

Travelling with an Asperger's child

Allegra Andersson

Julia Tuuri

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Author(s) Allegra Andersson, Julia Tuuri	
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<p>Accessible tourism has been a risen matter during this decade. Accessible tourism is all about equality which is luckily a famous discussion topic and affects this way to everything for instance to tourism industry as well. There are many segments of people who require this so-called inclusive tourism, accessible tourism or tourism for all. There are people with physical disability, sensory disability or intellectual disability. All these groups have different needs at the airport, at the destination or anywhere when travelling between home and the actual destination.</p> <p>In this thesis intellectual disability is in a big role since that section covers travellers from the spectrum of autism that this research is all about. As accessible tourism is a risen matter so is autism. 1 out of 60 kids are nowadays diagnosed in autism spectrum. Autism chapters covers information of different forms of autism, what symptoms they might face, what is typical for them and different kind of general information of autism from origins of it to the commonness of it.</p> <p>Research was produced with unstructured qualitative method by using theme interviews. There were four themes in the interviews. Planning a vacation, travelling, being at the vacation and back home after a vacation. Covering these four parts interviews gave full picture understanding of the trip. What kind of preparations are done with planning, what happens at the airport, what kind of trips are taking place at the destination and what happens when the trip is over and the family is back at home.</p> <p>Suomen Autismiliitto has acted as a commissioner to the research project and has guaranteed information with their webpage. Another useful resource has been Facebook group for Asperger's children's- parents peer support group where all the interviewees were found. All the interviews were conducted by phone since the interviewees live all over Finland and Germany. Interviews were conducted with every interviewee's native language.</p> <p>The concluding chapter condenses what was learned when producing the research including theoretical framework, interviews and the results. In its entirety combining the matter of accessible tourism and autism forms a unique handbook like research that provides information of accessible tourism with a focus of an Asperger's child. Recommendations form a platform of the actual tips for the families when travelling. Goal of the research was to gather trustworthy, useful and versatile tips when travelling with an Asperger's child. Also growing the consciousness of Asperger's travellers is hoped with the thesis.</p>	
Keywords Accessible tourism, Tourism for all, Autism, Asperger's, Intellectual disability, Travelling with a disability	

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1 Introduction

This chapter mentions the research introduction and explains the problem as well as the aim of this research paper. It includes a short introduction of the commissioning party and the delimitation of this research is explained. In the end of this chapter the complete structure of the thesis is presented and summarized.

1.1 Background of the research

The World Health Organisation predicts there are around 1 billion people in the world having a disability. That makes 15% of the world population. (WHO 2019a) Autism is one form of disability which will stay for a lifetime. Besides of the adults, 1 out of 60 children is dealing with an Autism Spectrum Disorder. (WHO 2019b) Therefore, autism is a part of many families' life. The world tourism organisation - UNWTO estimated that 1,45 billion people worldwide will travel internationally in year 2019 and numbers are growing continuously over the years (UNWTO 2019). Travelling is an enjoyment that should be possible for everyone. The tourism sector is well aware of this topic and it gained awareness and attention about accessible tourism in the last few years. Tourism for all is a topic discussed in many travel reports, articles and literatures. Lately, disabilities which cannot be seen immediately, especially Autism is discussed in many tourism channels and a lot of destinations and attractions started to offer special service for people with an Autism Spectrum Disorder – short ASD.

1.2 Accessibility with the autism spectrum

Accessibility is a common interest for the commissioner of this thesis - Suomen Autismliitto. The Association for Autism and Asperger's Syndrome is concerned of hindrances rising in such areas: communication, interaction, the environment and sensory activity. The Accessibility Program that Suomen autismliitto offers spreads information and influences attitudes to improve accessibility in society. Accessibility regarding to the autism spectrum can differ a lot if we compare to accessibility with for instance aged people. As discussed in the earlier chapters the three segments of accessible tourism by Buhalis and Darcy it is easy to see the cohesion to how Suomen autismliitto divides accessibility for autism in physical, social and mental accessibility. (Suomen autismliitto 2019.)

Physical accessibility need in autism spectrum might be a need of using color codes. For instance using a red card for "no" and a green card for "yes". Another example of physical

accessibility needs for autism is using earplugs or hearing protectors to be able to remove distressing noises. Social accessibility can be a common language that may take a form of speech, pictures, writing or sign language. Genuine interaction in a way that allows everyone to participate. Mental accessibility is mainly changing the attitudes and spreading information about autism for the public. (Suomen autismiliitto 2019.)

According to Suomen autismiliitto, accessibility means that everyone has an equal chance to participate, regardless of one's capabilities and as every person is an individual, accessibility does not mean the same things to every person with autism spectrum". (Suomen autismiliitto 2019.)

1.3 Research problem and aim

Travelling is more challenging for people with disabilities because of several reasons. For Families with an Autism Spectrum Disorder having a vacation, especially an international one is a huge challenge. The number for children having an Autism Spectrum Disorder is rising annually. For many families it is natural to spend their holidays in a foreign country, travelling internationally to see new places and have a time out of their everyday life. Families having a child with a disability, in this case autism would need so much a break of their stressful life. The problem is that it is not quite clear if the vacation will really bring them relaxation or if it might cause even more stress. The research problem is approached with a qualitative method since it is all about gaining a deeper understanding what things are needed or wanted for a trip with an Asperger's child. This research paper will offer recommendations and advice for families with an Asperger's child and how to prepare the kid in order to have a relaxing and memorable vacation. Those recommendations will help the families to have a stress-free holiday and make their travelling easier. How can the planning process be done so that the family will be better prepared for the holiday? What is important at the airport and what should be considered to have less stress at this crowded place? Which accommodation fits the best to a family with an Asperger's child and how to react after the vacation?

1.4 Introduction of the commissioner

Suomen autismiliitto is a national organisation of experts and citizens. It serves as the commissioner for the thesis traveling with an Asperger child research. Suomen autismiliitto webpage grants information about the autism spectrum, organizes training sessions and endorses events related to autism. Suomen autismiliitto association appraises information

of autism, reinforces its member associations and functions as a promoter in issues related to autism by offering counselling service. Counseling service's point is to guide people to the services in their local area and to find and acquaint options for cultivating and upholding the independence and everyday life of persons with some sort of an autism spectrum. Suomen autismiliitto's work promotes the realisation of accessibility, availability and human rights. Suomen autismiliitto provides information of accessibility for the people with autism which is the main focus of the research. (Suomen autismiliitto 2019.)

1.5 Structure of the thesis

This Bachelor Thesis is divided into 5 main chapters: Introduction (Chapter 1), Literature Review (Chapter 2), Research methods (Chapter 3), Data Analysis (Chapter 4) and the last chapter is the Conclusion (Chapter 5).

Chapter 1 tells about the research problem and the aim of the research including some important numbers of the research topic. Further, it offers an introduction of the commissioner. The structure of the thesis is described and explained.

Chapter 2 is the literature review which tells about existing research about the topic which has been researched by reliable and versatile sources. This chapter offers a devote framework for the thesis. It gives insides and definitions about the topic accessible tourism and tourism for everyone. Further it describes the whole Autism Spectrum Disease also including definitions, statistics and insights. In the end of this chapter research and services for travelling with an autistic child are mentioned. The authors got a great knowledge about autists and their struggles when it comes to travelling. This background knowledge is important and necessary in order to proceed with the research paper.

Chapter 3, the Research methods tell about the research methods that have been used for this thesis. Quantitative and qualitative research methods have been compared and considered. The chapter describes why the qualitative research method has been chosen. Further, it describes the theme interviews and illustrates the chosen themes for this research with a figure. Delimitations and Limitations are mentioned in the end of this chapter.

The next chapter, chapter 4 is the Data analysis. It evaluates the interviews, which were taken for this research. 8 Families with an Asperger's child have been interviewed intensively to get a better picture of this phenome. Similarities and Dissimilarities are evaluated

and listed. Recommendations are given and applied to the theory chapter in the end based on the interviews.

The last chapter (chapter 5) is the conclusion. It summarizes the research paper and offers reflections of the authors own learnings.

2 Inclusive tourism

This chapter defines tourism for all and accessible tourism. The accessible tourism also describes the potential for accessible tourism in numbers. Further, it describes also the barriers to travel for people with a disability. The end of this chapters explains the accessibility with the Autism spectrum. The Autism spectrum is described in detail, in the next chapter of this research paper. (Chapter 3)

2.1 Tourism for all

Tourism for all is a term that includes the entire population not merely the terms of accessibility but reflecting other aspects of tourism as well. Tourism for all is said to integrate other subtypes of tourism for example accessible tourism, social tourism and sustainable tourism, visualized in Figure 1. (UNWTO 2019.)

Social tourism examines the formation of population groups with divergent social and economic characteristics as factors involved in tourism integration. Term social tourism according to International Standardized Testing Organization is the effect and phenomena resulting from the participation in tourism, more specifically the participation of low-income groups. Young people aged 15-25, large families with three or more kids, seniors or people with disabilities are good examples of groups that can be classified under the social tourism. (ISTO 2019.)

Sustainable tourism is another segment that can be fitted under tourism for all concept. According to the World Tourism Organization, sustainable tourism can be defined as tourism that takes full account of its current and future economic, social and environmental impacts, addressing the needs of visitors, the industry, the environmental and host communities. (UNWTO 2019.)

