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“Eliminating Social Exclusion” (EliSE)  
Nr. 2019-1-LV01-KA204-060427

# Intellectual Output 1 Report

## ANNEXES



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## **Summary**

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### **Desk research report**

This document presents the desk research results coming from the project partners.

Partner perform the desk research in their countries collecting various available online and offline sources (such as scientific literature, reports, statistics, recommendations) checking for their reliability.

The result of the desk research is a collection of theoretical references as well as best practices, constraints, and barriers related to the mobility of people affected by behavioral disturbs.

In their research, partners focus on following key questions:

1. **What are the main traveling issues?** Indeed, the changes in routine, unpredictability, crowds, new noises and sights can all make the experience difficult for people on the spectrum and their families.
2. **What are the policies of subjects involved in traveling services?**
3. **What are the public and volunteers' support?**

Each partner realized a report illustrating:

1. Issues in traveling for families with children affected by behavioral disturbs, reporting the studies, investigations, etc. that have been realized in their countries in the last 10 years.
2. Regulations available to support the travel needs of these families;
3. Recommendation and advice available for these families;
4. Good practices, illustrating initiatives that have been realized to sustain these families;
5. Needs, identifying the primary and secondary needs for these families;

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6. Stakeholders, identifying the key stakeholders and their role in supporting these families.

Contents:

1. Ecoistituto report
2. SHEM report
3. Include report
4. RTA report
5. JKPU report
6. NAMCB report

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## **Ecoistituto report**

### **1. Issues in traveling for families with children affected by behavioral disturbs**

In general, kids can be especially vulnerable to travel-related problems such as motion sickness, diarrhea, and infections

Traveling with kids with behavioral disorders presents many supplementary difficulties and issues.

Behavioral disorders may include:

- attention deficit hyperactivity disorder (ADHD)
- oppositional defiant disorder (ODD)
- autism spectrum disorder (ASD)
- anxiety disorder.
- depression.
- bipolar disorder.
- learning disorders.
- conduct disorders.

It's difficult to predict kids' behavior when they are traveling, but the excitement and new environment can cause some of them to have meltdowns. In the case of kids with behavioral disturbs, tantrum and uncontrolled outbursts of anger and frustration are typical.

Literature on Autism Spectrum Disorders (ASD) includes article on traveling independently.

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For instance, there are research focusing on the collaboration with diverse stakeholders and communication with museum audiences to ensure the quality of special education programs (Cho & Jolley, 2016).

The National Dissemination Center for Children with Disabilities ([www.NICHCY.org](http://www.NICHCY.org)) (1996) lists 11 essential skills that are a prerequisite for traveling independently. Those skills are that the individual can:

- Cross streets safely with and without traffic signals
- Board the correct bus or subway (airplane or train)
- Recognize and disembark at the correct destination
- Make decisions
- Initiate actions
- Recognize the need for assistance and request help from an appropriate source
- Follow directions
- Recognize and avoid dangerous situations and obstacles
- Maintain appropriate behavior
- Handle unexpected situations, (e.g. re-routed buses/subways, getting lost etc.)
- Deal appropriately with strangers

Here following the most popular suggestions when traveling with kids:

- Take it Slow and Leave Plenty of Time.
- Don't Overpack.
- Pre-Book Everything You Can.
- Explain the Trip.
- Pay Extra for Good Gear.

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- Ask for Child Discounts.
- Accept Things Will Go Wrong.

Research shows that children with autism have trouble managing the stimuli associated with traveling to and from a vacation destination (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Wolfberg, P. J. (2015).

Materials to prepare children with autism for flying and air travel exist in various forms, such as books and Social Stories (Ruddy, Booth, Gaw, Liao, Dounavi, & Dillenburger, 2015).

The book series, ‘Off We Go’ was especially created to prepare children with special needs for new experiences of travel (<https://www.otb.ie/offwego/>). Downloadable cartoon-like apps (e.g., Luca Lashes and his first airplane ride, 2013:

<https://www.youtube.com/watch?v=C6anL9xvH5w>) can also be used to prepare children for going on the plane. Short guide books exist to educate parents and airport staff on how to meet the needs of children with autism

(<https://www.fau.edu/education/centersandprograms/card/documents/cardawarenessbrochureair.pdf> 14).

Many children on the ASD are fascinated by trains. However, as with all new situations, there are challenges to consider when traveling by train, taking a cruise, and even using city public transportation after you arrive at your destination.

There many web pages that give information and advice on how to handle safety, transitions, and time in traveling with children with ASD (e.g., <https://www.thezebra.com/traveling-autism/>).

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## **2. Regulations available to support the travel needs of families with children with behavioral disturbs**

In 1996, the European Parliament adopted, in the form of a written declaration, the Charter for Persons with Autism which states that people with autism should have the same rights enjoyed by all EU citizens, where such be appropriate and in the best interest of the person with autism, and that these rights should be enhanced, protected and enforced by appropriate legislation in each State. The Charter recommended that diagnostic services, individualized education, family support, housing, vocational training and lifelong care should have been adequately addressed and appropriate services provided at domestic level (Della Fina & Cera, 2015).

After the Charter’s adoption, the protection of the rights of people with ASD within the EU Member States is far from being uniform and satisfying. Among the European countries substantial differences exist with regard to the legal framework in favor of persons with ASD revealing that only a short number of countries has implemented the recommendations of the European Parliament.

In Italy, the first law on autism has been approved by the Parliament in 2015: "Provisions relating to diagnosis, treatment and habilitation of people with autism spectrum disorders and family assistance" (LEGGE 18 agosto 2015, n. 134; GU n.199 del 28-8-2015).

This new, important legislation includes measures aimed at ensuring the health protection, the improvement of living conditions and the social inclusion of people with ASD. In terms of regional policies, it foresees the updating of the essential levels of assistance with the insertion, as far as autism spectrum disorders are concerned, of early diagnosis, care and individualized treatment, through the use of methods and tools based on the latest scientific available evidences.

According to Siniscalco and Gallone (2015) this law has three major points:

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- 1) Promotion and supporting by the Ministry of Health research in autism biology and genetics, for better understanding the causes of the disease and identify possible medical treatment and rehabilitation to help people with autism.
- 2) Each three years the National Institute of Health will update the guidelines on the treatment of autism spectrum disorders, from children to adults, on the basis of evolving science.
- 3) The inclusion of autism in the Essential Levels for Care (ELC). These ELC comprise all activities, services and benefits that the National Health Service (NHS) provides to all citizens free of charge or with payment of a ticket, regardless of income and place of permanent address .

However, although this law introduce very advanced principles, it contains only good intentions that can not materialize because of lack of financial funds.

The Italian Regions (in Italy the health care service is provided by the Regions) should ensure the health care services, identify coordination centers and "to establish the diagnostic, treatment and care for children and adults with autistic disorder, as well as verify its evolution". Training of health workers and the creation of projects to support the families have been also planned. However, no new funds can guarantee these goals.

In the last few years, due to the economic and political crisis, many Regions cut to the economic contributions for rehabilitation therapies, recommended in the Guidelines but not paid by the Health Service. The results is that families are "forced" to turn to private therapists to give their children a chance of rehabilitation and social integration.

Pioneering initiatives have been implemented in some Italian Regions, where autism centers have been established following the interaction between a foundation of parents of persons with ASD and the local health agencies of the regional government. Here the collaboration between private social participants and the public health system also gave rise to regional guidelines for

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preventive, early diagnosis and treatment of persons with autism (Valenti, Cerbo, Masedu, De Caris, & Sorge, 2010).

In 2015, the Institute for International Legal Studies (ISGI) of the Italian National Research Council (CNR) published the book *Protecting the Rights of People with Autism in the Fields of Education and Employment* (Della Fina & Cera, 2015).

This book focuses on the analysis at national level of the perspective of people with autism.

It emerges from the study carried out by ISGI within the European Project ‘Promoting equal rights for people with autism in the field of employment and education’, conducted in partnership with Autism-Europe (A-E). Such Project aimed at improving the knowledge and understanding of the CRPD implementation in the fields of inclusive education and employment through the study carried out by ISGI on Articles 24 and 27 and a compendium of best practices in the field of employment prepared by A-E.

The Project also promoted the exchange of concrete v best practices with the aim of encouraging their replication in other countries. In this vein, the research activities have been coupled with the initiatives for dissemination of the results of the Project, such as the Final Conference, held in Turin on 29 November 2014 during the Italian Presidency of the EU, with the participation of a wide range of relevant stakeholders, including policy-makers. Following such researches, the present legal study identifies legislative models for implementing Articles 24 and 27 of the CRPD consistent with its principles and obligations and suggests the priorities to be incorporated into domestic legislations.

Accordingly, the book provides an in-depth assessment of domestic legislative, judicial and administrative practice of the EU Member States having developed laws on the rights of the persons with autism especially in the fields of inclusive education and employment. A chapter is also dedicated to the protection of people with autism in the framework of the Council of Europe

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and the European Union. Unique for its legal perspective focused on the rights of people with autism and their inclusion in the fields of education and employment, this book is a useful source of consultation for the community of professionals, academics, scholars and advanced students dealing with international human rights law; practitioners; government legal advisers and policy-makers interested in disability issues; trade unions; representatives of DPOs and other NGOs.



### **3. Recommendation and advice available for families with children with behavioral disturbs**

Most of the recommendations on travel for children with special needs refer to air travel that is certainly the most complex travel. At the same time these may also concern other kind of travels. The indications follow these three basic elements:

- preparation in time;
- clear and anticipated communication of the trip to the child;
- possibility of previously familiarizing the child with the spaces (stations, airport, transport ...).

These recommendations have been mostly developed for children with autism, but the practices are also appropriate for children with other special needs. We indicate below some tips for family of children with special needs to keep in mind when it's time to prepare for a trip whether it's via airplane, train or a road trip.

1. Practice makes progress! - Becoming familiar with what sights and sounds to expect during a new experience can help reduce anxiety for an individual with autism. A good way to help your child be prepared for and comfortable with the idea of travel is to use of teaching stories! Teaching stories are customized, very brief stories that can help explain a new social situation or behavior. Taking an airplane: A guide for people with autism is an example of a story used for Autism Speaks' Blue Horizons for Autism events, which help families expand their travel horizons. If possible participating in a realistic “dress rehearsal” can help your child become used to the sights and sounds they can expect, providing an opportunity to walk through their upcoming travel experience.

2. Contact guest services in advance! - Many families are unaware that they can contact guest services at airports, train stations and hotels for additional support. There are many travel-related companies that provide a variety of accommodations like advanced



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boarding times, special meals, rental equipment, travel companions and pre-registering service animals. Parents or guardians of children with disabilities should:

- Inform the Security Officer if the child has any special needs or medical devices.
- Inform the Security Officer if they think the child may become upset during the screening process as a result of their disability.
- Offer suggestions on how to best accomplish the screening to minimize any confusion or outburst for the child.
- Ask the Security Officer for assistance during the process by helping them put the child's carry-on items on the X-ray belt.
- Know that at no time during the screening process will they be separated from the child.
- Know that if a private screening is required, they should escort and remain with the child during the private screening process.
- Tell the Security Officer what are the child's abilities are. For example: can the child stand slightly away from equipment to be handwanded, walk through the metal detector, or need to be carried through the metal detector by the parent/guardian.
- Know that at no time should the Security Officer remove the child from his/her mobility aid (wheelchair or scooter).
- Know that if the child is unable to walk or stand, the Security Officer will conduct a pat-down search of child while he/she remains in their mobility aid, as well as a visual and physical inspection of their equipment

3. Provide choices! - The idea of a new environment can be intimidating for everyone, especially for an individual with autism. Allowing your child to feel they're in control is one way to relieve that anxiety. One suggestion is having them pack their own backpack

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to carry with them. They can pack a few of their favorite things such as calming toys, books, iPads (or other devices) and snacks for the trip. This step provides your child with something to feel responsible for and allows them to choose which comfort items they bring along for this new experience. These familiar items will come in handy to reduce stress and boredom during “wait” times.

