do in order to make it easier for these families to participate in tourism travel. The

parents had many concrete suggestions regarding how the environmental barriers could be reduced, for example by improving the accessibility of places and provide some aids at the accommodation. However, the most important change seem to be quite simple for the tourism industry to provide – more information. The results of this study show that if the parents can get information about which parts of the tourism trip that are accessible and which are not, it is easier for them to cope with the difficulties that they meet along the way. If they are aware of these difficulties beforehand, they can prepare for it. Information was therefore considered, among many parents, to be more important than top-accessible places. The different actors in the tourism industry also have to be clearer with what they mean with ‘wheelchair accessibility’, since the accessibility needed can differ a lot between different families. Furthermore, families with wheelchair carried children should not be seen as a homogenous group just because they have a child with a disability. The tourism industry has to understand this and become more flexible in order to fulfil the needs of each individual and family who are participating in tourism travel.

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APPENDIX 1 – Interview template

Background questions

- Can you tell me a little bit about yourself and your family? Family constellation?
- How does a regular day in your everyday life look like? What do you work with?
- Do you have any external care attendants to your child with cerebral palsy?
- Does your child with cerebral palsy have any leisure activities?

Questions about tourism travel

- How did you travel before you got children? Before you got a child with cerebral palsy?
 - Which kind of destinations did you choose?
- How often do you travel now, with the whole family?
- Why do you travel? Which are your main travel motivations?
- Do you consider it important to travel?
- Do you bring care attendants on your tourism trips? How do you experience that?
- Do you have any dream destinations?
- Do you think that you are going to travel there?
 - If no, why not?
- Have you tried to go on tourism trips that are specially designed for people with disabilities?
 - What do you think about these trips?
 - Could you consider to go on such a trip in the future?

Choice of destination

- Which kind of destinations do you usually choose?
- How do you find information about different destinations?
 - Do you think that it is possible to find information about accessibility, regulations and so on?
 - Have you experienced any shortcomings or inaccurate information?
- Do you have any suggestions regarding what different actors in the tourism industry could do in terms of information, in order to ease your destination choice?

Choice of transport mode

- On which criteria do you base your choice of transport mode when you are travelling for tourism purposes?
- Is there any transport mode that you deselect due to the fact that your child has a disability?
- Do you experience that you get enough help and information when you are travelling with public transport modes or airplane?
- How do you experience the physical accessibility when you are travelling with public transport or airplane?
- How are you treated by tourism personnel and other tourists when you are travelling with different transport modes?

- Do you have any suggestions regarding improvements that can be made in the transport sector in order to make it easier for you to travel?

Choice of accommodation

- On which criteria do you base your accommodation choice when you are travelling for tourism purposes?
- Is your child's disability a determining factor when it comes to the accommodation choice?
- Have you experienced that some accommodations have not been as accessible as they claim to be?
- Which improvements can be made with the physical environment of different accommodations?
- How do you experience that you are treated by tourism personnel and other tourists at the accommodation?

Choice of activities

- Which activities do you participate in during your tourism trip?
- Are there any activities that you would like to participate in, but that you deselect due to your child's disability?
- Which improvements can be made in order to ease your participation in different activities?

Summing up

- How would you say that your child's disability affects your travel pattern?
 - Do you think that you would have travelled differently if he/she did not have a disability? Would you have travelled more often? To other destinations?
- Which are the most important changes that the tourism industry can do, according to you?
- Do you think that tourism personnel should be educated about different disabilities and which needs people with different disabilities can have when they are participating in tourism travel?
- Is there anything that you experience as easier now than what you believed before you started to participate in tourism travel with your child with cerebral palsy?
- Do you have anything to add or is there something else that you want to talk about?

APPENDIX 2 – Presentation of the respondents

Respondent	Date of interview	Type of interview	Mother/father	Family constellation	Boy/girl with CP	Age of child with CP	Travel as a family
1	2016-02-09	Phone interview	Mother	Husband, 2 children	Boy	14 y/o	Yes
2	2016-02-11	Phone interview	Mother	Husband, 3 children	Boy	9 y/o	Yes
3	2016-02-11	Phone interview	Father	Wife, 2 children	Boy	5 y/o	Yes
4	2016-02-12	Phone interview	Mother	Husband, 2 children	Boy	5 y/o	Yes
5	2016-02-12	Phone interview	Mother	Husband, 3 children	Boy	13 y/o	Yes
6	2016-02-15	Phone interview	Mother	Spouse, 1 child	Boy	4 y/o	Yes
7	2016-02-15	Face-to-face interview	Mother	Separated, 3 children	Girl	16 y/o	Yes
8	2016-02-16	Face-to-face interview	Mother	Husband, 4 children	Girl	12 y/o	No
9	2016-02-17	Phone interview	Mother	Husband, 3 children	Boy	13 y/o	Yes
10	2016-02-18	Phone interview	Mother	Husband, 3 children	Boy	9 y/o	Yes
11	2016-02-18	Face-to-face interview	Mother	Husband, 3 children	Girl	9 y/o	Yes
12	2016-02-19	Face-to-face interview	Mother	Husband, 2 children	Girl	11 y/o	Yes
13	2016-02-24	Phone interview	Mother	Husband, 4 children	Boy	4 y/o	Yes