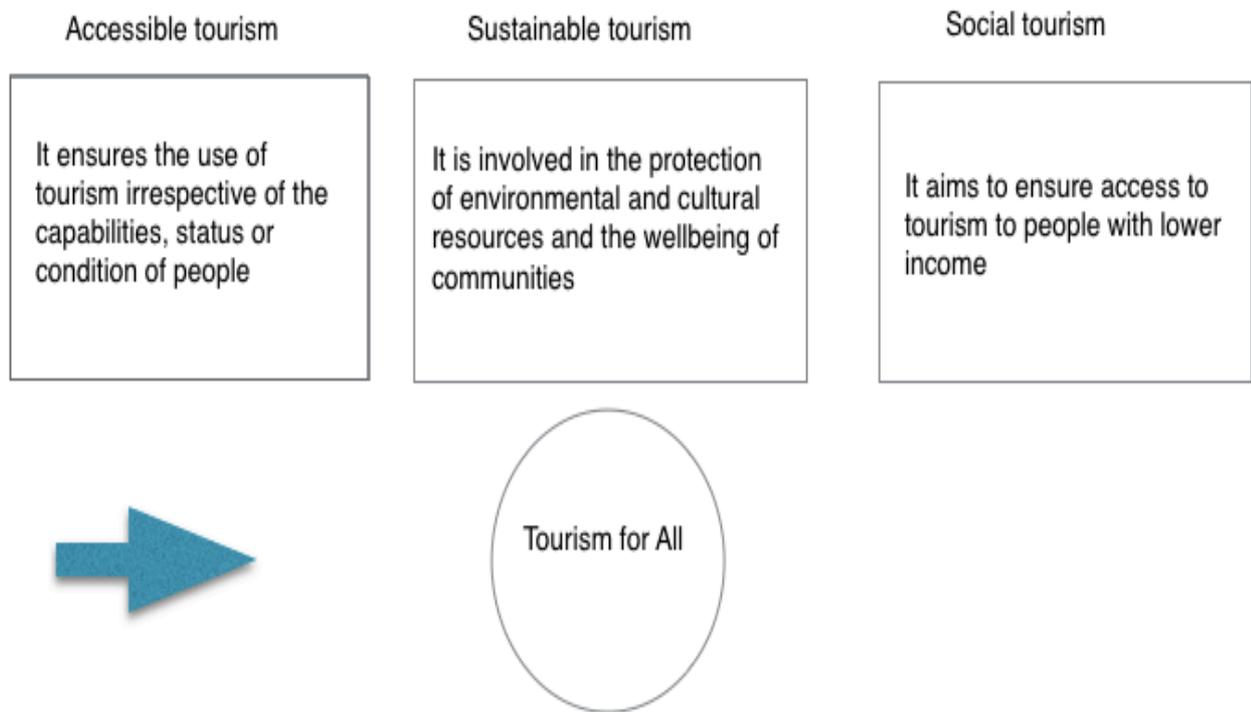


Figure 1. Tourism for all and its different subtypes (UNWTO 2015.)

Figure 1 of the different approaches to tourism as a social and responsible factor and the position of accessible tourism is given above.

2.2 Accessible Tourism

Accessible tourism is the activity that respects customer's individual needs according to their special needs. It is a concept that brings alive the equal rights for every traveller. Accessible tourism is defined as the ongoing aspiration to assure tourist destinations, products and services to be reachable to all people disregarding their disabilities, age or physical limitations (Darcy 2010,2.)

Accessible tourism term indicates tourism and travel that is available to all travellers disregarding of their physical limitations, disabilities or age. This consists of those with mobility, hearing, sight, cognitive, intellectual and physical disabilities. (CBI 2015.)

Accessible tourism is classified to be a form of tourism that involves processes between stakeholders that allows people with access requirements, such as: mobility, vision, hearing and cognitive special requirements, to function independently. Concept accessible tourism is created for instant for people with permanent and temporary disabilities, seniors, families with young children or anyone with special needs (Buhalis & Darcy 2010,10.)

Accessible tourism has been strongly linked in to inclusive tourism industry. Inclusive tourism is about diminishing uncertainty around what to expect from a destination or a service. Main focus of the industry is to form an environment where all people feel welcome and involved. Inclusive tourism is proofed to construct options and spreads confidence in people, empowering them to sign up for next experiences. Inclusive tourism provides an ability for tourism operators to have the opportunity to serve a wider range of tourists. (Rowet tourism school 2016.)

2.2.1 Potential for the accessible tourism market by numbers

World Health Organization (WHO) estimated that about 650 million people which is about 10% of the world population have some forms of disability. The number of the populations' disability has increased steadily in the last few years which signifies a potential necessity for the accessible tourism options. (WHO 2015).

In Finland for instance a huge amount of government's budget is used to the social service sector because of the aging population. In 2016, Finnish social security expenditure was 68.8 billion euros. Real expenditure growth was 2.1%. Relatively the largest share of social security expenditure was related to older generation. Approximately 40.0% 27.6 billion euros of all social security expenditure was related to older generation's pensions and services. The real increase in age-related expenditure was 4.3 % from the previous year. The study shows that the population is aging rapidly and disabilities with it and tourism industry should change with them and find alternative ways to travel. (THL 2018.)

It is measured that there are globally over 1 billion people with disabilities. 2 billion people, such as spouses, children and caregivers of persons with disabilities. This amount covers almost a third of the world's population. This signifies a huge potential market for travel and tourism and more importantly tourism for all and accessible tourism. (United Nations 2019.)

Figure 2 chart on the following page, shows disability statistics in certain regions. Europe forms approximately 9% of the total world disabled population which is more than 60 million people with permanent or temporary disability. North America constitutes disabled population of about 54 million and the biggest are with disabled population is in Asia, Africa and South America forming approximately 528 million of the total disabled population. (WHO 2011.)

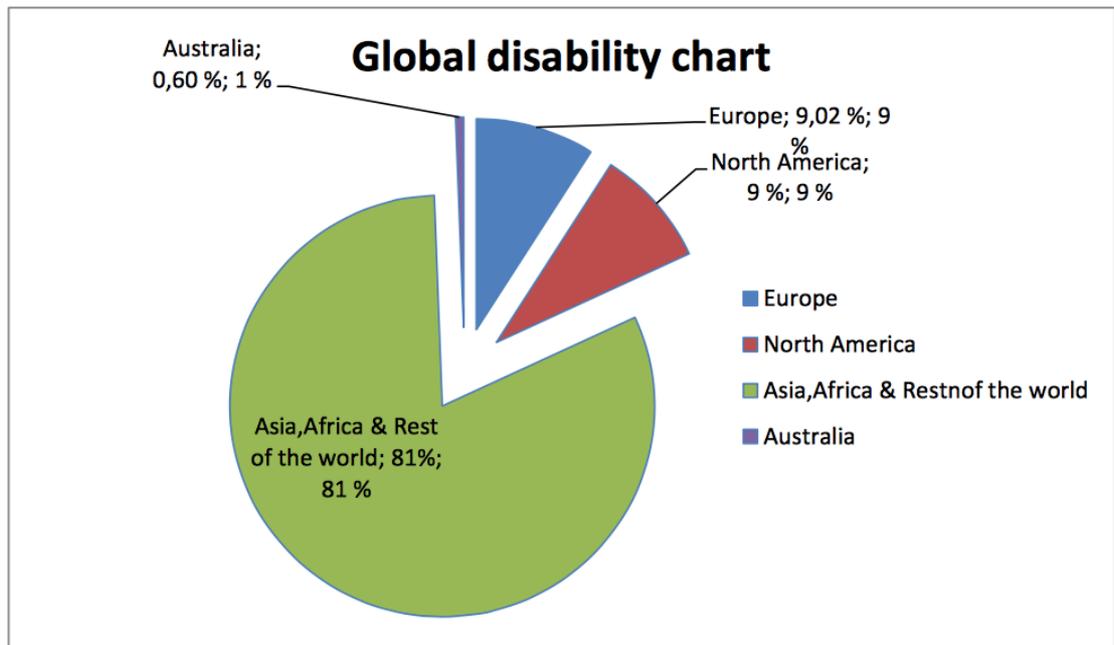


Figure 2. Global disability chart (WHO 2011)

2.2.2 Barriers to travel

Words 'access' and 'accessibility' are complex concepts and have different meanings to different individuals in different contexts. Different researchers have segmented the term - "accessible tourism" in a different way but many of them agree on the fact that physical barriers are the biggest problem. (Daniels 2005; Packer 20017; Smith 1987; Yates 2007) Tourism involves major barriers to people with a disability if they are not taken into account beforehand. Aspects included to physical barriers can be for instance: inaccessible transportation, accommodation facilities or attractions that require special concerns for disabled people. Most critical access issues are staircases, elevators, parking, sidewalks, ramps, paths and restrooms. (Israeli 2002)

When considering term accessible tourism, physical barriers are a critical concern but not the only segment of it and it is crucial to notice the different dimensions of it. The use of segmentation is examined to give a better picture of the individual accessible barriers and to make visible interrelations. According to Dimitrios Buhalis and Simon Darcy there are three categories when investigating barriers to accessing tourism. Physical accessibility, attitudinal accessibility and lastly lack of information dimension. (Buhalis & Darcy 2011)

Physical access dimension is said to be the biggest barrier to travellers with disabilities. Physical access covers a major part of traveling. Transportation, accommodation facilities and attractions. All of these have issues when considering physical obstacles. For example how do people with wheelchairs move to the airplane, how can travellers with sight problems move into an attraction that is in the middle of the woods or how can an old person climb up to the hotel's seventh floor if there is no elevator. (Buhalis & Darcy 2011)

Attitudinal barriers is all about changing the public awareness and increasing knowledge of accessible tourism. By overcoming attitudinal barriers, a real difference could be made to experiences. (Murray 2002) Attitudinal changes are stated to be the start of the whole accessible tourism. When accepting and acknowledging the issue can it be developed with practical solutions. (Packer 2007) We have probably heard someone being annoyed by screaming kids in the public transportations without knowing that they might have for instance ADHD or autism and not just behaving badly.

Lack of information can be linked into attitudinal barrier but Buhalis and Darcy have used tourism staff as an example of lack of information issue. Skeptical or negative attitudes go usually hand in hand with inability to provide correct and reliable services for disabled people. (Stumbo & Pegg 2005) This means that if for example hotels receptionist is not educated with what is autism and how it appears it can cause a negative attitude towards the customer. What is said to be the need of the lack of information segment is flexible packages that meet the travellers needs and educated staff. (McKercher 2003)

While an accessible infrastructure is claimed to be the basis of accessible tourism it is unlikely to solve all the barriers and that is why all the segments should be taken into a consideration when dealing with accessible tourism. (Puhretmair 2004)

UNWTO the World Tourism Organization divided persons with disabilities in to three wider categories. Categories are persons with physical disabilities, persons with a sensory disability and persons with intellectual disabilities. The table on the following page (Table 1) compiled by these categories gives answers to what kind of people can be categorized in certain group, their most common problems and example situations where these groups might experience troubles while travelling. (UNWTO 2016, 28-30.)