4. Prepare for sensory concerns! Unfamiliar noises during travel may be problematic, but packing ear plugs, noise cancellation headphones or music players may help. If your child has difficulty handling crowds or standing in line, ask the gate attendant if you can board early to get settled in a seat quickly or plan to board last, so you spend less time waiting before departing. Also, for plane and bus trips, you might want to try to obtain seats toward the front, where your child might not feel as cramped and crowded as they would in the back.

5. Safety first! - Changing routines and new environments during travel make having a safety plan even more important. If your child tends to wander from safety, make sure to have copies of your family wandering emergency plan. Consider additional safety products such as wearable ID tags to make sure your child has a form of ID on him at all times. For more safety and wandering prevention tips and resources [click here](#).

6. Prep your environment! - When staying in a hotel, it is a good idea to call ahead and ask for a quiet room (think corners!) and request a room with a refrigerator if your child follows a specific diet. You also might want to explain your child's particular needs in advance of arrival to see if there are any additional accommodations the hotel can provide. This will also give you an opportunity to discuss safety precautions such as door alarms and access to pools and bodies of water. If your child tends to wander from safety, provide copies of your family wandering emergency plan to hotel staff. The same goes if you're staying with a friend or a relative.



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7. Family watch system! - Another way to plan for a safe trip is to set a family watch system which may reduce stress and anxiety on the parent’s behalf, as well as other members of the family. Having one person at a time provide one-to-one supervision for your child and rotating that responsibility throughout the trip will help keep your child safe and give you peace of mind. This type of teamwork will allow everyone to navigate smoothly throughout the entire trip and help diminish stress.
8. Reinforce good behavior! - This can be done with the simple reward of praise, a sticker, a small toy or anything else that is reinforcing for your child. You could even consider having your child earn a special reward at the end of a successful drive, flight, or cruise! Remember to try and notice the times when your child is doing a great job and reinforce them with a reward. These positive behaviors might include sitting with their seat belt, reading quietly or sharing.
9. Keep your routine! - Deviating from a routine can be challenging and stressful for an individual with autism. Try keeping to as normal of a routine as possible when your child is going to be traveling. If your child likes to do certain activities in the morning and then have quiet time in the afternoon, you should try to follow that routine, even if you are en route. Think of your child's daily routine and the items they like or need for it, and bring them along to make it feel more like home.
10. Create a schedule - Since strictly keeping your everyday routine during a trip can be tough, creating a schedule will allow your child to develop a sense of a new routine for your trip. Your child can predict what is going to happen next and will relieve some of the anxiety of being in a completely new place. This can be something simple such as 8am-9am breakfast, 9-9:30 bus ride, 9:30-12:30 sightseeing, 12:30 lunch, 1:30 break, etc.



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It is possible to create a schedule for the type of travel for the child with instructions to follow (in written form and with visual supports) for all the step actions of the trip. This promotes predictability and anxiety control. Below we report an example of a guide built as a task analysis of the different steps related to airplane travel:

➤ Taking an airplane:

1. Getting to the airport - After you pack your bags, you and your family go to the airport. You may take a car or a train to get there. There may be lots of traffic because a lot of people take airplanes for travel. You get to the airport about 1 to 2 hours before your flight.
2. Checking in - Once you get to the airport, you check in for your flight. You give your name, and a worker gives you a boarding pass. It may be a paper pass, or it may be on your phone. If you have a big bag, the worker puts it on the plane for you. If it's a small bag, you carry it on the plane yourself.
3. Going through security - Once you have your boarding pass, you go through security. Security helps make sure everyone on the plane is safe. You wait in line for the scanners. You put your things, like your jacket, shoes, belt, phone and tablet, in a bin that slides through the scanner. Don't worry—you'll get everything back on the other side! When it's your turn, you step into the tall scanner. Stand very still and raise your hands to let the scanner work.
4. Going to the gate and waiting for your flight - Now it's time to go to the gate. This is where you get on the plane. The gate number is written on your boarding pass. You may have some time to wait for your flight. There may be shops, places to eat and restrooms near your gate. And lots of people, too. There are lots of seats at the gate where you can sit and wait with your family. You can read a book or use your tablet while you wait.



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5. Boarding (getting on) the plane - When your plane is ready, the airport worker makes an announcement over the loud speaker. You get in line and show your boarding pass to the worker. Then you walk down a ramp to get to the plane. Sometimes you may even go outside and then go up some stairs to get into the plane.
6. Finding your seat - Your seat number is on your boarding pass. Find your row and your seat. Then sit down and buckle your seat belt. You're most likely sitting with someone in your family.
7. Finding the bathroom - The bathroom on the plane is smaller than your bathroom at home. It may be at the front or the back of the plane. You can go to the bathroom during the flight. If you do, be sure to buckle your seat belt when you get back to your seat.
8. Getting ready for takeoff - Flight attendants are on the plane to help take care of you during the flight. Before takeoff, they make some announcements over the loud speaker. The pilot may make an announcement, too. When the plane takes off, you hear the sounds of the engines turning on. They can be loud! The plane goes super fast down the runway. Before you know it, you're in the air!
9. During the flight You can read, color, play with small toys or even use a phone or tablet while you're flying. Your phone or tablet has to be in airplane mode —your mom or dad can help you with that. The flight attendants bring you a drink and a snack. Or you can bring your own snacks, if you want. You can stand up and move around if you need to. Be sure to buckle your seatbelt when you sit back down.
10. Landing - The pilot and flight attendants tell you when it's time to land. You put your toys away for landing and make sure your seatbelt is buckled. After you land, you may have to wait a few minutes to get off the plane. Then you'll be at a

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gate like the one where you got on the plane. If you had big bags, you pick them up at the baggage claim.

It may be helpful to use a visual support such as a schedule board with bathroom breaks listed or “First-Then” boards (e.g., “First bathroom, then trip to the restaurant”). Still other visual supports can include photographs or icons that prompt your child to think about taking a bathroom break.

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#### **4. Good practices, illustrating initiatives that have been realized to sustain these families.**

In recent years many transport and travel agencies have been working to help children with special needs and their families travel. These experiences have mostly been developed at airports and in favor of children with autism. For example several USA airports have organized services to make the journey comfortable for these passengers (e.g. Philadelphia, New York, Detroit, Washington DC): various training programs are provided here to allow children with special needs and their family to explore every phase of the process travel, from check-in to real landing simulations on an airplane.

In Atlanta at the F. Concourse airport has been organized a multisensory room: inside there are tactical panels for sensory activities, games and other entertainment tools where you can spend your waiting time with the children.

It's possible to find similar programs for the safety and serenity of children with special needs traveling by plane. In Dublin for example guides have been prepared to help children with autism to familiarize themselves with new spaces and noises.

Some other world experiences are listed below:

Gatwick ([gatwickairport.com](http://gatwickairport.com)) leads the airport pack in the UK, offering passengers with special needs an interactive sensory room and a calming lounge that avoids duty-free, as well as familiarisation “open days” and lanyards to identify people who need extra support. Other UK airports offer special assistance.

The [Association of British Travel Agents](http://abta.com) (Abta) stresses the importance of informing an operator of your family's needs when booking. It also offers advice for people with physical challenges at [abta.com/tips-and-advice/accessible-travel](http://abta.com/tips-and-advice/accessible-travel).

Virgin Atlantic ([virginatlantic.com](http://virginatlantic.com)) offers guests with autism priority boarding and seat selection. It has created a symbol identifying anyone who needs extra help and it allows passengers to visit a mock aircraft at Virgin's training base near Gatwick Airport to see how everything works.

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British Airways ([britishairways.com](http://britishairways.com)) can, if given 48 hours’ notice, offer priority boarding and early meals on board. It also has a dedicated check-in area at Heathrow Terminal Five for people with special needs and offers seat selection for customers travelling with a disability.

Tui ([tui.co.uk](http://tui.co.uk)) can liaise directly with hotels and offers pre-departure photo guides. It can arrange private transfers, special assistance at the airport and suitable plane seats.

Thomas Cook ([thomascook.com](http://thomascook.com)) has a specialist accessibility team, which, if contacted, can support arrangements for the holiday, the journey, transfers and accommodation.

Center Parcs ([centerparcs.co.uk](http://centerparcs.co.uk)) offers assistance to families by arranging early check-in procedures before crowds arrive, booking quiet tables in restaurants and arranging one-to-one instructors for certain activities.

In Italy since 2015 the ENAC project "Autism-Traveling through the airport" started, with a series of recommendations addressed to cares to help children with autism to accept their journey serenely. As for the procedure to be followed at the airport, the tips found in the various blogs of travelers with autistic children are the same: avoid doing rush things, prefer online check-in to avoid waiting times, book a place in the inner part of the plane - perhaps near the window - and board last to minimize waiting times inside the plane. At the security check, notify the staff that you are traveling with an autistic child, so as to speed up the checks, as well as on board the aircraft, especially if the choice of places is not possible and you could travel far from your child. Barbara Milani, mother of an autistic child, created a useful blog (“[unafamigliainblu.it](http://unafamigliainblu.it)”) that offers everyone the opportunity to share experiences lived with his family, from the most welcoming accommodations to the technical and precious suggestions to follow during the trip.



## **5. Needs of families with children with Autism Spectrum Disorder**

Children with autism and other kind of special needs experience differences in sensory processing, meaning they can find noisy, bright and busy environments overwhelming. They may also have difficulty understanding what other people mean, and have trouble understanding their own emotions, which they may find hard to communicate in socially expected ways. These children also have learning and/or language difficulties, so may not understand instructions or explanations and may need more time to process information. Lots have quite specific preferences when it comes to food, and are very sensitive to even small differences in taste and texture. On holiday, they may be very limited in what they can eat. Children with autism really struggle to be flexible about this – it is not a question of just not liking the food. While in an unfamiliar place, the child is likely to need familiarity wherever they can get it, including having the reassurance of their parent nearby. When you add it all up, a ‘journey’ isn’t actually a single action: it’s a complex set of man oeuvres which involve dealing with people, information and changes – all of which can be a lot to manage when you have autism. It’s not surprising that confusion, stress and occasional meltdowns can occur. What particular challenges can complicate public transport for someone with autism? Let’s look at them one at a time.

Social interaction and communication: For a child with special needs, communicating with people can be difficult even if those people are loved and familiar; when they’re unknown, unpredictable and potentially unsympathetic, they can become positively scary. Though the people you encounter might actually be quite nice, a child with autism may communicate in ways that the average commuter doesn’t understand such as using a picture system or sign language. Even if your son or daughter does have some verbal skills, the rhythm of conversation can be difficult and approaching strangers might feel too intimidating to try.