Table 1 Categories of persons with disabilities based on UNWTO (UNWTO 2016, 28-30)

Category	Physical disability	Sensory disability	Intellectual disability
What kind of person	Person with diminished capacity of movement	Person with visual, hearing or speaking disabilities	Person with diminished higher mental functions
Most common problems	Physical moving from place A to place B	Communication and language difficulties	Mobility, language, comprehension and affective skills.
Example problem	Natural sightseeing in a destination where it is not possible to access with wheelchair	Hotel that does not have any blind marks for a person with sight problems	Airport is full of new situations, new people and other social situations which is challenging for this group

Physical disability is defined with the following sentence “Diminished capacity of movement or a partial or general difficulty in performing conventional motor activities” UNWTO. More humanely it indicates people with disability that can affect their lower or upper limbs which can be caused by multiple factors such as congenital, hereditary, acquired or caused by an accident. Sensory disability includes people with visual, hearing or speaking disabilities. According to UNWTO this is the second biggest group when talking about travelers with disabilities. These groups include a lot of people who can have a milder version of the disability such as one does not have to be blind to need accessible services with vision. Communication barriers is the biggest challenge for this group, and it affects to the communication with other people and the environment itself. (UNWTO 2016, 28-30.)

Intellectual disability sometimes known as cognitive disability is referred to the group with diminished higher mental functions. It is probably the hardest one to categorize since as seen in the table it has various aspects to it. Generalizing the group is not easy. In this group we can find travellers with down syndrome, mental retardation, autism and cerebral palsy. Next chapter delves into accessibility with the autism spectrum and is highly linked to the intellectual disability sector. (UNWTO 2016, 28-30.)

2.3 Autism

Around 1 out of 60 children has an autism spectrum disorder – short ASD. Though the number is increasing all the time. Some studies have published figures which show way higher numbers, as the ASD in most of the low-income countries are unknown. The number of ASD children is rising constantly, based on studies made over the last 50 years. This increase is due awareness, better diagnostics and enhanced recording. Whereas the National Institute of Environmental Health Science says that 1 out of 59 children has an ASD. Figure 3 below supports the numbers published by NIELS. It is done by the Autism Community in Action based on numbers studies from the Center for Disease Control and Prevention. (WHO 2019b; NIELS 2019; TACA 2019.)

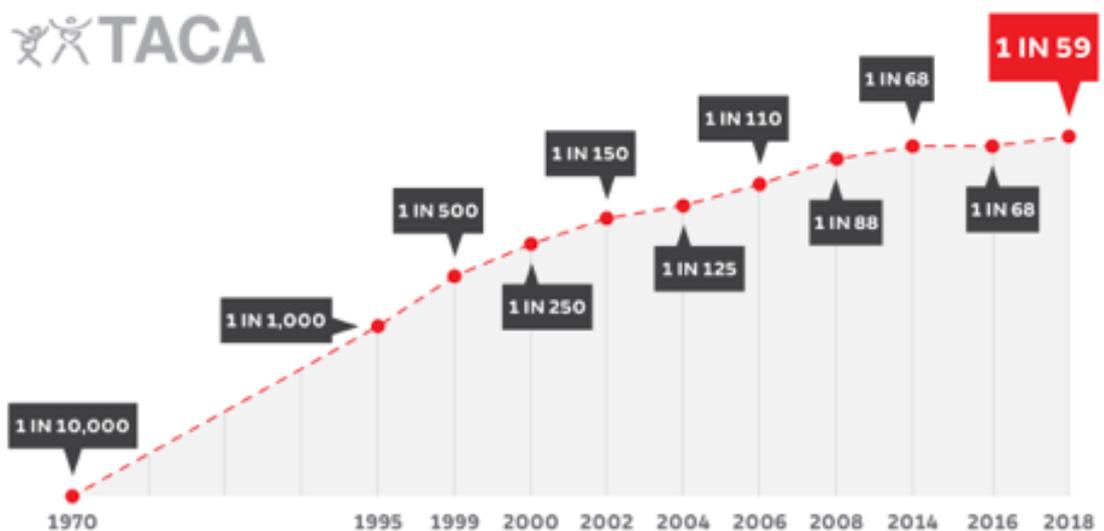


Figure 3. Children with ASD (NIELS 2019)

2.3.1 Definition

The word Autism is Greek and means oneself, because people with autism are suffice themselves by excluding social contacts and cannot even watch into others' eyes. (Rieger 2018, 6.) The World Health Organisation, as well as, the institution Autismspeaks defines autism as a wide area of circumstances symbolized with challenges in social competences, constant behaviours as well as struggles in speech and nonverbal communication. There are several forms of autism which are mostly caused by a mixture of genetic and environmental factors. (WHO 2019; Autismspeaks 2019.) This thinking supports the definition of the autism organisation in United Kingdom, which defines autism as a development defect that influences the way a person communicates and relates to others as well as how they see the world around them. (Autism 2019.) Autism can not be healed (Rieger 2018, 5.)

2.3.2 Reasons

The reasons for an ASD are not quite clear. Though, there are many factors, that higher the chances to have an ASD. Genes are a big aspect, but also specific drugs which include valproic acid or thalidomide taken by the mother during pregnancy can rise the chances for ASD. Children who have older parents also have a higher risk, as well as a sibling having ASD. In Figure 4 below, those factors are visualized. (CDC 2019.)

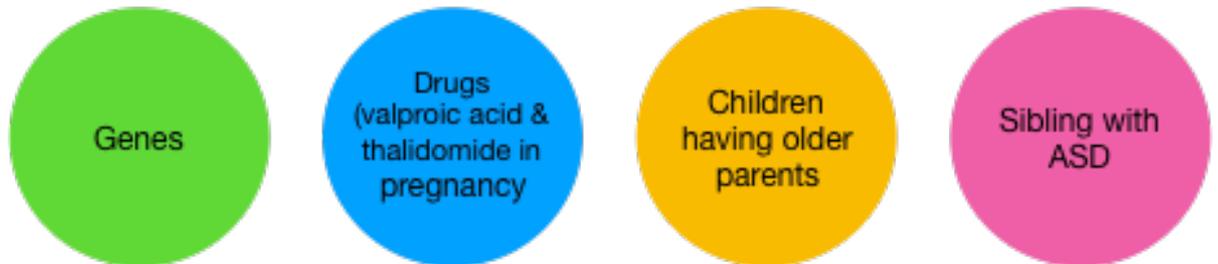


Figure 4. Factors increasing the risks for ASD. (CDC 2019.)

The National Autism Society agrees with the CDC, that the reasons of autism are not known. It says that there might not be a single reason and rather a combination of causes and genetic aspects. (National Autistic Society 2018.)

2.3.3 Symptoms of Autism

No Autist is like the other one, that makes it hard to define the symptoms. It also depends how strong the ASD is. A common symptom is the social awkwardness and strong opinion about the exact place, where the food has to go on a plate. Those children struggle in sociality and are often seen as unacceptable or even bad raised children. Some of them are non-verbal and some feel no pain or fear. Another common symptom is a delay in the speech development. Some Autists have a memory over average and remember a whole book word by word. One boy from America could not remember his mother's name but he could remember the whole passenger list from the Titanic. There are other cases like this with numbers as well. Simple questions can often not be answered but more complex and difficult, almost impossible questions are answered very quick. It is also very hard for ASD children to understand humour or body language. Most of the children can not keep eye contact, though there are also exceptions. They can not imagine how other people would do it or feel it. They also have strange ways to communicate such as a high or flat voice. ASD children have it hard to get accepted in this world and often are outsiders. (Cresswell 2008, 27-33.)

2.3.4 Forms of Autism

There are several forms of autism which all belong to the ASD. The classical autism – Autistic Disorder, Asperger’s Syndrome, Pervasive Development Disorder – PDD-NOS, Rett’s syndrome – mostly girls and Childhood disintegrative disorder. Image 1 below shows the several diseases. (Autismag 2014.)



Image 1. Classical Interpretation of Autism. (Autismag 2014.)

In this classic Interpretation of autism, those diseases have all seen as separate, as shown in Image 1, above. Whereas there are modern interpretations, as shown in Image 2 on the following page. The difference is that the modern version defines all the disease as Autism Spectrum disorder, and they are somehow overlapping. (Autismag 2014)



Image 2. Modern Interpretation of Autism. (Autismag 2014)

There are huge ranges in the depth of the illness. The disease can be diagnosed in a mild, average or hard form. The classification is important for the amount of support a person with ASD will and can receive. As mentioned earlier, every autism is an individual with less or higher difficulties in this world. Table 2 below shows the several diseases and what forms there can be for each of them. The Classic Autism can be on all three levels depending on how strong symptoms the person has. Compared to the Asperger's which can only reach level one. The PDD-NOS can be diagnosed in level one and two. Rett's syndrome and the CDD always come with strong restrictions, that it reaches at least level two or even level three. (Autismag 2014.)

Table 2. Types of ASD and what support levels they can reach. (Autismag 2014)

Autism Forms	Support Level	Classical Autism	Asperger's	PDD - NOS	Rett's Syndrome	CDD
Mild Autism	Level 1	✓	✓	✓	✗	✗
Moderate Autism	Level 2	✓	✗	✓	✓	✓
Severe Autism	Level 3	✓	✗	✗	✓	✓

Table 1: A How the different types of autism align to the 3 major categories of severity

Asperger's are known to be very intelligent and over average in work life and education. The huge problem of Asperger's is the lack of social skills. This lack develops over the

time and can not be seen in early stage of the childhood as their development in language and communication skills is the same than every other child's. Pervasive development disorder is the diagnose for people who can not be put in any other type of the ASD. They often show some signs of the classical autism but not all of them. The Childhood disintegrative disorder - short CDD or Heller's Syndrome, does not show in the first two years. Children develop normal till then. Out of the blue they drop in social behaviour and communication skills. Many times, parents think it is only a phase, but unfortunately, the symptoms stay and might even get deeper. The Rett's syndrome can only be diagnosed for girls. The disease shows a strong lack of communication as well as a limitation of how to use the hands. The Classical Autism has a huge range of symptoms from very mild to really deep autistic symptoms and restrictions. The brain of this people has a higher amount of impulses. Though, there are those five main diseases children can have symptoms from all of them and therefore, there is a high need for several therapies and support for the whole family. (Autismag 2014.)