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Flexibility of imagination: Most children can adapt if something changes unexpectedly, and find it fairly easy to apply general rules from specific instances. For a boy or girl with special needs, though, it's not so easy. If a train is delayed or a bus goes on diversion, that might feel less like a minor inconvenience and more like a slide into frightening chaos. Kids with autism can also get fixed on an overly-narrow mental image of a bus or train: as far as they're concerned, the right bus looks like this, and if the company changes the logo or plasters some colourful ads all over the sides, your son or daughter might be determined that this is the wrong bus and they're not getting on it. Finally, there's the issue of safety, and this is a big one. People with autism often have trouble using their imaginations – not just in the ‘making up stories’ sense, but in the ability to predict what might happen next. When you can't predict what'll happen next, you don't have a sense of danger: the idea that jumping off a moving vehicle might injure you may simply not occur to your son or daughter.

Sensory issues Autism a intellectual disability can bring with it a lot of uncomfortable sensitivities. It's quite common (though not universal) for a boy or girl with autism to be overwhelmed by certain sounds, sights or smells – and of course, public transport involves a whole host of noisy, bustling, highly stimulating places. Tannoy announcements, buzzers and bells, the creak and rattle of an engine, the judder and vibration of an old vehicle, the slamming and sliding of doors, the smell of fuel and exhaust, the glow of schedule boards: these can either be mesmerizing or horrifying to a traveler with autism. Either brings its own problems: a horrified kid suffers great distress, and a mesmerized kid might have a tantrum if you try to keep them moving. To add to the difficulties, some people with autism (though not all) are uncomfortable touching or being too close to other people. In an empty carriage that's one thing, but during rush hour, it's a serious ordeal: being hot and crammed together with a lot of people can feel truly awful.

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Obsessive or inflexible behaviors: It’s quite common for people with autism and intellectual disability to have trouble doing what’s known as ‘transitioning’ – which simply means moving from one activity or environment to another. You may know it’s time to get off, but if your son or daughter has settled down, he or she might not be so keen to move, or able to move quick enough to get off before the train slams the doors and carries you past your destination. Children with autism can also bond to experiences and find it hard to vary the pattern ever after. If your son or daughter always has to sit in the exact same seat, busy times can prove difficult.

Planning, organizing and prioritizing: To make a safe and successful journey, it’s important to plan what you’re going to do and do it safely – but for a child who has trouble organizing their thoughts, limited ability to predict the consequences of their actions and perhaps even some problems understanding the basic concept of time, that’s no small ask. Arriving on time or waiting patiently for the bus or train – especially if there’s a longish wait – can prove very stressful for everyone involved.

The more staff and companies understand about autism, the more their customers can relax and enjoy their holiday. However, it’s important to know that every child is different. Making small adjustments (for example locating a quiet room, letting parents know schedule changes in advance) and checking in with parents regularly can prevent difficulties. Many parents say that dealing with other people’s attitudes is their biggest challenge when they are away. Members of the public may complain or make hurtful comments about the child’s behaviour, and judge it as “naughty”. Staff can make a big difference by showing that they understand, and by supporting parents.

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## **6. Key stakeholders and their role in supporting families of children with behavioral disturbs.**

According to the Action Plan for Disability of Italian Cooperation, approved in June 2013 by Directional Committee of DGCS (General Directorate for Developmental Cooperation), inclusive education:

[...] is a process aimed at guaranteeing the right to education for all, independently from diversities, disabilities or psychophysical, socioeconomic and cultural disadvantages. The final aim of inclusive education is not limited to school inclusion, but it is the social inclusion of any person, the promotion of every person’s whole development and of the society at large. On this basis, it is important to enhance interventions focused on individuals’ and groups’ life projects, so that the life project is developed at school as well as in the social context. (Directorate General for Development Cooperation, 2015).

Here following the key stakeholders and their role in supporting families of children with behavioral disturbs:

- Governmental institutions, developing policies, organizing services, funding projects of private nonprofit organizations.
- Educational institution, training social educators and social volunteers, spreading the awareness on social issues.
- Research institutions, investigating on the various aspects related to people with special needs (diagnoses, rehabilitation and socialization practices, integrating knowledge, experimenting new therapies and services.
- NGOs, supporting families with interventions of volunteers, increasing the integration climate.
- Policy makers, proposing and discussing regulations to support the governmental action as well as the activity of the educational institutions.

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- Social services, organizing interventions, fostering social inclusion programs.
- Local inhabitants, actively contributing to social integration.

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## APPENDIX 1

### Hotel stays and autism

Any time an individual with autism is away from the home environment, it can trigger anxiety and meltdowns. Staying in a hotel may feel like a luxury to you, but to your child, it can be a stressful experience. All of the sounds, smells, and sights that your child is familiar with are not close at hand, and that can make sleep elusive. These tips can help make everyone more comfortable in the hotel when you travel with a child who is autistic.

- **Request a room that will be quieter.** Rooms near the stairs, elevator, or ice machine are likely to be noisier, and that can disrupt your child’s sleep. Ask for one that is not near these hubs of activity. Some hotels even have designated “quiet rooms” for travelers with autism, so if you call ahead you can get this access.
- **Consider adjoining rooms.** Getting adjoining rooms gives you the ability to set up one room with your child’s special needs in mind while having another room where you can stay up watching TV or otherwise function without disrupting your child’s sleep. Make sure, however, that the room is equipped with locks that your child cannot access, so you are not left to deal with a child who has locked you out of her sleeping quarters.
- **Ask about the security in the room.** From locks on the sliding doors that access the patio to alarms for kids who wander, consider a hotel that has room security as part of its amenities.
- **Protect your child from wandering out of the hotel room.** Choose a second-floor room away from the stairs if your child is a wanderer. This will give you the ability to find your child quickly if they do manage to get out of the door without your knowledge and will prevent injuries.

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## **SHEM report**

### **1. INTRODUCTION**

#### **The purpose of the research**

Although Autism Spectrum Disorder, which was first described in 1943, is not a disorder related to mental retardation of individuals, individuals mostly experience different degrees of problem perception, regulation and integration.

Sensory features commonly encountered in individuals with ASD it can manifest itself as being insensitive to physical pain and interaction, reacting to loud sounds, changes and surprises, and showing extreme sensitivity to some or all of the senses (seeing, hearing, taste, smell, touch) (Lane, Young, Baker, Angley, 2010 ).

The cognitive, sensory and motor skills of individuals with autism spectrum disorders are not sufficient. These individuals, who need to have a very good special education process, can partially improve their quality of life if they can adapt to social life.

Occasionally, a voice or anything else can cause them to change suddenly and change their control. They may also show interest obsessions such as excessive dealing with one or more extraordinary issues, and order obsessions such as performing certain operations in daily life, reacting to the disruption of order (Ökcün, 2008). There are anger attacks that occur as a result of such changes, behavior that harms the environment or itself, problem behaviors and behavioral features that manifest with repetitive body movements. For this reason, changes such as emotions and places should be done very carefully or applied in individuals with autism spectrum disorders.

Individuals with autism may experience various problems while traveling. Individuals are stressed during travel, a sudden triggering noise, traffic and many other travel factors can cause individuals with autism to have problems. During the journey, he may show temper tantrums, crying crises or similar mood disorders. The main purpose of this study was to be able to develop suggestions about the negativities that individuals with autism may experience during their travels and the precautions that can be taken in return. In addition, the

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problems and suggestions that can be encountered in all types and forms of travel such as private car travel, bus travel, air travel, sea travel will be examined.

The problems of families of individuals with autism during travel in Turkey, and the examination of the measures taken by the state in this regard have been identified as one of the aims of the study.

### **The Importance of the research**

In Turkey, the majority of studies about Autism Spectrum Disorder are focused on the developmental characteristics, education and families of individuals diagnosed with ASD. Few studies have been conducted on the problems and negativities that individuals with ASD may experience while traveling.

### **Research Problem**

The question of "What are the difficulties that individuals with autism spectrum disorders encounter in traveling and how their effects reflect on individuals" has been identified as the main problem of the study.

The sub-problems in the research are listed as follows:

- What features should be added to public transport so that individuals with autism spectrum disorders can travel?
- What measures should be taken in vehicles to prevent individuals with autism from being triggered by sudden changes?
- Does the ability of individuals with autism to travel have a positive effect on them?
- To what extent does the impact of the society that individuals with autism spectrum disorders encounter on public transportation in the city and on intercity travel?

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- Are the families of individuals with autism planning regular travel or do they travel when they are compulsory?

### **Research Hypothesis**

H<sub>1</sub>: families of individuals affected by autism in Turkey, are using public transport to travel with their children in case of necessity.

H<sub>2</sub>: Individuals with autism often using road transport in Turkey.

H<sub>3</sub>: The vast majority of autistic individuals in Turkey are unable to travel alone.

H<sub>4</sub>: There are no specially designed applications for individuals with autism in buses and planes. This situation causes individuals with autism to experience great difficulties. Only price reductions are applied in trips.

### **Research Method**

The research will be carried out using the qualitative method.

There are very few studies in Turkey made so far. Studies on this subject will be compiled and approaches and practices in the country will be examined. In addition to academic studies on this subject, reports prepared by government agencies, laws and provisions will also be included in the study.

## **2-AUTISM SPECTRUM DISORDER**

### **2.1- Causes and Diagnosis of Autism Spectrum Disorder**

Autism was defined by the American psychiatrist Leo Kanner in the 1940s. It has been described by Kanner as early childhood autism.

According to Kanner, children with autism use reverse pronouns, have delayed speech, can repeat the same movement continuously, often repeat what is being said (echolalia), use pronouns in reverse, have good memory, have similar repetitive movements (stereotypes), difficult to interact and are sensitive to change. (Şahin, 2015).

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Kanner listed the characteristics of children with autism as follows (Darica et al, 2017):

Repeating verbal expressions directed to himself in the same way, using personal pronouns like you instead of me, repeating the spoken words with the same tone and emphasis and delayed language development,

Having a very good memory,

Having a limited amount of self-initiated behavior,

Having stereotype movements or showing extreme dependence on certain movements,

Who wants to protect the sameness,

Having difficulty in establishing relationships with people,

Children who prefer inanimate objects or pictures

These features have been revised by Rutter and Lockyer (1969) and four basic features have been identified to date, containing all the opinions put forward for autistic children. These features are:

- Frequency of autism appears before thirty months.
- There is a marked delay in the speech and language development of children with autism.
- There is an inadequacy related to social development which is not related to mental development. For example; It is seen that children frequently refuse physical contact such as hugging and embracing, there is a general indifference towards people and inability to establish eye contact.
- Although stereotyped game skills are observed, it is among the clear behaviors to insist on maintaining sameness and to react to change.

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There are many theories about the causes of autism spectrum disorders. Important theories are in the research process. There are no identified causes or causes in individuals diagnosed with autism. It is thought to be the result of multiple causes or a combination of causes. However, it has been recognized that autism is not a mental illness and it is not caused due to psychological problems.

Researchers believe that, along with genetic modification, many biological factors cause autism. Genetic studies related to the emergence of autism in twins were focused on, and the same degree of autism was found to be 65-90% in identical twins and 5-10% in fraternal twins of same sex. In non-twins siblings, the probability of having autism was found to be 2 - 3%. While all siblings of children with autism develop normally, 10-15% of siblings are shown to have varying degrees of cognitive disabilities (language or reading difficulties, mental retardation). This situation shows that some genetic factors may cause varying amounts of cognitive difficulties (some siblings are autistic while others have only reading difficulties) so autism has a genetic side (Yanardağ, 2007).

Kanner stated that the families of children with autism have a high level of education and that they are made up of mothers and fathers who have obsessive personality traits, who are cold, perfectionist, and who do not have enough emotional relationships. However, these findings have not been shown again in the studies performed in the last 50 years (Şakar, 2008).