2.3.5 Differences between an Autist and an Asperger

There are two huge skills, which an autist as well as an Asperger struggles with. Social communication and a small range of interests. The big difference between them is the Intelligence quotient. - IQ. Asperger's reach at least average and mostly even a high IQ, whereby the IQ of a classic autist can be anywhere. (Baron-Cohen 2008, 29-30.) Howley (2019) proves these differences, by also saying that a huge difference between Asperger's and Autists are the language development. Asperger children have no struggles with speech or language. However, they still lack the skills in sociality and behavior. Therefore. Asperger is seen as a mild form of autism. Asperger's are also seen as high intelligent, many genies might have been Asperger's, such as Albert Einstein and Isaac Newton. (Howlen 2019.)

2.3.6 Comorbidities

Almost one third of children with ASD have another disease on top of it. Those can appear any time even after many years. One of them is anxiety: shows symptoms such as hyperactivity worries, and fears and those people are often restless. Anxiety combined with Autism can be seen as continuously asking questions. They might hurt themselves and having problems with the sleep. Around 40 – 50 percentage of children with ASD have also Anxiety. The Anxiety can be treated with therapies and medication. Another comorbidity is the Attention Deficit Hyperactivity Disorder- short ADHD. Huge problems with sitting still,

thinking before actions and problems with the focus. The characteristics are similar to those of ASD so it is hard to say how many people also have an ADHD. The treatment is the use of specific medications and, or therapies for good behaviour. The bipolar disorder children have enormous emotional feelings. They are either very happy or very down and the change in between those can be very quick. The symptoms of the down is the same as a depression shows: no motivation, no appetite and sleeping problems. The symptoms for the happy moment, called mania, are not that obvious, less sleeping, talkative, huge self-system and strong activity. The bipolar disorder is not very common with young children. Treatment is usually made with medication. (Raisingchildren 2018.)

Clinical depressions are very often, especially for older children as they know they are different and have big troubles to accept their restrictions. The therapy is often a combination of medicine and psychological meetings. There are several other comorbidities such as Down-Syndrome and Fragile X Syndrome but the numbers are rather small. Children with ASD have more struggles with gastrointestinal symptoms, for instance constipation and diarrhoea, than others. About 40 % of children with ASD also have an intellectual disability with an IQ under 70. This also comes very often with a development delay. Most, 80 % of the children with ASD also have motor problems. Another common comorbidity is Epilepsy with a percentage of 30 of ASD children. Sleep problems are another illness that most of the ASD children go through. Just a small amount struggle with a Tourette Syndrome. (Raisingchildren 2018.)

2.3.7 Therapy of ASD

As mentioned above every Autist is different. Therefore, the therapy has to be chosen individually. However, there are common therapies for ASD children. The therapies for autism can be split in four different main categories, shown in Image 3 on the following page. The therapy might be a combination of all of them or just some of them, depending on the child's needs.



Image 3. Therapies for children with Autism. (Agency for Healthcare Research and Quality 2014)

Behavior programs concentrate on social competences as well as psychological matters such as ADHD or anxiety. The therapy can take place in day care or schools as well as at home. The Education and Learning Programs concentrate on development skills. Those therapies take place in an educational institution. Medications are mostly antipsychotics, but also medicine for depressions or digestions problems can be prescribed. Under other treatments belong all the therapies which do not belong under the other sectors. For instance, speech therapy, music therapy, riding therapy or sleep therapy. (Agency for Healthcare Research and Quality 2014.)

2.4 Travelling with an autistic child

Travelling with an autistic child can be very stressful for the whole family. For ASD children holidays can also be fun, but they might be causing fear and hard to understand for the child. However, holidays can be unforgettable memories even for ASD children. Vacations just have to be more planned. Starting with the right location a hectic place is not the right one and rather a calm beach holiday or camping should be considered as a vacation. Planning is everything. Some attractions are less crowded at sometimes. Another option is to travel off-season when there is no mass tourism. It also has to be considered how to get top the vacation. Airports can also cause a lot of stress and downgrades the comfortability as the child might even get touched by the security. Still, families with ASD children need a lot of nerves and have to stay calm even if others act not correct to their child. (Klein 2015, 17-20.) Especially security checks and the queuing at the airport causes stress for an autistic child. Travelling to an unknown destination might even cause a de-

pression for some ASD children. Spontaneous activities, which are a basic part of travelling, are frightening for those children. Public transportation is also a huge challenge for children with ASD. The travel industry started to give special attention for autists' needs. For instance, Ireland has an airport with a sensory room aimed for those people. It is a quiet area that makes it possible to avoid the hectic airport. (Flaherty & Neo 2018)

As mentioned before every autist is different. Therefore, their needs are also depending on individual preferences. However, there are still a lot of common issues which can be found in almost every autist. Figure 5 below shows the common problems from autists when it comes to travelling.



Figure 5. Challenges for Autistic Travellers (Hamed 2013, 4-5.)

Sensory demands are having a huge impact on autist. Most of the autists show a hyper sensibility towards senses. Some autists do not feel any pain and some need to be stimulated all the time in order to feel comfortable. When travelling people face a lot of senses which might be hard to handle for an autist and cause an attractive spate. Stereotyped or Repetitive behavior can also be typical for autists. For instance, moving the upper body front and back continuously, walking on tip toes or a permanent hand flutter. Others have a high interest in watching continuously movement such as a washing machine which is spinning around. This behavior might be even stronger during a vacation, as there are so many irritations. Changes in routine come automatically while travelling and are a huge

issue for autists. Autists need clear structured days with the same routines. (Hamed 2013, 4-5.)

Social Interaction and Inclusion Difficulties are a big problem as autists have troubles with social interaction. They often do not get what others want or express and also do not show themselves what they think. This strengthens the feeling to be alone because it is easier and might also make the repetitive behavior stronger than usually. Many Autists have troubles with sleeping in the night. These troubles could increase on a vacation, as they are under a lot more stress and irritations than usually and mostly lack the routines on top of it. Medical problems are caused by comorbidities which are mentioned above and need medicine treatment. Depending which illness comes on top of the autism it might cause challenges when travelling. Communication challenges can be verbal or non-verbal. Lacking communications skills is a big problem. Autists can not clearly say or show what they like and dislike. This causes frustration for the autist as well as for the person trying to communicate with them. Autists communicate a lot better with visual tools and technology devices. The use of technology while travelling can make it easier for the autist and people travelling with the autist. (Hamed 2013, 4-5.)

There are some destinations having certificates for how to handle ASD guests. Flights should be not too long especially if it is the first time the child flies. It is also wise to include the child in the planning process. That might prepare them for the vacation. Images and flyers of the destination, hotel, beach, attractions and so on will help to prepare the child and will not surprise them. Routines are important for these children and a structure of the day should be kept as much as possible. The National Autistic Society offers some stories about different situations coming up during a vacation. For instance, airport simulation or virtual hotel tour. Another important step is to talk open to the child and let them ask any concerns they are having about the trip. Many travel providers are able to even give a special service when travelling with an autistic child. They should be contacted beforehand and might even suggest special check-in times to avoid the rush or priority boarding. London airline offers a visual guide especially for ASD people. It also offers a quiet area. Some airports in the US, Washington Dulles, Philadelphia International, Atlanta and Boston Logan let family come before the actual flight to familiarize with the airport. (Alternative Airlines 2019.)

Another tool making travelling easier is to create some fact cards about Autism which can be handed to any person or provider. Some airports in the US and UK hand out a discrete sign for special service required people. British airways recently received an Autism

friendly award. The price was given by the National Autism Society. British airway makes seamless travel possible for ASD people and trains the whole staff in this matter. They offer special services when contacted latest 48 hours before the flight. They offer special seats or personal safety guidance. (Alternative Airlines 2019.)

There is a website available called Autismtravel, which is mechanized by the International Board of Credentialing and Continuing Education Standards – short IBCCES. The organization offers trainings and certificates. They are cooperating with the Autism Society to provide better awareness about locations trained to handle autism and make the vacation more enjoyable for families with an ASD child. Certificated locations are used to handle autism children and families will not have to feel afraid on the behavior of their child. (Autismtravel 2019a) Several hotels and even cities which received those certificates are listed as shown in Image 4 below (Autismtravel 2019b.)

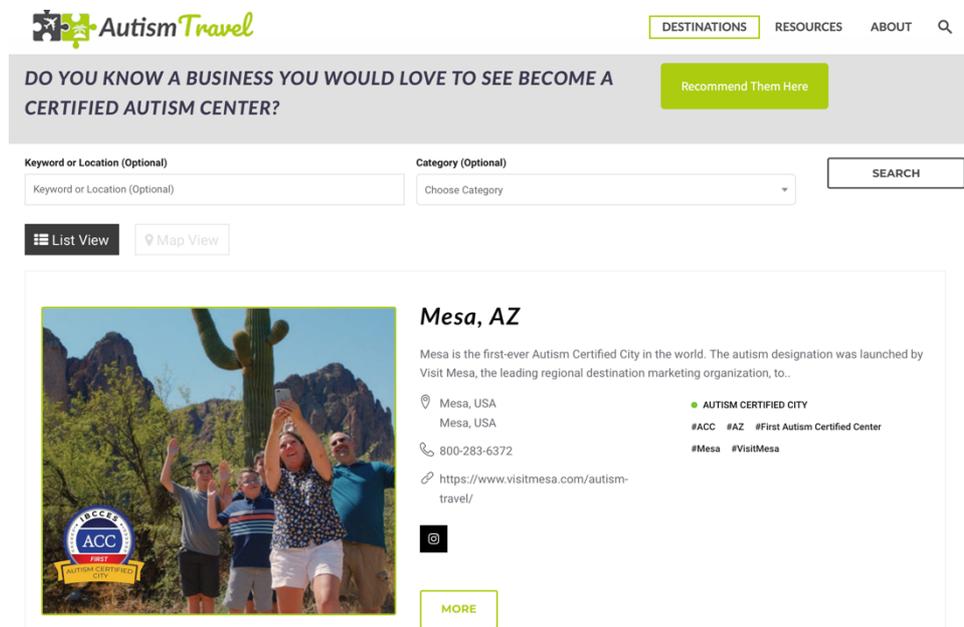


Image 4. Screenshot List of certificated locations. (Autismtravel 2019b)

2.5 Holiday planning for people with accessibility needs

There has to be paid special attention to the customer journey for people with a disability. Also ASD is a disability, even if it can not necessary be seen from outside. The customer journey includes 3 different stages: planning process, transportation and being at the destination. The customer journey in travelling starts with the first thought of taking a vacation. Table 3 on the following page visualizes those main stages including the several steps from each of them. (Amadeus 2019.)

Table 3. Customer journey for travelling (Amadeus 2019)

Planning process	Transportation	Being at the destination
Thinking of a vacation	Transfer from home and back home	Accommodation
Research	Plane, train, bus, car	Excursions
Choice of destination, transportation and accommodation	Transfer to the accommodation and back	Attractions
Booking the destination, transportation and accommodation		Going out

Most of the planning process is done online, but in accessible tourism there is a challenge. Many websites do not have enough information for special needs and therefore, a contact person is needed. This makes the whole planning process already stressful. It makes it more complicated or even more expensive as some special offers are only available by booking it online. People with special needs might also face troubles with the online check-in for flights. It is not always visible which seats are suitable and again they have to call to customer service, which costs money. Assistance points are rather hard to find in the airport, due to a lack of signs. There is also a limited number of places to sit down and take it easy. Also train stations and car rental providers lack of signs and assistance for those with special needs. Once people are at the location, many face struggles with staff members, who are not trained for accessible tourism. Therefore, the planning point is important for choosing the right accommodation. However, even if a destination is marked as accessible, the truth might be different. Finally, at the hotel, people also want to go out and see something of the destination. Again, a lot of research needs to be done to find accessible attractions and places because unfortunately, not all of them are. (Amadeus 2019, 9-14.)

Most reported problems during the last trip

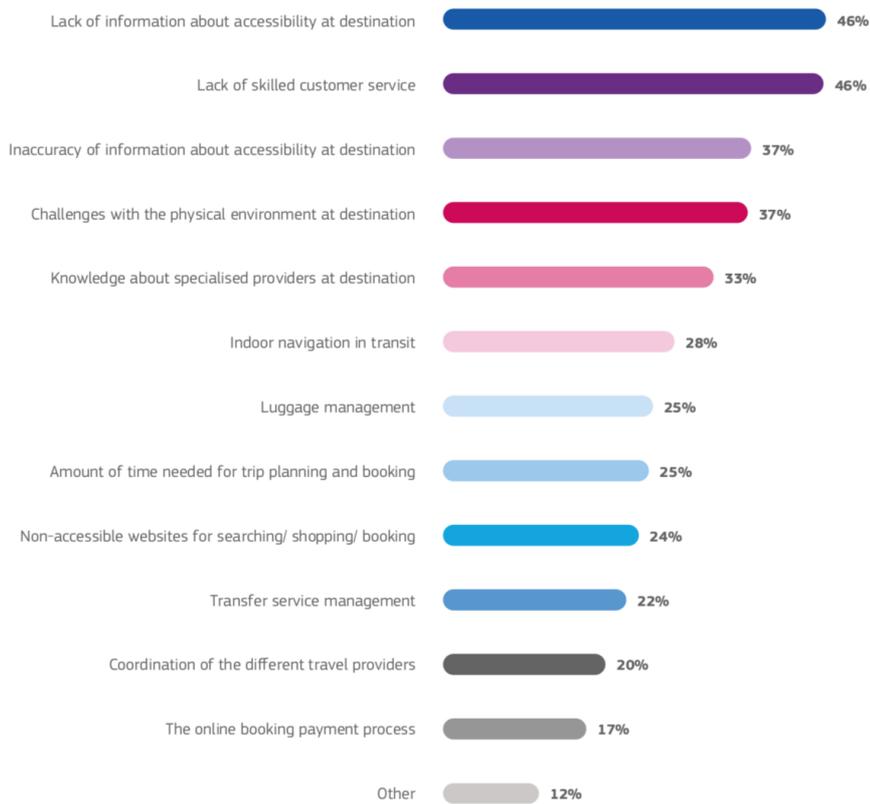


Figure 6. Screenshot Amadeus report Voyage of discovery. Most reported problems during the last trip. (Amadeus 2019)

People with disability face many problems while taking a vacation. Figure 6 above shows the possible pains from people with disabilities. There is clearly a need for development to improve in accessible tourism, but a change has already started. (Amadeus 2019, 15.)

To give a better picture of the issues for people with disabilities, consumer behaviour has been taken under consideration. Consumer behaviour in travel behaviour includes many steps. Several researches have described different steps, some have researched the concepts, some the influences and others the research contexts. Cohen, Moital & Prayag (2014) have made a concept based on these researches which combines all of these steps and applied it to a specific travel concept. This concept is divided into Pre-visit, On-site and Post-visit. (Figure 7)

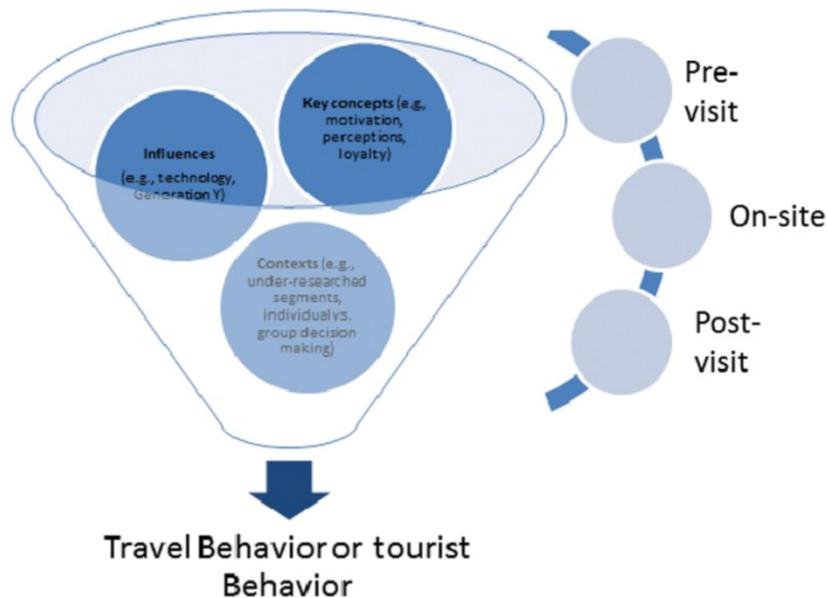


Figure 7. Conceptual model of link between concepts, influences and research contexts. (Cohen, Moital & Prayag 2013, 873.)

The key concepts include different aspects for instance, the decision-making process, values, motivations, expectations, personality, satisfaction, loyalty and trust. Understanding these concepts is important for the success of the marketing. External influences cover technology aspects such as social media. People's decision and planning process is influenced by technology. Different generations act in a different way and show similar behavior when it comes to travelling. The last point in the model are the concepts. This point concentrates on researches which have been done. It is divided in individuals and group decision making because studies show there is a difference in making a decision. In group decisions their key concepts might still be different and influenced by others. One research segment which goes under this, is also the behavior of disabled people. Autism goes under this point. Families with an Asperger's child are automatically influenced by the disability of their child. This one child affects the decision-making process of the whole family and expectations might differ in the family. Or they have to slow their wishes down due to the lack of accessible tourism offers. Researchers agree, that there is a need for more accessible tourism. (Cohen, Moital & Prayag 2013, 873-896.)

3 Research methods

This part of the thesis describes the research methods and why they have been chosen for the topic. The qualitative research method is described and compared to the quantitative research method. Further, the theme interview is explained, and a figure of the chosen themes can be found. The data collection is described as well as the reliability and validity.

3.1 Qualitative research

Qualitative research is a mechanism of lifelike inquiry that searches in deep understanding of some social phenomena within its natural settings. It targets the question “why” rather than “what”. Qualitative research builds its focus on direct experiences of human beings. (Cresswell 1998, 82-84)

As mentioned above qualitative research focuses on understanding and this is why it is often categorized as humanistic or idealistic approach. Qualitative method is based on understanding examinees beliefs, attitudes, experiences, behaviour or interactions. Qualitative research has given the opportunity to generate non-numerical data. It has added a totally new dimension to research objects that can not be measured with numbers. Qualitative research gives voice to the participants of the study. There are also big differences with data collection between qualitative and quantitative research. Qualitative research data is often collected by interviews, observations and documents whereas quantitative research data is collected by surveys, tests, scales or inventories. (Gibson & Timlin 2004)

As said qualitative approach to a research seeks for a deeper understanding and with theme of travelling with a kid who has characteristics from the autism spectrum it is all about understanding how they behave, what do they need and what are the feelings they are going through. These mentioned things can not be measured with numerical data that quantitative research focuses more on. Table 4, on the following page, represents the main differences between qualitative and quantitative research.

Table 4. Screenshot of differences between qualitative and quantitative research. (Research gate 2019)

	Qualitative Research	Quantitative Research
Focus	Quality (features)	Quantity (how much, numbers)
Philosophy	Phenomenology	Positivism
Method	Ethnography/Observation	Experiments/Correlation
Goal	Understand, meaning	Prediction, test hypothesis
Design	Flexible, emerging	Structured, predetermined
Sample	Small, purposeful	Large, random, representation
Data Collection	Interviews, observation, documents and artefacts	Questionnaire, scales, tests, inventories
Analysis	Inductive (by the researcher)	Deductive (by statistical methods)
Findings	Comprehensive, description detailed, holistic	Precise, numerical

Qualitative and quantitative research methods are said to represent two different worlds. Qualitative research is frequently viewed with scepticism and considered not so trustworthy because it most of the times involves small samples which does not represent required part of the population. Results of a qualitative research are often seen as tendentious or biased by the researchers' own assumptions or attitudes. Most simply put quantitative research focuses on measurements and numbers while quantitative research gives attention to understanding the research subject and words that come out of it.

(Hammarberg & Kirkman & de Lacey 2016) Qualitative research will be conducted in travelling with an Asperger child because deeper understanding of problems travelling with special needs is required.