According to Cook and Leventhal (1996) and Ernst et al. (1997); The neurobiological foundations of autism are based on; genetic diseases leading to autism, immune system disorders frequently seen in individuals with autism, the emergence of autism due to subsequent diseases, neuroanatomical disorders or neuroimaging findings in the brains of children with autism, neurochemical disorders detected in body fluids, the relationship of autism with epilepsy, neurological examination, deficiencies, specific disorders detected in neuropsychological tests and results obtained in animal experiments. Recent research is

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thought to be caused by the disruption of biochemical balance in some structures in the brain due to a genetic cause (Görgü, 2005).

Nowadays as a result of the project led by Hamamatsu University of Japan, autism was identified as a neurological disorder by Japanese professors. In the study conducted by the research team, tomographies of 20 autistic individuals and 20 normal individuals aged 18-26 years were examined. As a result of the study, it has been shown that the division and deficiencies occurring between the neurons of the brain reveal the reasons such as inability to explain the feelings of autism and communication disorder (Soğancı, 2011).

### **Diagnostic**

Similar to Kanner's definition, autistic disorder was first included in the DSM-III (Diagnostic and Statistical Manual of Mental Disorders) classification system in 1980 as "infantile autism".

Then, it was determined that if DSM-III-R has 8 of the 16 subspecies belonging to three sub-areas (impairment in social relations, impairment in communication area, limited activity pattern), it can be diagnosed.

The age of onset of DSM-III-R has been criticized for being no longer the main diagnostic criterion and for the widening of the diagnostic range. DSM-IV criteria have been adopted which predict at least one disorder in 3 developmental domains (social development, communication skills, symbolic and imaginative play) and symptoms to start before the age of 3. Autistic Disorder is classified under ICD – 10 (International Disability Classification-10) under the title of Common Developmental Disorders (PDD) and defined similarly to DSM-IV (Mutluer, 2013).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) published by the American Psychiatric Association (APA) in 2013; Autism Spectrum Disorder is defined as a developmental insufficiency, whose symptoms are very intense since the 24th



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month after delivery, which is manifested by limited / repetitive behavior patterns, persistence in the same, persistent insufficiencies in social communication and interaction, excessive dependence on routines, hypersensitivity or insensitivity to sensory stimuli (Uluoyol,2015).

The most commonly used diagnostic criteria in autism are DSM V (American Psychiatric Association), ICD (International Classification of Diseases) and WHO (World Health Organization), which are accepted by experts in research on autism. Below, these criteria are given in detail according to DSM V.

**A.** Continuous inadequacy in social communication and social interaction seen in different ways now or in the past.

**1)** Insufficiency in social-emotional response (eg inability to share mutual dialogue in an unusual social approach, from inability to share their interests, emotions or affect, to not respond to social interaction.)

**2)** Insufficiency in nonverbal communicative behaviors used for social interaction (eg poorly integrated verbal and nonverbal communication, abnormal eye contact and inability to understand and use body language or gestures, and obvious deficiencies up to facial expression and body language.)

**3)** Difficulty in developing, maintaining and understanding relationships, (for example, behaviors that seem to be unsuitable for different social environments, not to share imaginary games and make friends, not to be interested in a friend. Current violence: Violence is determined by inadequate social communication and limited, repetitive behaviors)

**B.** Repetitive behaviors, interests or activities that are presently or in the past, manifested by the presence of at least two of the following.

**1)** stereotyped or repetitive motor movements, object use or speech (Simple motor stereotypes, stringing or turning toys, ecolali, idiocentric sentences)



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2) Insist on being the same, strict adherence to the routine or ritualized verbal and non-verbal behaviors (extreme stress in minor changes, difficulty in transitions, hard thinking, greetings rituals, choosing the same way or the same food every day.)

3) Limited, fixed interests abnormal in terms of subject or intensity (abnormal excessive attachment to uncommon objects, excessive repetitive or limited interests.)

4) Sensory hypersensitivity or low sensitivity or excessive interest in the sensory dimension of the environment (hypersensitivity to pain / heat, unexpected response to certain sounds or touches, excessive sniffing or excessive touch to them, being too busy with light or movement.) Current violence: Violence is determined according to the social communication deficiencies and limited, repetitive behaviors.

C. Symptoms must be present in the early stages of development (may not be noticed until social expectations exceed the limits or may be masked by strategies learned later in life.)

D. Symptoms should lead to clinically significant impairment in social, professional and other important areas.

E. This disorder should not be due to mental disability or general developmental retardation. Though mental disability and ASD often coexist, but for the diagnosis of ASD and mental disability, the social communicative level must be below the overall development (Aydemir, 2015).

## **2.2- Developmental Features of Autism Spectrum Disorder**

Individuals with autism spectrum disorders (ASD) have different degrees of problems in the sensory perception, regulation, and integration (Rogers, Hepburn, Wehner, 2003).

Sensory features commonly encountered in individuals with ASD; insensitive to physical pain and interaction, reacting to loud sounds, changes and surprises, and showing extreme sensitivity to some or all of the senses (seeing, hearing, taste, smell, touch) (Lane, Young, Baker, Angley, 2010) .

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Intelligence section in approximately 40% of individuals with ASD; It is below 50-55 (moderate and severe mental retardation), about 30% between 50-70 (mild mental retardation), and about 30% is 70 and above. It is suggested that there is an important relationship between the intelligence department and Autism Spectrum Disorder (Yorbik, 2007).

It is stated that individuals with ASD exhibit limitations in their ability to understand the opinions, thoughts and feelings of others, which are called cognitive and adaptive skills, to express their own thoughts, to recognize the effects of their behavior on others' feelings and thoughts, and to solve problems. Individuals with ASD show inadequacies in cognitive processes such as coding and classifying information, as they create concepts in certain formats in their minds and find it difficult to get out of these formats. These individuals have problems in memorizing based on memory and have difficulties in understanding abstract ideas and social rules (Yarimkaya, 2016).

Individuals with ASD generally prefer to use a single problem solving approach and especially try to use this problem solving approach they have in the face of concrete situations. However, the use of a single problem solving approach in abstract situations may be insufficient (Friend, 2006).

Individuals with ASD are insufficient to establish social interaction. Characteristics observed in autism are listed as social disabilities including nonverbal communication skills; lack of eye contact required for social interaction, inability to use facial expressions, gestures and mimics in communication, limitations in imitation skills and inadequacy in game skills (İrtenk, 2011).

Behavioral characteristics of children with autism vary from different levels of indifferent behavior towards parents and other people, to behaviors such as not knowing important people such as siblings, parents and teachers in their lives and not showing any separation anxiety.

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Children with autism have sensory responses such as special fears, unconsciousness of the dangers, laughing or crying behavior for no reason, and reacting to changes. There are temper tantrums, behaviors that damage the environment or itself, problem behaviors and features of behaviors that manifest with repetitive body movements. Children with autism may exhibit behaviors resistant to change at an early age. They may also show interest obsessions such as excessive dealing with one or more extraordinary issues, and order obsessions such as performing certain operations in daily life, reacting to the disruption of order (Ökcün, 2008).

Children with ASD may have some deficiencies in performing gross and fine motor skills. The causes of these deficiencies are often associated with sensory functioning, muscle weakness and motor planning problem. Therefore, children with ASD may not participate in group activities that require the use of gross motor skills. These children may have trouble performing motor skills that require sorting and planning, such as drawing, folding paper, and turning a bicycle pedal. In addition, children with ASD may experience motor problems such as balance problems, lack of coordination, weakness in the toes and walking on the toes (Uluyol, 2015).

Although physically normal, all children are less developed. He may not shake his arms properly while walking. And they can tilt their heads and shoulders forward. By opening their arms to the sides, they can run cumbersome. Although they are at the age of changing their feet, they can stand on each step as the stairs go up and down. The physical posture of many is also different. They can open or bend their arms, hands and fingers from certain angles. Thin finger and thin muscle coordination may be weak (Ünlüer, 2009).

An abnormality does not appear in the physical development characteristics of children with autism, but there may be delays in sitting, crawling and walking skills. There may also be some differences in how they use great motor skills. Examples are fast or slow, forward leaning or fingertip walking.

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Generally, fine motor development also lags behind its peers. They learn skills such as writing and painting limited areas later than their peers (Dikmen, 2008).

### **3- THE CHALLENGES OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS DURING TRAVEL**

Individuals with autism may experience various problems while traveling. Individuals are stressed during travel, a sudden triggering noise, traffic and many other travel factors can cause individuals with autism to have problems. During the journey, he may show temper tantrums, and may display problem behaviors such as crying crises or similar mood disorders (Sucuoğlu, 2012).

Problem behaviors lead to inadequacies in the development of interaction and communication skills of children with autism, disrupting teaching and causing these children to socially separate by preventing them from interacting with their normally developing peers (Koegel, Fredeen, Kim, Danial, Rubstein, & Koegel, 2012). For these reasons, it is necessary to prevent, reduce and eliminate the problem behaviors of children so that children with autism can effectively benefit from the prepared education programs, continue their education in general education classes and participate actively in social life (Cihak, 2011).

Problem behaviors exhibited by children with autism based on the literature; it is possible to classify itself as stimulating and recurring behaviors, self-harming behaviors, aggressive behaviors, unusual eating behaviors, and obsessive behaviors (Yücesoy-Özkan, 2015).

Self-stimulating and repetitive behaviors are bodily movements that do not serve a specific purpose and repeat in an external environment, such as hitting hands, swinging, turning objects around, and arranging toys in a certain order (Bishop, Richler, & Lord, 2006). While self-harming behaviors are behaviors that cause physical injury or damage to the child's tissues, such as self-hitting, self-biting, self-nail, self-throat and pulling his own hair

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(Berkson & Tupa, 2000; Erbaş, 2001); aggressive behaviors are behaviors that cause physical injury or damage to objects around the child, such as shouting, swearing, hitting, pushing, biting, nailing and pulling hair (Mukaddes, 2013; Roane, 2014). Unusual eating behaviors are the child's eating unusual food, selective or unwilling behavior in eating behavior and eating too little or too much (Mukaddes, 2013; Roane, 2014). Obsessive behaviors are the behaviors of the child in developing unique rituals, preserving sameness, connecting to unusual objects or activities, and having difficulties in changes and transitions (Neitzel, 2010).

The obsessive behaviors of children with autism cause them to have difficulties in adapting to the changes in the environment and situation and they adhere to certain routines (Cihak, 2011). These difficulties in adapting to changes in environment and situation often cause them to display problem behaviors during transitions (Lequia, Wilkerson, Kim, & Lyons, 2015).

Traveling by individuals with autism is basically a transitional element. It refers to the transition from one event to another (Sterling-Turner & Jordan, 2007).

The concept of transition for individuals with autism; It is defined as situations that require ending an activity at home, school, workplace or social environments and starting a new activity or leaving an environment and moving to a different environment (Graber-Juhnke, 2015).

Their travel is also considered a transition. As with other transition issues in travel, structuring, planning and behavioral forms were made much less than teaching subjects. In this context, it does not reveal how children will behave. It can also cause children not to have problem behaviors (Angel, Nicholson, Watts & Blum, 2011).

Considering that the time spent on travel is shorter than all the time spent in school, it can be said that children who have problems with transitions are more likely to exhibit problem behavior during these time frames. Children show problematic behavior while traveling,

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rejecting a transition to a new environment and resisting changes in activity or environment (Hume, Sreckovic, Snyder and Carnahan, 2014).

Since children with autism need to seek unity (Flannery & Horner, 1994), need predictability in changes in environment (Banda & Grimmett, 2008; Flannery & Horner, 1994; Schreibman, Whalen & Stahmer, 2000) and have limited behavioral patterns (Neitzel, 2010), they have more difficulties in transitioning from one environment to another and adapting to their routine changes compared to children with normal development (Cihak, 2011; Lequia et al., 2015; Zane, Carlson, Estep, & Quinn, 2014).

In addition to the reasons arising from the characteristics of children with autism, excessive attention towards these children during their travels may cause them to get nervous by creating negative effects (Graber-Juhnke, 2015).

Refusing to travel or resisting also challenges families of individuals with autism. In order for children with autism to cope with this situation, educators need to make a training plan about the transitions, including traveling, so that children learn to develop adequate and problem-free behaviors in traveling (Hume et al., 2014).

In order to ensure that children with autism participate effectively in this type of inclusive practice, it is important to eliminate the behaviors that may arise during travel and to provide appropriate transition behaviors. Enabling them to travel to children with autism at an early age will help them to be more independent in such environments and enable successful implementation of inclusion practices (Bakkaloğlu, 2009). In this context, one of the aims of the education programs to be prepared for the benefit of children with autism is to organize them in a way that they can prevent the behaviors that they can gain the freedom to travel and display them. (Hume et al., 2014).

Support for transition strategies is received in planning to prevent negative behaviors that may arise during travel. Traveling is also considered as an element of the concept of transition (Graber-Juhnke).

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These strategies consist of strategies used to facilitate transitions and create a positive transition environment by increasing predictability for children who have problems due to transitions in activity, environment or routines (GraberJuhnke, 2015).

In this context, preparing children for travel are strategies that can be used before or during travel to facilitate travel (Angel et al., 2011).

When strategies that are suitable for the characteristics of children and travel (weather, land or sea) are used, the time spent on the problems of travel decreases, the appropriate behaviors during travel increase, and the need for an adult tip is less, and participation in social life becomes easier (Taylor & Seltzer, 2010).

In order to prevent problem behaviors that may arise during travel, it is necessary to determine the transitions experienced, to choose the appropriate transition strategy to facilitate the transition, to apply the selected transition strategy and to determine whether the strategy is effective.

In order to support children with autism during travel, one of the first things to do is to determine when, on which seat and with whom children have problems during travel (Graber-Juhnke, 2015). It is important to carefully observe the children and to reveal the problems experienced during the trip (Yücesoy-Özkan, 2015).

Traveling describes transitions that require an environment change, such as moving from one place to another for individuals with autism.

Transition strategies that can be used to make it easier for children with autism to travel include preparation strategies, reminder strategies, timing strategies, and facilitation strategies (Graber-Juhnke, 2015). To decide on the appropriate transition strategy, it is necessary to consider children's interests and needs, what strategies practitioners are aware of, and available resources (hardware, software, etc.) (Hume et al., 2014).

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After deciding on the appropriate transition strategy, the step to be followed is to plan by who, when and how to use this strategy.

The chosen transition strategy can be implemented by the parents, teachers or other individuals working with children (Banda and Grimmett, 2008). The characteristics and attitudes of the individuals who will take part in the implementation process (being patient and encouraging etc.) are the factors that increase the effectiveness of the strategy (Bainbridge and Smith-Myles, 1999).

After determining who will implement the strategy, it is necessary to plan the implementation time. It is also important to transform the strategy into a part of children's daily routines and to use it during times when all other transitions other than travel are experienced during the day (Lequia et al., 2015).

It is necessary to decide on the path to be followed in the implementation of the selected transition strategy, taking into account the ages, needs and learning characteristics of the children (Hume et al., 2014).

The last step of the process to be carried out to prevent problem behaviors that may arise during travel is to collect data regularly in order to determine whether the implemented strategy is effective. In order to determine the effectiveness of the strategy, it is first necessary to create data collection forms and share these data collection forms with all individuals working with children.

What to do next is to collect data on children's behaviors during travels by observing and decide whether the chosen strategy has an impact on travel behaviors (Banda & Grimmett, 2008; Hume et al., 2014).

Transition strategies to be applied for children with autism to have a smooth process while traveling; preparation strategies, reminder strategies, timing strategies and facilitation strategies are handled in four ways (Angel et al., 2011).

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Although each strategy has features that make it different from the other, all of the transition strategies are related and interconnected.

Priming strategies are strategies that allow children with autism to understand what the next activity is before the event starts and make the transitions predictable (Ayres, 2005).

The basis of the preparation strategies lies in preparing the children for a new activity or informing them about what awaits them before moving to a new environment and thus preventing possible problem behaviors that may be exhibited during the transitions (Yücesoy-Özkan, 2015).

Preparation strategies are used especially for children who display problem behavior in the form of refusing to travel or resisting not to travel. Preparation strategies include preparatory videos, preparative (social) stories, and preparative images.

#### Preparatory Videos

The preparatory videos contain video images that will be used effectively in preparing children with autism for transitions and providing children with travel skills (Tetrault & Lerman, 2010). Preparing videos (video priming) is a strategy in which children are watched before their travels in order to prepare the children for the stressful situation that may occur during their travel and to prevent the problem behaviors caused by anxiety due to environmental changes in children and the behaviors to be displayed during the transition process (Ruddy et al., 2015).

The purpose of the preparatory videos is to increase the predictability of traveling, thus preventing problem behaviors that may be exhibited during travel (Gengoux, 2015).

The preparatory videos are easily used in the home or school environment and are more effective when turned into a part of the child's daily routines.

Another of the preparation strategies used to prepare children with autism for travel are preparatory stories, also called social stories. Preparing stories (print priming) are illustrated

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and written stories that depict travel or the environment to be visited after the trip, showing the behaviors to be displayed during the trip and revealing what is expected from the child for travel (Okada, Ohtake & Yanagihara, 2010).

Preparative stories are used to describe the travel transition focused on and the steps required for this transition, as well as to increase predictability by giving information about changes in the environment, activity or routines (Hume, 2008).

When it is decided to use preparatory stories, first of all, it is necessary to prepare stories containing the things that children with autism experience problems during travel and that describe these transitions in accordance with the levels of the children. It is important to make sure that the stories prepared describe the environment to be traveled and the content of the trip appropriately, clearly indicate what the behaviors expected from children, the pictures or photographs used accurately reflect the behaviors, and the expressions used are appropriate for the level of children's development. After the preparatory stories are created, these stories are read to the children before the trips they have problems and the children are expected to join the trip without any problem behavior (Okada, Ohtake & Yanagihara, 2010).

#### Preparative Images

Another preparation strategies used to facilitate travel are preparatory images with photographs, pictures, drawings, signs, symbols and icons (Yücesoy-Özkan, 2015). Preparing visuals (visual priming) are strategies using visuals such as photographs, pictures, drawings, signs, symbols or symbols that allow to understand what travel is, understand the relationship between travel and destination, and increase predictability of travel situations (Cihak, 2011).

Activity charts and before-after cards are some of the preparatory images used to support children with autism before the transition (Murdock & Hobbs, 2011).

#### Reminder Strategies

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Reminder strategies (behavioral reminders) are strategies that provide tips for children with autism and remind them that travel will be made and make it easier for them to travel.

These strategies are the strategies that allow children who have difficulties to realize that travel is approaching, have difficulties in traveling on their own and who need tips for travel, and that they can switch to travel without problematic behavior (Graber-Juhnke, 2015).

Audio reminders (auditory reminders) are audio cues or warnings that tell children that travel is approaching. While alarms, applause, bells, music and songs are some of the audio reminders to choose from, the most commonly used audio reminders are verbal instructions (Sterling-Turner & Jordan, 2007). When audio reminders are used, first of all, the factors that children have problems should be determined, and then audio reminders (s) that are suitable for the characteristics of children associated with travel should be selected.

#### Visual Reminders

Another reminder that can be used to prevent problem behaviors that may arise during travels is visual reminders. Visual reminders (visual reminders) are visual cues that warn children about traveling, but also tell children what behaviors are expected from them while traveling. Visual reminders are examples of pass cards or power cards (Banda and Grimmert, 2008; Dettmer et al., 2000; Schmit et al., 2000).

Transition cards are reminders, which are used to prepare children for travel, with photographs, pictures and illustrations, as well as written explanations that show clear and understandable behaviors during the trip.

The children take the pass cards showing the environment or activity to be transitioned from the schedule following the completed activity and place them in the new environment, in a previously prepared and on the image where there will be a hint of travel. The purpose of the use of these cards is to remind the child about the trip as well as to help the child understand

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that he / she has moved to the right activity or environment by matching the pass card in his hand with the card in travel (Hume, 2008).

### Timing Strategies

Timing strategies (timers) are strategies using visual or audio-visual tools that show how much time is left for children with autism (Hume, 2008; Hume et al., 2014; Newman et al., 1995). These strategies enable the concept of abstract time to be made more tangible by concretizing it through visuals (Newman et al., 1995).

Timing strategies are very suitable for children who need predictability during travel and more time for transitions. There are studies in the literature that show that timing strategies are effective in reducing the transition time of children with autism (Dettmer et al., 2000).

Timing strategies; It can be examined in two ways: timers and countdown visuals.

## **RESULT**

Travel causes problem behaviors in children with autism. The behaviors of children with autism in the course of travel limit the education period of both children with normal development and autism, and it causes a lot of time and effort to deal with problematic behaviors.

The aim of the education programs to be prepared for children with autism should be to provide children with independent and smooth travel behaviors. Transition strategies are used to prevent problem behaviors displayed during travel and to provide appropriate transition behaviors. Transition strategies are classified into four groups as preparation strategies, reminder strategies, timing strategies and facilitation strategies. Although each of these strategies has its own characteristics, they are connected and interrelated strategies.

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## APPENDIX 2

### **Difficulties of parents of children with ASD: a literature analysis**

Recently, Saccà, Cavallini & Cavallini (2019) carried out a literature analysis to study the difficulties mainly reported by parents who daily interface with the Autistic Spectrum Disorder in their children. In their review, the key points and the most difficult macro areas have been presented.

Referring to the main difficulties that emerged, parental stress occupies a position of considerable importance. Indeed, it has been empirically shown that parents caring for a child with Autism Spectrum Disorder experience significantly higher levels of stress than parents of typically developing children.

The presence of stress in parents inevitably affects the relationships that they establish both at an intra and extra-family level, increasing the difficulties arising from the presence of the disorder and establishing dysfunctional relationships with the child, which further increase children's behavioral problems.

The wide range of symptoms that distinguishes a child with autism and that accompanies them throughout their life, cannot fail to affect parents, who mainly suffer from lack of interaction with the child their restricted and repetitive behavioral repertoire and social misunderstanding surrounding them.

A parent who lives their role thinking to not be able to manage the child's problems can feel overwhelmed and powerless, with inevitable repercussions on the family climate and the couple's relationship.

Overall, the analysis of literature on parents and children with autism allows to underline the importance of support that parents receive in deficit conditions. In fact, both the themes of the guidelines and the diagnosis can be linked to parental stress and to the support they experienced, as if they were subclasses that increase or decrease the difficulties of this experience. In literature there are numerous scientific evidences attesting that families, and mostly parents, if adequately supported, can reach good functioning levels, learning to use effective strategies to manage family situations and reconcile personal needs with family ones.