3.2 Theme interviews

The theme interview can be used for getting a better understanding about a specific topic. Important is, that all individuals have the same experiences or going through the same topic. (Hirsjävi & Hurme 2008, 47). As the name says, different themes are chosen which will be discussed in the interview. Great insights and good results can be achieved about the unknown topic. That is the reason the theme interview has been chosen to achieve insights from parents with an Asperger's child. The theme interview is an often-used method for the qualitative research. The interview can be done individually or in a group. Though, in a group interview people might be influenced by other and some might not open completely.

As the topic is a very emotional and sensitive the chosen kind of interview is the individual interview and no group interview. The goal of the theme interview is to get a picture from different angles about a phenomenon. Each theme starts with some general questions and ends in depth. After this the next theme can be discussed the same way. Important for the theme interview is, that no questions are prepared, and the interviewer will only stick to the different themes. The different themes will give a lot of understanding of the topic and cannot be put down with short answers. The theme interview has two stages: the themes and the interview. The themes cannot be sent via message and requires an interview. (Kananen 2013, 110-115)

The interview guide, which can be found in the Appendix 1, in this study comprised the following themes (Figure X below). The themes were divided into Planning a vacation, Travelling, Being at the vacation and back home after a vacation. 8 different mothers with an Asperger's child have been interviewed. The origin did not matter for this research. Important was, that those families have been travelling internationally to a vacation by a plane. Figure 8 below shows the information of the Interviewees.

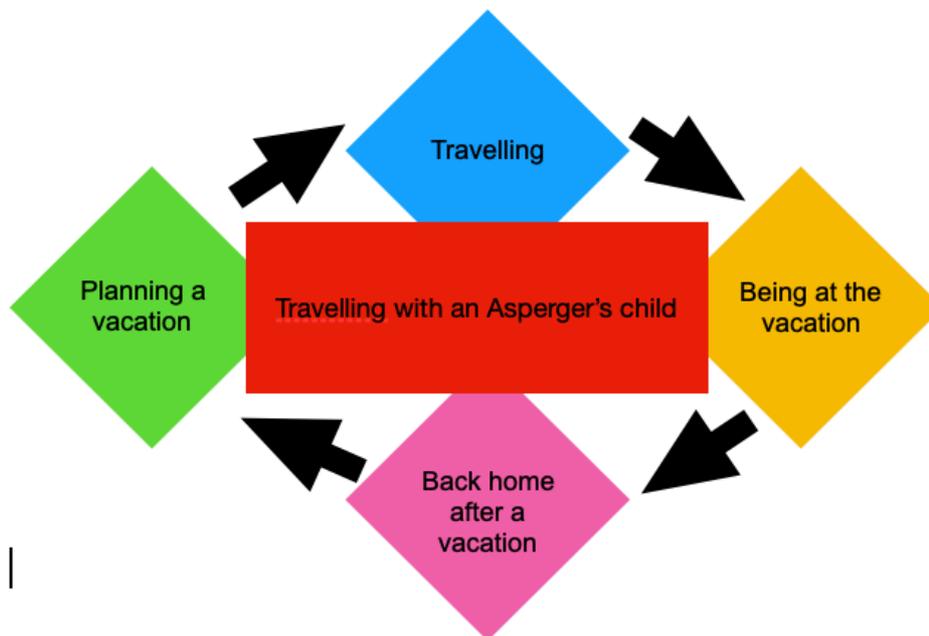


Figure 8. Theme interviews. (Kananen 2013, 109.)

3.3 Data Collection

Data collection is a mechanism of assembling, measuring and analysing information of targeted topic. Accurate insights can be gathered with variable, but validated techniques.

Data can be collected for example by observing people, choosing a focus group that is being followed during the research, surveys or interviews that are chosen in the research of travelling with an Asperger child. (Lotame 2019) A research can evaluate a hypothesis of the research subject on the basis of data collection. Data collection is said to be the most important step for the research because that is part where theory can be proved to be right and answers for the research question are revealed, which the whole point of making researches. (Northern Illinois university 2019.)

There are multiple ways to collect data. Researchers can collect data for instance with mail, phone, online or in-person interviews. Each one of these methods have their own pros and cons. Mail is easy and reachable but on the other hand to receive answers can take a while and it might be that researcher can not be understood in a correct way. Phone surveys which were conducted in the travelling with an Asperger child- thesis are also very reachable, but faster than mails. It is also examined that phone interviews are better than mails because the interviewee can not think of answers and this way, they are more genuine and trustable. Cons for the phone interviews can be that they might become expensive if you have many of them.

Online interviews are a lowkey options since the sampling is easy in online. It is also cheap to do online interviews. Problem with online data collection is that all the interviews must be done according to general data protection regulation also known as GDPR. It is a European Union regulation that regulates how personal data should be handled. Another issue with online interviews can be that interviewees do not want to reveal delicate information which information of an Asperger child can be classified as. In-person interviews are most of the times the best option, but it can be very time consuming and with topic such as Asperger kids sampling can be difficult since it is not something most of the population has experienced. (Bhat 2019)

Table 5. Interviewees base information

Gender	Nationality	Number of children	When interviewed	Type of interview	Code
Female	German	3	1.12.2019	WhatsApp Call	F1
Female	German	2	2.12.2019	WhatsApp Call	F2

Female	German	2	2.12.2019	WhatsApp Call	F3
Female	Finnish	2	2.12.2019	Skype Call	F4
Female	Finnish	3	3.12.2019	Phone Call	F5
Female	Finnish	2	4.12.2019	Phone Call	F6
Female	German	3	16.12.2019	WhatsApp Call	F7
Female	Finnish	2	16.12.2019	Phone Call	F8

In the table above (Table 5) is gathered all the relevant base information of the people interviewed. All the interviewed people were females and nationalities divided half between Finland Germany. Interviewees number of kids varied between 2-3. Interviews took place in December 2019 and they were conducted by different calls such as old school phone calls and alternative option WhatsApp calls. WhatsApp calls were made in the app platform that works in a same ways as normal phone calls but instead of using your call time it uses wifi connection or internet data connection to conduct the calls. Interviewees are coded in the last column and codes are used later in the data analysis section. The interviewees have been allocated a code to make the analyzation easier and more structured.

Interviewees were searched from different Facebook groups that afford peer support for parents of Asperger kids. With their approval interviews were done in the phone. No records were done during the interviews. Notes have been taken and a summary has been made straight away after the call.

3.4 Reliability and Validity

When evaluating the quality of a research can reliability and validity concepts come up. With reliability and validity can researcher indicate how accurately the chosen method measured something. Reliability is often referred as the consistency of a measure, when validity is referred as the accuracy of a measure. If it is possible to accomplish the same result routinely by using the same methods and the same circumstances, the measurement can be considered as reliable. If research reaches the high validity it means that it gives results that correlate to real characteristics and variations. With quantitative method it is considered crucial to acknowledge reliability and validity since there is no numbers

that indicate the result straight. Table 6 below shows the differences between validity and reliability. (Middleton 2019)

Table 6. Differences between validity and reliability

Questions	Validity	Reliability
What does it give to you?	An answer if the results measure what they are supposed to measure	An answer how many of the results can be reproduced if done under a same circumstance
How is it determined?	Checking how the results fit together with the already existing theory of the subject	Checking the consistency of results
How are they similar?	A valid research is often reliable. If the research gives accurate results it should be reproducible as well	A reliable results are not always valid. The results might be reproducible but that does not mean that the answers are correct

Reliability and validity go hand in hand in many things, but they mean different things. Can a measurement be reliable without being valid? Yes, but if a measurement is valid, it is most of the time also reliable.

Reliability can be estimated for instance by comparing different interview answers of the same questions. Does the same thing come up with different people? Validity can be examined by for example comparing the results to the relevant theory collected beforehand. (Research Methodology 2019.)

Reliability can be measured in the thesis by comparing the interview results. Same answers come up from different participants which can be linked to tables part if results can be reproduced under same circumstances. Validity of the thesis research can be proofed with the fact that interview answers can be linked into the existing theories in the beginning of the thesis. Receiving answers that are relevant and give usable answers the questions show some validity as well.

When comparing similarities and proofing the validity it is visible that certain things come up in the already existing theory as well as in the research interviews. For instance, attitu-

dinal barriers which are discussed in the 2.2.2. barriers to travel chapter reflects the correlation. Attitudinal change is all about changing the public awareness of accessible tourism and in many of the interviews it came up that they received judgmental looks that bother their trip and parents wish that people would know better that it is not always about bad behavior. Clear connection can be discovered also in the physical accessibility for Asperger's children chapter where they mention, that physical stuff for Asperger's kid can mean using for example earplugs or headphones which is also mentioned in the interviews that their kids use these during flights.

Comorbidities subchapter lists symptoms that ASD kids might have such as restless and fears that both are discovered in the interview results as well. All of these work as a validity and reliability evidence for the thesis. Saturation of the data collection is received in the thesis. Data saturation mean that researchers can assume that doing more or another data collection would still give similar results. (Bowen 2008)

4 Data Analysis

This research investigated the experiences of families who have been travelling with their Asperger's child. One requirement was that the family has been travelling internationally by plane. The research concentrates on four main themes: Planning a vacation, travelling, being at the destination and being back home after a vacation. (Figure 8 above)

4.1 Planning a vacation

When it comes to the planning of a vacation half of the families book their trip online and few families have a look for cheap offers. Three out of eight families only book all-inclusive hotels and mostly package holidays. There should be activities nearby the hotel say half of the interviewed families. A bit over half of the interviewed families said they are preparing the child for the vacation. Talking a lot about it, showing some images, making visualizations in head, or watching videos. The respondents gave the following comments related to the planning phase of a vacation:

"We only book all inclusive." (F3)

"Planning a vacation requires an all-inclusive hotel and mostly package holidays."
(F6)

"All inclusive makes a vacation easier for us." (F7)

"We need activities close by as our child is really active and likes to walk, rather than taking a bus." (F3)

"Activities have to be easy to reach by a walk." (F7)

"It is a lot easier if everything is nearby and we do not have to wander around the city." (F6)

"We want to make our son excited for the vacation and show him pictures and videos of the destination." (F3)

"We include our child in the planning and show him where we want to go." (F2)