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The review focuses on the analysis of parents and children with autism by adopting a broader perspective to explore the problems that they have to face on a daily basis and that distinguish them from other parents.

Authors argue that future research could deepen the most widely used interventions to offer greater parental support, including the behavioral parent-training (PT-behavioral) and Acceptance and Engagement interventions (ACT) that are significantly developing in recent years within the framework of parent education. The latter includes all the interventions and/or preventive families' programs with the aim of contributing to the improvement of relational and functioning problems presented within the family context.

Saccà, A., Cavallini, F., & Cavallini, M. C. (2019). Parents of Children with Autism Spectrum Disorder: a systematic review. *Journal of Clinical & Developmental Psychology*, 1(3).

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Include report

**Scientist responsible for the Erasmus+ ELISE project in Greece**

Andromachi Nanou, PhD, Research Coordinator, Include

**Members of Elise Project Team**

Astaras Alexandros, Associate Professor, Department of ICT, Anatolia College of Thessaloniki

Mikiki Foteini, Dr. Transportation Engineer, Municipality of Serres, Greece /International Hellenic University, Serres Campus

Oikonomou Andreas, Associate Professor, Department of Pedagogy, School of Pedagogical and Technological Education



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## **Critical issues concerning travels of families with children with behavioral disturbances<sup>1</sup>**

### 1.1. Definition of behavioral disturbances in children and adolescence

Childhood and adolescence are critical life stages affecting mental health and wellbeing. In these early stages, cognitive, emotional skills and social behavior are developing and subsequently affect the available choices and opportunities in adulthood. The social-economic environments in which children live and grow up have a critical impact in their lives as adults. Vital skills in social interaction, learning methods and strategies, self- control and social skills that develop during this time, determine behavior across the lifespan. The development of these core cognitive and emotional skills may be adversely affected by negative experiences that children face at home or at school. Families facing adversities, poor parenting practices, poor social and economic life circumstances have all been well documented as the factors affecting mental health and behavioral difficulties (WHO European Region, 2020). Behavior difficulties (BD) are, also, frequent among children with intellectual, developmental or other disabilities (Horbach, 2020, Jansen, 2020, Ngashangva, P. & Dutt, S. 2015). Behavioral difficulties vary from aggressive behaviour, acute psychomotor agitation to apathy. Behavioral difficulties are often chronic and often there is more than one difficulty present in every individual. These difficulties in addition to their associated disorders have significantly negative impacts on the individual, the family and society.

### 1.2. leisure activities, travel and well being of children with behavioral disturbances

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<sup>1</sup> The term disturbances is used in sameness with difficulties or disorders

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The European policy for health and well-being, aims at reducing social and economic inequalities according the Sustainable Development Goals. Goal 3.4. (WHO European Region, 2020).

Social communication difficulties and behavioral problems are parameters that affect ones participation in leisure activities. According to Kim (2013), individuals with developmental disabilities due to their social communication difficulties have been excluded from leisure programs and services. As a consequence, families with children with behavioral difficulties may find themselves restricted from leisure social activities, though they may have just as much natural desire to participate as other families,. From this point of view well being of families with behavioral difficulties children is in danger.

The participation in recreational and leisure activities enhances overall family well-being, promotes inclusion and enhance long-term physical and mental well-being. The participation of families with a behavioural disturbed child in leisure and recreation activities is key priority, as this participation is a way to overcome the pressure that results from living with a family member wit disability (Glidden, 1993).

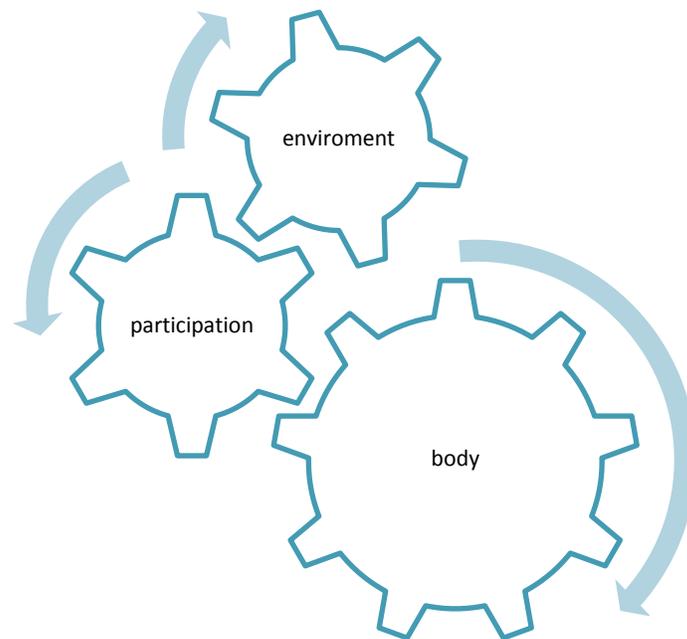
Family is regarded as an essential component in providing creational and developmental opportunities for disabled children. Parent’s motivate children to be involved in creative and leisure programs ( Schleien & Ray, 1997). Specific researches have been conducted concerning the results of individuals’ with developmental disabilities involvement in creative and leisure programs. These results intctes development of skills that are they are necessary in independent functioning (Retish & Reiter, 1999). Improvement in Self-concept (Van Andel & Austin, 1984), social skill development (Savage, Novak, & Heal, 1980), language, cognition, and physical fitness (Schleien & Wehman, 1986) was found after their participation in leisure related experiences. Green & Schleien, also, demonstrated that the development of friendships between individuals with developmental disabilities and their non-disabled peers may be promoted by skills developed during leisure and creative activities.



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Trip experiences are also kinds of leisure activities. Researchers in order to understand how families with disabled children experience travelling, use existing frameworks from leisure activities bibliography. Family leisure trips have, also, specific characteristics (Kim 2013).

Body function, participation and environment are three parameters that interact in travelling (Yau, McKercher, & Packer, 2004). The harmonious interaction of the three parameters positively affects the process of travelling. For families with disabled children all three of the aforementioned variables body function, activity participation and the environment are potential triggers of dysfunctional scenarios. If any of these parameters don't interact smoothly the whole system may dysfunction.



**Fig. 1** : The concept of travel as an positive interdependence of 3 elements from Yau, and colleagues point of view ( Yau et.al., 2004)

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These families participation in a travel experiences is of great importance, as leisure travel is a desire shared by disabled individuals as much as others (Murphy, Carbone, & The Council on Children with Disabilities, 2008 ). “How can travelling with children be a positive experience?” This question that was asked by Leggat, and colleagues, very early at 1998, now could be customized as “How can travelling with children with behavioural disabilities be a positive experience?”

### **1.3. Fair traveling key considerations**

A fair travelling model may take into consideration the interdependence of the parameters that affect travelling of families that includes children with all kinds of disabilities. There are specific issues that have to take into consideration in order to develop a fair travelling model for families with behavioural disturb children. Some of these issues that emerged from the bibliographic research are presented below:

- In the context of travelling needs to be carefully considered that families with children of disabilities have a much closer interpersonal dynamic. The family members during travelling play an important role since the children with disabilities spend more time interacting with family members than their typically developing peers (Buttimer & Tierney,2005;).
- There is an acute need for investigating perceptions, and preferences of families of children with disabilities, based on their real travel experiences. Little research has been developed in these field.



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- Needs of families with disabled children may differ from typical ones. Differences in physical, mental, or emotional conditions between families with and without disabled children may lead to different needs, interests, and limitations when it comes to participation in tourism activities. Those various special needs have to be carefully addressed if the hospitality and tourism industry intends to provide this market segment with quality services.
- The viewpoints of families with one or more child with a disability have to be linked with industry practices and the needs of disabled consumers. Family that include children with disabilities should be studied as a distinct tourist population.
- Living with children with disabilities can have intense effects on the entire family (Reichman, Corman, & Noonan, 2008).
- Such families may need and stand to benefit from a holiday far more than an average family, but may find it particularly daunting to plan for and embark for one.
- Travel activities have to be affordable, accessible, and inclusive.

There are also several key considerations that emerged from informal interviews with Include members, parents of children with behavioural disturbs. are presented in below in table 1

**Table 1. :** A list of subjects that, usually, interact in a travel of families with children affected by behavioral disturbs

<b>Travel preparation (e.g. travel agencies)</b>	<b>Travel activity (e.g., transportations, accommodations, etc.).</b>
1. Parents of children with disabilities may approach travel with elevated levels of stress, because children with disability need more assistance and the continuous attention of their parents while traveling, as compared to	2. Travel activities are linked to external or circumstantial factors. These factors are flexible and adaptable for families to participate?



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typically developing children

3. The travel preparation for a trip varies depending on the type of disability.
  4. Are travel agencies aware of the specific types of information that the parents of a disabled child are likely to need?
  5. How families could have access to specific and meaningful information they need for every destination?
  6. Parents need information regarding their destination
    - specific kind of food they would need
    - specific medicine
    - means of transport
    - accessibility ( e.g. of museums)
    - special health institutes
    - special therapies
  7. Parents have to know how to prepare their child and how they will be prepared for the new physical and social environment of the country they will visit.
1. Tourism industry provides relevant and meaningful services to these families?
  2. Are there child-friendly programs and experiential activities that are oriented toward that goal adaptive and accessible sports and recreational activities?  
Activities which are modified or designed to allow children with disabilities to participate and may thus attract these families?
  3. Do service providers have positive attitudes and suitable communication skills ?
  4. Are there specific and aware officers in every embassy that would inform families for special services and needs in the country that the family visits?

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## **2. Report on Travelling with children with behavioral disturbances in Greece**

### **2.1. Introduction**

This report is the result of research done to capture data on travelling of children with behavioral difficulties in Greece. To this end, bibliographic research has been conducted in search of scientific sources, but we have also consulted reports from international and national organizations. We also searched for information by contacting natural persons, specialists, representatives of organizations and Ministries. In this case, the communication was either face-to-face, or by telephone, or by e-mail. In each case, an unstructured small interview was sought in order to have an overview of the services that the organizations offer and the general experience they had on the subject. One in six people in the EU, that is approximately 80 million citizens, is facing difficulties due to disability of differing kind or severity and very often barriers of physical and/or attitudinal nature, depriving them from being appropriately integrated in social and economic activities (EC, 2014). Families with reduced mobility due to behavioral disturbs of their young members can be found all around Europe and Greece makes no exception. Achieving social integration these families in Greece as elsewhere. Providing these children the appropriate treatment, tailored to their functioning level is really demanding, requires constant efforts of actors involved and coordination of initiatives. Primarily, for a rigid and insensitive system, educational integration remains hard to achieve. Education is closely linked to everyday trips that are often difficult to perform, such children depriving from such children to achieve their full potential and it often requires extra resources and with doubtful success. It is common secret that struggle to attend mainstream school and to go through their everyday challenges. Behavioral disturbs are disabilities less obvious and explored and due to the scarce available materials, this study is not exhaustive in covering in a detailed way the variety of issues linked with the overall concerns of these children. Thus, the aim here is not a thorough

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analysis but an essential, brief overview of the situation of families travelling with children with this kind of difficulties in Greece. This report sheds light on several critical issues and barriers faced by children<sup>2</sup> suffering from behavioural disturbs and their families, in the framework of rights and principles recognized at an EU level.

The structure of the report involves first, the difficulties faced by such families according to different mobility characteristics, everyday short trips, long distance trips and travelling for tourism. Next, it presents briefly the Greek legal and institutional framework for protecting this vulnerable group and reports on national provisions related to the UN Conventions. It then takes a look on specific efforts that were located through a relevant bibliographical research. Finally, the report draws basic conclusions for Greece’s “performance” as regards the legal framework implementation mechanisms for social inclusion of these children, underlying deficiencies and problems, tracking down best practices, and it ends up with recommendations derived by the bibliography or via short interviews undertaken with relevant stakeholders, public entities or private bodies.

## **2.2. Issues in travelling for families with children affected by behavioural difficulties in Greece**

Disability is a complicated concept, with multiple dimensions and a dynamic, evolving nature. Living with disabilities affects living conditions as a whole and people’s potential in many aspects, among which, mobility, transport equipment use or accessibility, jobs or hobbies, or more basic issues, like social contacts and economic independence (EUROSTAT, 2015). Children with disabilities and their families are confronted with specific concerns everyday: from the deficit of assistance for their educational and other activities inclusion, to experiences of discrimination and justice allocation issues, as well as barriers in accessing infrastructure or services, overall obstacles in having their voice heard and in being involved in decision-making

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<sup>2</sup> Source: [www.autismaroundtheglobe.org/countries/Greece.asp](http://www.autismaroundtheglobe.org/countries/Greece.asp)



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with high impact on their lives<sup>3</sup>. Admittedly, travelling with children affected by behavioral disturbs is a complicated issue no matter provisions for people with reduced mobility (PRMs), that are or are supposed to be in place. Basic rights, like free movement, freedom of choice and non-discrimination, accorded to these families as all citizens, fail to be performed. Against this background, this report attempts examining problems related with such individuals’ mobility in Greece, covering a range of cases and providing relevant analysis from available sources. As regards mobility, difficulties can be met according to the functioning level of the individual in different contexts in both local, everyday transport, as well as, longer or different trips on special occasions, so there is a distinction (Bekiaris et al., 2018) as follows:

### **2.2.1. Everyday transport**

In Greece, it includes private car use and personal mobility aids as well as public transport services, that is bus and taxi, in most Greek cities. In Athens, transportation system is more complex as there more public transport means available like trams, metro and short-distance rail transport which often make a trip multimodal and more complicated. No matter the means used, everyday activities can be a real struggle for such families however they are more manageable, following a specific routine. Change in patterns can be a real challenge though. Therefore, a reliable transportation system is a prerequisite for less stressful travel.

### **2.2.2. Long-distance transport (including road, rail, air, and maritime transport)**

Some families face longer trips to meet their needs either because they leave in isolated places or because their children are in need of services that are not provided in their proximity. The longer the trip, the more demanding it may get for these families. The frequency and the regularity of such trips impact on the severity of their complexity for the families in question. Conditions like comfort, lack of distractions like noise or crowd, information provision and special services are

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<sup>3</sup> Source: [www.autismaroundtheglobe.org/countries/Greece.asp](http://www.autismaroundtheglobe.org/countries/Greece.asp)

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essential for trips that are long and tiring. Moreover, long-distance trips may be multimodal ones and thus more demanding as regards transfers, ticketing and operators.

### **2.2.3. Holidays and tourism**

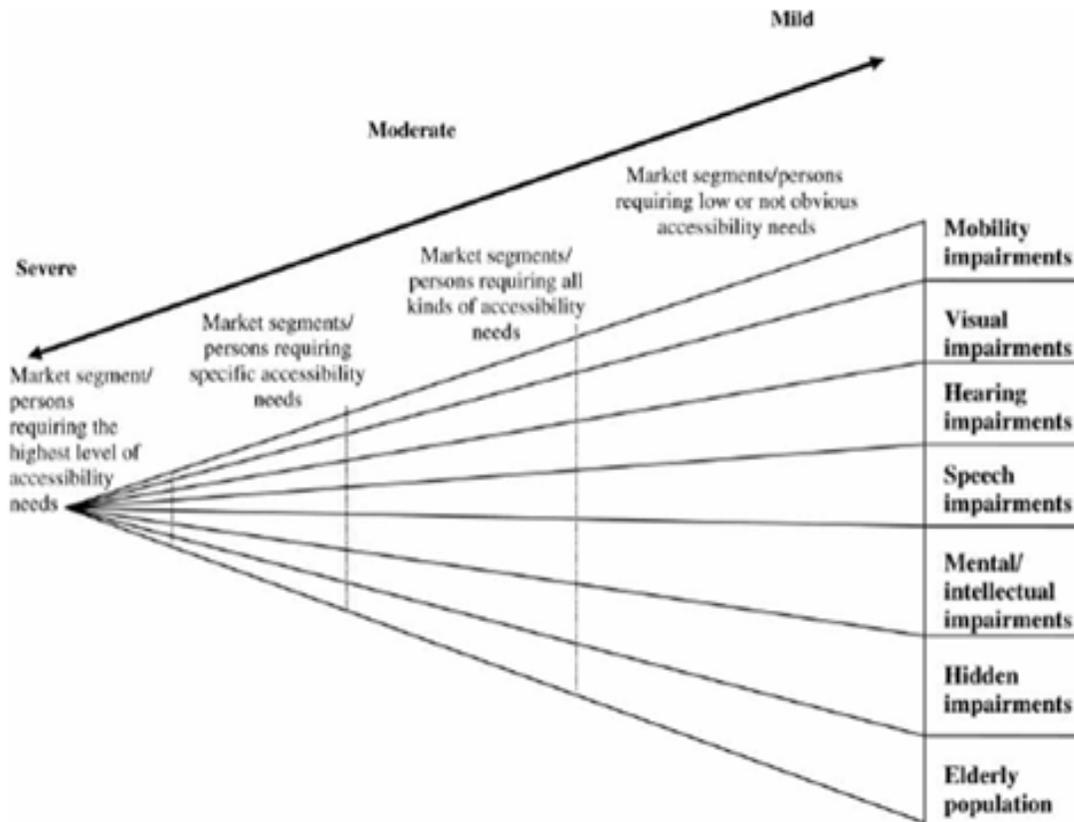
Enjoying holidays is vital for any family, providing benefits for all its members: it provides new scenes, chances to enhance family ties and new experiences that broaden one’s mind and enrich a personality. But for the families in question, the idea of a family vacation can seem a “mission impossible”, with extreme stress, as many destinations are beyond their routine with new sounds, different people and different rhythms. Parents need to be proactive and address particular travel agencies that provide information and services tailored to their needs<sup>43</sup>. This is also a challenge for tourism industry in turn, given the appropriate scientific input, to adjust to the special demands of such clients. A relevant ‘Pyramid of demand types’ (Figure 1) is presented below, as regards accessibility needs related with tourism, with a detailed clustering of persons with disabilities in broad categories and furtherly, according to their disability level (mild, moderate or severe) (Buhalis & Michopoulou, 2010).

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<sup>4</sup> Source: <http://www.amillionsenses.com/articles>



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**Figure 1. Pyramids of demand types** [Source: Buhalis & Michopoulou, 2011]

Accessibility in general is vital as well as a range of services, information material and assistance for the parents while preparing a trip or during it. Of course, provisions for all users-friendly transportation and services oriented to tourists with disabilities are also aspired by local people. Addressing one group’s accessibility needs can be beneficial to a broader community. This holds true for other mobility occasions short or longer ones beyond tourism. Figure 1. Pyramids of demand types [Source: Buhalis & Michopoulou, 2011]

### 2.3. Regulations available to support the travel needs of these families

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Vulnerability of children with disabilities is obvious due to their early age and inevitably enhanced because of their personal limitations. As such, they are entitled to particular care from the European Union and its Member States in line with international conventions<sup>5</sup>. By becoming a party in CRPD in December 2010, the EU recognized the fact that these people are confronted with many challenges, regarding their rights and underlined the necessity for turning the agenda of the EU towards justice for all. Greece has ratified both conventions and is committed to fight disability-related discrimination and to undertake initiatives of legislative or policy nature (Ballesteros et al., 2013). The key elements deriving from international conventions, regarding children with disabilities include putting in the forefront the best interests of the child, with no discrimination and consideration of the evolving capacities of the child; defending rights of participating; rights of being heard or free of violence; rights to family life, assistance and education, including inclusive education. Given the ratification of both UN Conventions, Greece is obliged to take appropriate action for the respect of “the above rights set forth for each child or person with a disability within their jurisdiction”. The above-mentioned elements cover mobility issues as well, so Greece should make provisions for the protection of these children against any kind of discrimination while travelling, including adopting all appropriate measures (legislative, administrative and other ones) for the implementation of those rights. According to UN report, there has been recently in Greece an admittedly heightened attention to the implementation of UN Conventions in the most recent past, its efforts to give effect to the standards through considerable legislative reforms, putting in place a new legislative framework and mechanisms in challenging circumstances and with considerable resource constraints. Efforts concern measures to render public transport in Athens and other major cities accessible and the preservation of the nominal level of disability allowances during the economic and financial crisis (UN, 2019). However, concern is expressed for the lack of a transparent system in Greece for granting transport benefits and ensuring the mobility of persons with

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<sup>5</sup> United Nations Convention on the Rights of Persons with Disabilities (CRPD), UN Convention on the Rights of the Child (CRC)

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disabilities without any discrimination. It is particularly concerned about the limited and impeded access to parking space and reported instances of denial of exemption from fees and taxes for vehicles of persons with disabilities owing, inter alia, to the requirement for certification of lifelong disability under the current secondary legislation. UN Committee recommends that Greece take effective measures to improve the system of personal mobility support, ensuring its transparency and equity in access of all disabled persons to benefits and means facilitating their personal mobility. It also recommends that Greece provide specific training in mobility skills for persons with disabilities and specialized staff working with them. As regards access to information, official reports are rather sceptical for the barriers that persons with disabilities in Greece face in accessing information, particularly in the public sector, owing, inter alia, to the lack of documents in accessible formats and the lack of sign language interpretation. Moreover, there seems to be insufficient information on national action plans or long-term strategies to improve the accessibility of persons with disabilities to information, including AudioVisual Media services and the Internet, by, inter alia, providing Easy Read formats. According to international conventions, State Parties are obliged to provide transport systems accessible equally to all users (Article 9, CRPD). Therefore, EU and national legislation, either new or revised one, will have to mainstream accessibility, taking into account EU legal provisions for transport and tourism with Greece currently far from achieving this. No matter the numerous legislative initiatives towards transport accessibility improvement at EU level, they have a really sectoral character, i.e. air transport. Instead of having partially and mode-specific measures for ensuring access for persons with reduced mobility, accessibility requirements need to be integrated properly in all strategies, legislative proposals, projects, and other initiatives in order to make the most of their potential and have a long-lasting impact (Bekiaris et al., 2018). Our literature review came up with a number of reports of UN and EU for Greece’s performance as regards social inclusion and overall respect of rights of children with disabilities<sup>6</sup>, where