“Already when we plan a vacation, we include our child. It makes it easier for him and we do not want to exclude him.” (F7)

The parents do not take care of special arrangements, except the priority boarding service. Half of the interviewed families books this extra service to make the vacation less stressful for the child. This service offers the families to be the first ones when boarding and the last ones when going off the plane. Meaning that the family does not have to queue with many other people. As mentioned in the literature research Asperger’s lack the social competences and queueing is very difficult for them. The respondents said for instance the following:

“Since we know about the option of booking the priority-boarding we only fly this way.” (F1)

“One thing worth of mentioned we have most of the times taken the priority boarding because we have the chance for it from my husband’s workplace and maybe that have helped us” (F8)

“After we had some terrible experiences and mental breakdowns due to waiting for the boarding, we only book priority boarding.” (F3)

“We book priority boarding because our child can get so called “tempre tantrums” and start crying.” (F6)

“Priority boarding makes travelling by plane easier for us.” (F7)

Another very important thing is the packing. Five out of eight families said that their child needs a specific toy or blanket with them. Other important items for three out of eight families are: headphones especially on the plane it helps the child to cut of irritating noises. The interviewees said following about the packing stage:

“Our son needs his own sleep gauze as well as his favorite stuff animals.” (F6)

“He needs his wristband to chew on it, a calendar to see what happens on certain days and different sort of toys to relieve stress.” (F4)

“He needs his blanket everywhere; it is a piece of home.” (F7)

“We have special headphones to cut off noises.” (F3)

“We use headphones on the flight to make it easier for him.” (F7)

As every Asperger’s child is different there also have been points which only one family mentioned. One family only flies off season to avoid mass tourism and, in the night-time, that the child can sleep on the plane. The same family only books accommodations without pool due to security reasons and prefers to rent a house. Though, F3 also mentioned they had bad experiences with the child dropping in the pool. Some Asperger’s do not feel fear or can not judge the situation right. The respondents mentioned for instance:

“We only fly at off season times to avoid mass tourism.” (F1)

“Once my husband had to fish him from the pool with all his clothes on.” (F3)

F4 said that they can not tell the boy beforehand that they are going on vacation. Their son can not wait for things and would ask all the time when they are leaving.

“We can not tell him that we are going on a trip because he can not wait for things and it would make life difficult for everybody.” (F4)

F6 said that for their child it is very important to know that his brother will go with them to the vacation. The parents have to confirm many times that his brother is coming with them. She said:

“His brother is very important for him and we have to tell him many times that he comes with us.”

F1 said that they are taking a lot of short trips during the year to make travelling easier for the child. They put the child into rush hours and stress situations. They use the train a lot. F1 told:

“We often put him into stress situations, so that he can handle stressful situations when they appear. For instance, we are taking the train in rush hours.” (F1)

4.2 Travelling

Majority of the interviewed families consider the “physical” travelling part as the hardest one. Most of the issues of the whole trip appear at the airport. Stressful and restless were adjectives that came up in every single interview, mainly in the actual travelling part, meaning the airport in this case. Keeping the kids busy with different kind of activities was also something that the majority of the interviewed moms mentioned as one of the key factors. The respondents said for instance following, when it comes to the actual travelling:

“During the trip the most difficult part is the actual travelling part” (F4)

“The actual travelling is always stressful.” (F7)

Every interviewed family mentioned that the biggest challenge is queuing. Waiting for something is a problem that causes chain reaction of restless behaviour five out of eight families continue. Half of the families also confirm that their Asperger kid needs to be watched over at all times and should have some sort of activities going on. The interviewees said for instance:

“We need to be with the boy all the time since he is so energetic and moves all the time” (F4)

“Already mentioned books that she wants to pack help at the airport. She is “reading” them with her sister” (F8)

“At the airport it is crucial to keep the kid busy with different kind of irritations such as games, videos and other stuff” (F6)

“Waiting and queuing is the worst for him, and he starts to flip out.” (F7)

“Brothers play with a stuffed animal and entertain each other” (F6)

“We can not take our eyes from him.” (F7)

Security check was the most stressful place according to five out of eight families. Security check is probably the biggest time consumer at the airport and this way can easily be linked to the problem of queuing. Another issue with security check according to several moms was that their Asperger kid does not want to be touched by strange people and this

causes some aggressive behaviour. Aggressive behaviour in different forms popped up as well. Shouting, crying, hitting, rolling on the floor and other restless behaviour was mentioned by every family interviewed. Four out of eight families said that they have received some “judgemental” looks by the other travellers when their kid is acting out. The respondents said:

“Many people look at us for example when the boy is rolling on the floor or making noises” (F4)

“Metal detector alarmed on him and he panicked and got hysteric” (F5)

“The security check is the most stressful at the airport. The child does not want to wait, take off his jacket or shoes and does not want to walk alone through the security check. He also, does not want strangers to come too close to him” (F3)

“The child does not want to get touched by the security staff. He hits them or pushes them away” (F1)

“We hate security checks. He can not take it.” (F7)

Another time-consuming part is queuing to the airplane and for this reason half of the families book priority checking to get in the airplane first and one of the mums tells that this would have been a really useful but have not used the service yet. The interviewees mentioned for instance:

“We always book priority checking to get to the airplane first because queuing is difficult for us because my kid can get so called “tempre tantrums” and start crying, shouting and getting really restless” (F6)

“It would have been a huge help to get in the plane before the others, because the boy is restless, and queuing is difficult for him” (F4)

As mentioned in the planning part almost every family packs some toys, blankets or something that is familiar to the kid. These items become important at the airport or in the airplane. These items were only mentioned in the packing phase and then in the travelling phase, which indicates that they are crucial for the actual travelling. Few families said that their kid sleeps in the airplane while the others mentioned the toys, headphones or blankets help in the plane. The respondents mentioned for example:

“It is important to take the favourite cuddle blanket for the child with them to the plane” (F1)

“She gets to choose 3 most important things that she wants to pack with her” (F8)

“She mostly wants to pack books. I pack for her sleeping blanket. We have experienced that her taking part into packing process has relieved her stress during the trip” (F8)

4.3 Being at the destination

Being at the destination is also challenging. Three out of eight families reported their child needs a lot of activities and likes to walk. Also, half of the families said that the evenings can be hard if there is too much irritation during the day or late evening. The interviewees said for instance:

“It is important to have a lot of activities. We can not just lay on the beach the whole day. He is very active and needs a lot of movement. He likes to walk.” (F1)

“He likes long walks and boats. He needs action and activities.” (F3)

“We have to keep him busy all the time.” (F7)

“We avoid crowded places and irritation in the evenings. Otherwise he would have troubles to fall asleep” (F1)

“He is very uncalm in the evening if we do a lot during the days.” (F2)

“If he had a stressful day he rages in the evening.” (F7)

The child is hanging a lot on the parents and wants to be very close to them say three out of eight families. Those three families said:

“He wants to be with us all the time and takes care we are close to him.” (F1)

“He is only hanging on my arm. He also sleeps next to me in the bed.”(F2)

“He needs us all the time close by.” (F7)

Third part of the interviewed families explained they are only doing activities close by because it is easier not to travel. Whereas one family told public transportation is not a problem. Two families also said the boy would need to know each and every detail and it is easier to do something spontaneous and close by. The respondents said for instance:

“We only do activities which are close by. He does not like to travel a long time.”
(F2)

“We do not use any public transportation and the activities have to be close by.” (F5)

“We try to do activities which can be reached by a walk.” (F3)

“We do a lot of activities in the hotel area. All-inclusive has a lot to offer.” (F6)

“We do activities close by and spontaneous. Otherwise he wants to know every detail about transportation and travelling.” (F4)

“Public transportation is not a problem we practice it a lot at home.” (F1)

Three out of eight families told their child throws himself a few times on the floor if the situation is too stressful. Those three families said:

“He might throw himself on the floor a couple of times.” (F1)

“He likes to throw himself on the floor and screams if it is too much for him.” (F3)

“He rages several times.” (F7)

Over a half of the families said that pools are really dangerous for their child as they can not see or know about any danger. Those interviewees said for example:

“We do not book places with pools due to the safety of our boy.” (F1)

“Once my husband had to fish our son from the pool with all his clothes on. It is really dangerous at the pool area. We have to keep an eye on him all the time.” (F3)

“Our boy has to get watched all the time especially near the water.” (F6)

“He needs to be watched all the time. Safety is a big issue and he moves fast.” (F4)

“We have to keep our eyes on him 24/7.” (F7)

There are also individual experiences which were only reported by one family. Though many people said during their interview that others do not have much understanding for the illness. F1 and F6 said the following:

“We are used to people judging us or reacting weird to his behavior.” (F1)

“It helps to go to the same place many times. The children call it as their second home.” (F6)

4.4 Back home

Half of the interviewed families said that their child acts completely normal again back home and has no troubles to find back to his routines. The other half said their child needs some time to get back to routines. The child might act a little different than usually. For the third of the families it is important to explain the child how things work at home. The respondents said for instance the following:

“We explain our child that now we are home again, and things work different at home. He recovers quickly. We also tell him we will visit there again and dream about the holiday together.” (F6)

“Back home he is totally fine, no problems. He is happy to have all his toys back. He wants to go swimming every day like we did in the holiday. It is always stressful to be at a vacation, but it gives so much more than it takes.” (F3)

“We do not have troubles back home; he likes to be home as long as he can travel daily by train.” (F1)

“When coming home from a journey we want to get back to the ”lost” routines asap” (F8)

“No problems being back home. He acts like nothing ever happened.” (F7)

“At home he does not always know how to react and might be a bit restless.” (F5)

“Our boy needs a couple of days to relax and have own peace. In a way life starts from the beginning, he might not remember how things work at home. It is important to specify that now we are back home, and this is how things work at home.” (F3)

“At home he needs a couple of days to be himself again and does not want to talk to us for a short period. T is very stressful for me to go on vacation. I am very tired and frustrated, but I like to travel and do not want to give up on it.” (F2)

4.5 Recommendations

First of all, it is important to mention, that every Asperger’s child is different in a way and might have individual needs. Those recommendations are made based on similarities from intensive interviews, which have been made for this research paper. The recommendations will help a lot of families and have great suggestions for future vacations for families with an Asperger’s child.

The authors applied the Cohen, Moital & Prayag (2013) model, which can be found earlier in this paper to give recommendations to families travelling with an Asperger’s child. Figure 9 on the following page visualizes those.

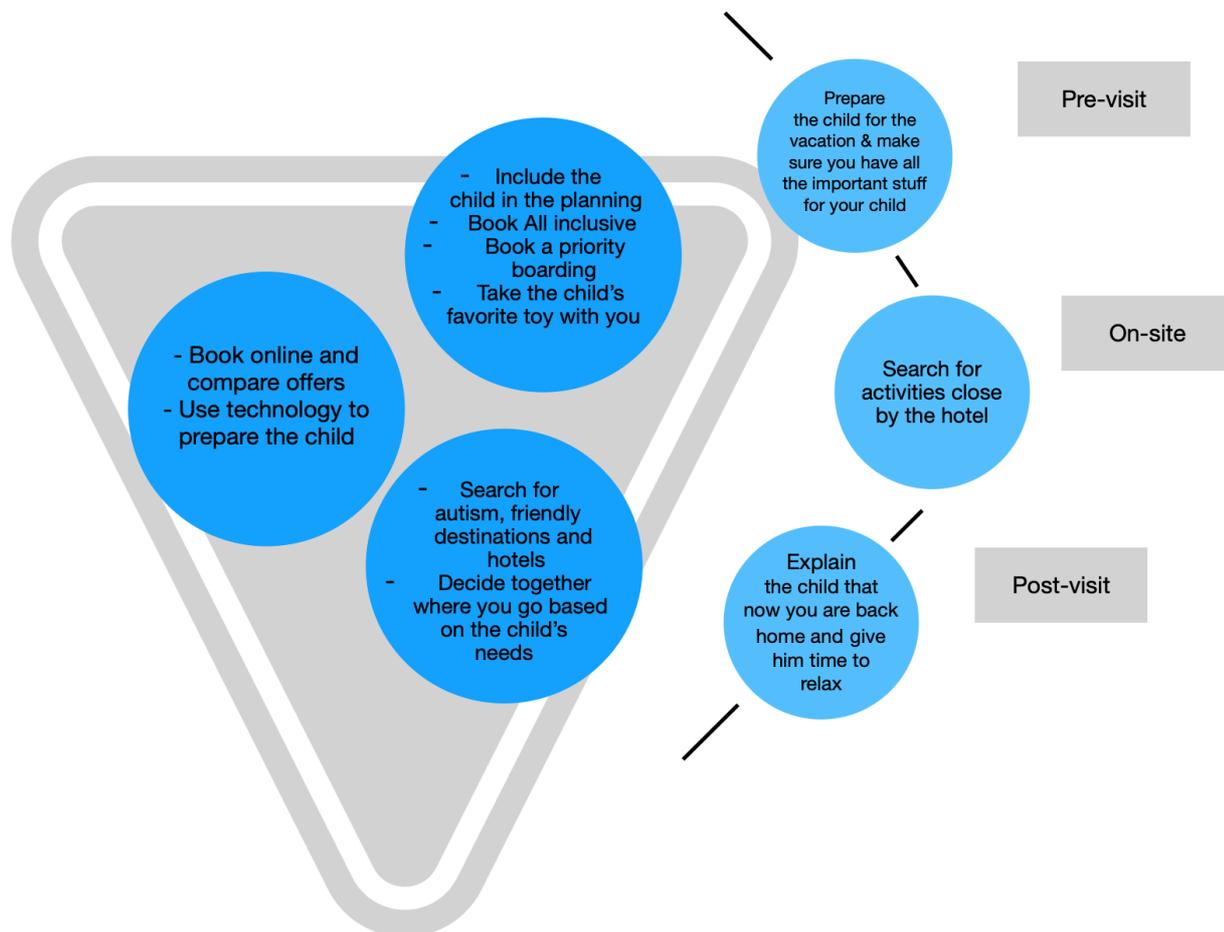


Figure 9. Recommendations applied to the Cohen, Moital & Prayag model (Cohen, Moital & Prayag 2013)

Planning a vacation

Planning a vacation carefully is important for families with an Asperger's child. The child should be included in the planning and prepared by talking about the trip and using several technology tools, such as videos and pictures. A great stress releaser is the priority boarding, which can be booked beforehand by contacting the airline. When packing for the holiday, the most important things for the child should be taken with them. For instance, the favourite stuffed toy, blanket, Legos or whatever is necessary for the child to feel safe. Headphones make the flight more relaxed as irritating noises can be shut down. It might help to book a vacation at off-season, if arrangeable for the family.

Travelling

This is usually the hardest part, but also for the travelling there are suggestions which might help to increase the stress. There should be always one person watching the child the whole time, talking to him and use tools such as books or phones to redirect the child's attention. The child can be prepared for the security check by showing videos or even playing some role game at home to let him know what to expect when it comes to

the actual travelling stage. As mentioned above, the pre-booked priority service helps to make the boarding as stress-free as possible for the child without queuing with many strangers. The earlier mentioned toys and headphones can also help to make the child feel safe and the child might even sleep during the flight. It might also help to tell staff at the airport that the child is an autistic, most workers are trained and can react with more understanding and adapt if they know about the illness. Some airports offer small stickers for those children, to get recognized by the staff.

Being at the destination

Autists are often restless and therefore, activities can help to keep the child entertained. Those activities should be close by the accommodation and easy to reach by a walk. This makes it possible to avoid public transportations which is again stressful for an Asperger's child. It helps a lot to avoid too much irritation during the day to have a more relaxed evening and that the child can easily fall asleep. The child should be watched all the time to guarantee his safety because many Asperger's children do not see or evaluate danger.

Back home

Give the child some time to relax and explain that now you are back home and how things work at home. Keep the same routines as before the vacation. Have understanding for different behaviour, they will go away after some time.

5 Conclusion

The aim of the research was to give recommendations and advice for families with an Asperger's child and how to prepare the child for a stress-free and memorable vacation. Intensive research has been done to reach a great understanding of this phenomena. Inclusive tourism and accessible tourism have been defined and described. The Autism Spectrum is explained in detail and some existing studies of travelling with an autistic child are mentioned. The qualitative research method has been chosen and theme interview was the right tool to receive as much information as possible from the interviewees.

Eight families with an Asperger's child have been interviewed intensively through video chats or phone calls. Similarities clearly showed up and just a few dissimilarities came up. Planning a vacation is the first theme of the interview and over 60% of the families include and prepare their child in the planning process and showing images or videos to their kid. But one mother pointed out she can not tell her child beforehand because he can not wait and would ask all the time questions. Half of the families book their trip online. 3/8 families only book all-inclusive hotels. There should be activities close by the accommodation say 4 out of 8 families. The priority boarding is a nice stress releaser for those families and half of the interviewees make use of this service. 5/8 families said their child needs a specific toy with them. Also, 3/8 families said they are using headphones on the plane to cut off irritating noises. Only one family said they only go on a vacation off-season to avoid mass tourism. The actual travelling is the hardest part for the families. 8 out of 8 mothers mentioned that the queuing is the hardest part and half of the families said their child has to be watched all the time at the airport. For 5/8 mothers the security check is challenging and stressful. Half of the interviewees experienced judging looks from strangers. As mentioned earlier half of the families make usage of the priority boarding to avoid stress when it comes to boarding.

Being at the destination can also be stressful. Almost half of the families said their child needs a lot of activities and 6/8 said those should be close by the accommodation. 4/8 mothers avoid too much irritation to make the evening easier. 5 out of 8 said their child has to be watched all the time to make sure the kid is safe. Only one mother said they are always going to the same hotel to make it easier for her child to adapt at the vacation. Half of the interviewees said their child has no troubles being back home. The other half said the child needs some time and might act weird a couple of days. For 3/8 families it is important to explain the child, now they are back home and how things work at home.

Recommendations have been given based on the interviews. The most important ones are before the vacation to prepare the child by showing images and videos of the destination, accommodation, activities and more. There are autism friendly destinations and hotels which can make the whole vacation a lot easier. Parents should make sure to have the favourite toys with them and headphones to make the flight easier. All-inclusive might help to have a more stress-free holiday. Priority boarding allows a relaxed boarding at the airport without queuing. Online booking is the cheapest, but some service might need a phone call on top of it. On-site families should search for a lot of activities which are close by the hotel and reachable by a short walk. In the post-visit stage explain the child you are back home, how the routines are at home and stick to them. The child should be given time to relax and process the holiday for themselves.

Learning process

The learning process discusses the reflection on the researchers own learnings. The process of a thesis is time consuming and it is definitely important to make a plan and a schedule for the whole process and most importantly stick to it. It was hard to estimate how much time is required for producing certain things such as theory frame or the interviews. Time frame could have been stricter to keep the flow on and not to lose the learned information. However, the authors improved in their time management skills as well as multitasking by working on the thesis while having a full- time job.

Conducting the interviews in everyone's mother tongue was a challenge since some of the phrases used in the interviews were difficult to translate and sometimes there was not even a corresponding translation. This might have caused some misunderstandings as well. Another demanding task was with the unstructured interviews. It was sometimes hard to keep the conversation on and get answers without leading the interviewee to give certain answers. Authors improved written communication skills. Especially forming a dialogue between the topics and chapters and applying the theory part to the data analysis. It required logical thinking and writing skills. Academic writing has become more familiar to the authors and separating trustful sources from the quality less ones has improved.

Obviously, gathered information has taught a lot of the examined subjects such as autism, Asperger's syndrome, tourism for all, accessible tourism and everything between those. This is a growing theme in the tourism field and will help the authors in their future tourism careers. Also, the authors will have a better understanding and tolerance for disabled travellers and their families.

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Appendices

Appendix 1. Theme interview

Theme interview <ul style="list-style-type: none">– Basic information: gender, nationality, the number of children
Planning the vacation <ul style="list-style-type: none">– booking– research
Tarvelling <ul style="list-style-type: none">– At the airport– Security checks– Boarding– Flying– Transfer to the hotel
At the vacation <ul style="list-style-type: none">– hotel– activities– Free time– sleeping– eating– behaviour
Back home <ul style="list-style-type: none">– Routines– Issues– Different behaviour