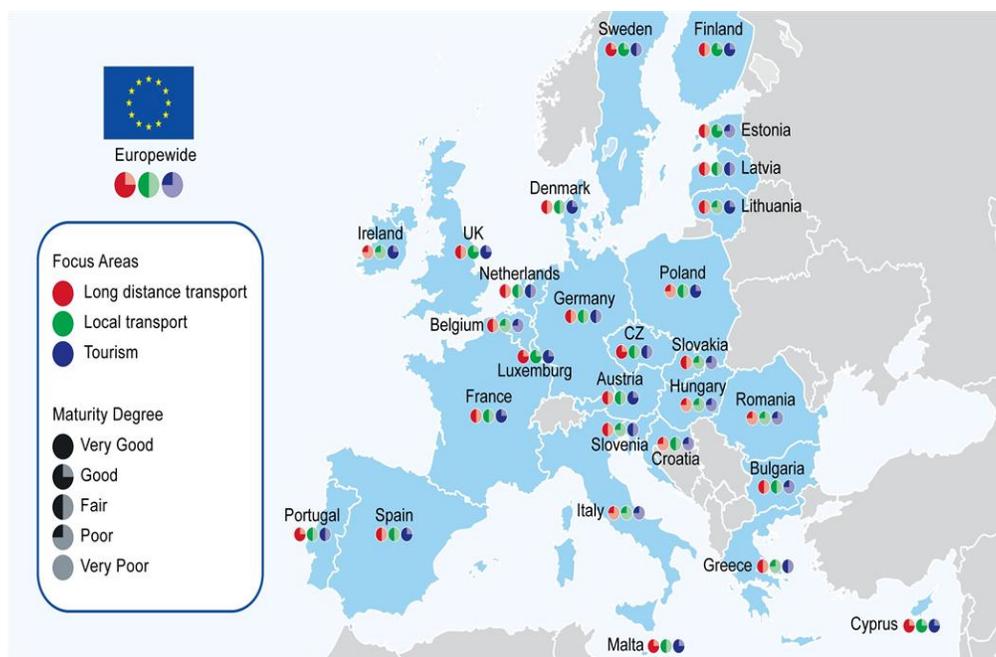
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<sup>6</sup> e.g. the Study on Member States' Policies for Children with Disabilities, mandated by the European Parliament's Committee on Civil Liberties, Justice and Home Affairs, (Ballesteros et al., 2013; Kaltsouni, 2013)



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Greece’s performance is assessed in multiple topics, without however giving detailed information for this work. However, it has to be noted that there exist special allowances for families with disabled members and there is also the important institution of Children’s Ombudsman that could be exploited in favour of children with behavioral disturbs and their entourage.



**Figure 2. Qualitatively assessed accessibility status of each Member State and the EU**

[Source: Bekiaris et al., 2018]

The most enlightening document for our cause was a comprehensive Research for TRAN Committee focusing on persons with disabilities and reduced mobility and their transport and tourism needs (Bekiaris et al., 2018). This work, coordinated by Greek researchers, elaborated a wide range of available resources and provided at an EU level a valuable insight in the field of accessible transport and tourism (Figure 2). As already mentioned, there is a critical mass of



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entities in Greece that are active and provide help to families in question. For example, there is a growing community of Greek scientists studying cognitive disabilities and working in order to determine their prevalence in Greece and to ameliorate living conditions of concerned individuals and families. Attica Psychiatric Hospital for Children is a leading structure in Greece and families can address to the Health Care Centre and its competent team for assistance.

#### **2.4. Recommendation and advice available for these families;**

Recommendations for families with behavioral disturbed children are not included in official Greek Tourist WebPages. In the official webpage of Greek Tourism Organization (EOT) which have been designed and being updated by Greek Ministry of Tourism there is no specific domain for recommendation for traveling in Greece for families with disabled children or individuals. The webpage is not assessable even from people with disabilities<sup>7</sup>. The same in the EGT website which is the official website for the promotion of Greek tourism, with a lot of information on Greek tourist destinations such as cities, beaches, activities, events and much more! In this web page there are not specific recommendations for families with disabled children or disable persons<sup>8</sup> Specific Recommendations are included in travel portals. In more details, at one large and valid travel portal in Greece with specialized information and images for travels in Greece and around the world, advices for travel and accommodation for people with disabilities are provided<sup>9</sup>, Also in Emirates <https://www.emirates.com/gr/greek/before-you-fly/health/special-needs/> there are information but for persons with motor disability. At the website of national association for blinds<sup>10</sup> and at the webpage AMEA CARE<sup>11</sup>. Families need to have access to accessible and disability friendly places to visit in order to prepare their children and prepare

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<sup>7</sup> <http://www.gnto.gov.gr/el>

<sup>8</sup> <http://www.visitgreece.gr/>

<sup>9</sup> <https://www.travelstyle.gr/6-sumboules-gia-synarpastiko-taxidi-sta-atoma-me-eidikes-anagkes/>.

<sup>10</sup> <http://www.eoty.gr/main/text.asp>

<sup>11</sup> <https://www.amea-care.gr>



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them shelves. Children with behavioral difficulties needs to be prepared by social stories Social Stories are social learning tools that supports the safe and meaningful exchange of information between are taught to the children with behavioral disturbs in order to learn how to behave in social circumstances (Gray, 2020)<sup>12</sup>.

Parents in include that were participated in informal interviews highlight some trips necessary for travelling with their child:

- A checklist of issues to consider before beginning travel plans
- A list of possible resolutions to anticipated problems to consider, based on mental health and special education specialists’ advice, as well as other families’ experiences
- Advice on the need for pre-emptive preparation and contingency planning
- including sample material to serve as a template for brainstorming/preparing
- Comic strip or multimedia-based social stories to help familiarize the child with what to expect
- Simulated and/or theatrical enactment of key parts of the travel
- Particularly parts where restlessness, sensory overload, tantrums and/or meltdown incidents may be anticipated
- Actual dry-run walkthroughs of key parts of the travel experience
- e.g. familiarization with an airport/railway/bus terminal, security checks, waiting in queues, climbing escalators, seating in modes of transport, hotel lobbies, etc.

## **2.5. Good practices, illustrating initiatives that have been realized to sustain these families**

Progress has been made in different fields that cover: a) Raising awareness: cognitive disabilities is an issue now discussed publicly, covered (although not as much as the involved ones would

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<sup>12</sup> <https://carolgraysocialstories.com/social-stories/>

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like) by the media and addressed as such by the educational community. A lot of NGOs are working in this direction and are active in EU projects being the channel for knowledge transfer and experience sharing. Campaigns like “Blue for Autism” or celebration of Autism Day in April, are initiatives that make behavioral disturbs a social matter. b) Legislation: A number of legislative acts concerning autistic people’s rights have been passed (although with dubious results). However as regards transportation, physical disabilities are gaining more attention and “hidden ones” are poorly addressed. Detailed information can be found in the appendix the appendix. c) Research: A growing scientific community (inadequately funded) is trying to move things forward as regards diagnosis and intervention. When academia is cooperating with competent stakeholders, impressive results come up with direct social impact like the “Travelling with autism” initiative (see below).

Public entities invest progressively more resources on disabilities and relevant Ministries of Health, Education or Transportation and Infrastructure are faced with new departments mandated to deal with such matters although not yet really efficiently, as claimed by the concerned families. Local authorities (Ministry of Interior) are also involved with their social welfare services, neglecting for the time being behavioral disturbs. All this gives the room, fortunately in a way, to private sector initiatives to cover the gaps. A really interesting initiative in Greece was the creation of the platform [www.noesi.gr](http://www.noesi.gr) which provides for free a remarkably large range of information to individuals and families related with ASD. Such platforms are precious for the concerned community and thankfully there are other NGOs also active in this field. Autism – Asperger Hellas is an NGO in Greece working for the improvement of autistic people’s living standards and their leading a decent life which enables them to explore their full potential. It has launched web platforms, it provides support to the Special Day Care Unit of the Attica Hospital Aglaia Kyriakou and through AUTISMPRAXIS website, it enables social networking community for autistic people, families and autism professionals in Greece. Active associations can be found all around Greece, even far from the capital like the city of Kastoria in the North-west part of the country. The Greek Organization for the Protection of Autistic People - People

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with Pervasive Developmental Disorders (PDD) of Kastoria, founded in 2006 and registered in the Special Registry for Voluntary Non- governmental Organizations and is supervised by the Ministry of Health as registered member of the National Registry for Private and Certified Non-profit Agencies that provide Social Care services. Since 2012, the organization has been running a day Center for children, teenagers and young adults with autism (aged 4-25). This is the only facility in Western Macedonia which provides services for people with autism exclusively. Such associations keep on being born in order to support such families even in islands, where some services are poorer than in the continental country<sup>10</sup> and usually they seek grants to survive.

A leading private philanthropic organization, the Stavros Niarchos Foundation provides grants to non-profit organizations in the arts and culture, education, health and sports, and social welfare. A lot of grants have been attributed to associations and other entities dealing with children with disabilities and they often concern the facilitation in transportation of concerned families, like the purchase of a specially modified minibus to provide transportation to the Agios Vasilios day centre (Alexandroupoli, Greece), the grant for ELEPAP or DADAA - Association of People with Pervasive Developmental Disorder, Autism and Asperger in Komotini, Greece. As already mentioned, long distance trips are quite a challenge for families with children with APD. Reaching distant destinations by plane could eliminate travel time and fatigue on the one hand but constitute a stressful experience, even for healthy <sup>10</sup> In Chios island "CENTER FOR CHILDREN AND YOUTH" (CCI) is a non-profit Civil Society, founded in March 1996. Since November 2005 it has been recognized as a specially certified body of the National Social Care System, according to a decision of the Deputy Minister of State and the Deputy Minister of State. individuals.

In order to meet these families' air travel needs and in line with big European airports' good practices, a remarkable initiative was undertaken in the Athens airport “Eleftherios Venizelos”. The cooperation of academia, Onassis Foundation gave fruits and a qualitative manual was elaborated addressing people with AD. educational materials produced for the “Boarding Pass to

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Autism” program (Figure 3), which aims both to help children with Autism Spectrum Disorder familiarize themselves with the procedures of air travel and to raise awareness of these children’s special needs and profile as air travellers among fellow passengers, therapists and parents. The educational program is an Onassis Foundation initiative staged in collaboration with Athens International Airport under the academic auspices of the National and Kapodistrian University of Athens, with the support of AEGEAN airlines<sup>13</sup>.



**Figure 3: Boarding for autism brochure**

[Source: [www.airport-athens.com](http://www.airport-athens.com)]

<sup>13</sup> For more information on the “Boarding Pass to Autism” Special Education program, please visit [www.onassis.org](http://www.onassis.org).

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What would be crucial in the effort to develop a Model for fair Traveling development is to consider the emerging concept and of “Mobility as a Service” (MaaS) which, according to Maas4EU project<sup>14</sup>, it can provide the public with access to a wide range of transport mode through digital platforms, offering travellers and commuters the ability to optimize their trip by benefiting from different types of transportation. By the sole use of a smartphone and an app, consumers are empowered to handle all aspects of their journey – from planning to payment”. MaaS can take into account user’s general preferences concerning travel aspects like speed, convenience, comfort and cost, but also journey specific needs, for example a need to take along large pieces of luggage, a buggy or accessibility. This is particularly important for users with a momentary or permanent impairment to mobility (ERTICO, 2019). The personalized approach of MaaS may give pace to sustainable transport solutions for all citizens, especially those who with difficulties in using traditional public transport, elderly or disabled ones, by easing access to on demand, tailored transport provision. Apart from enabling a fundamental right, mobility provision can help meeting social and economic goals: – keeping people active positively impacts on their physical and mental well- being. Transport service levels for people with reduced mobility can vary enormously from place to place: tailored solutions implemented tend to be organized and supported by public authorities or volunteers as “traditional” services (public or private) are likely to be really expensive. Personalized services for vulnerable social groups could meet the deficit and ameliorate access to mobility (POLIS, 2019).

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<sup>14</sup> <http://www.maas4eu.eu/>



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Disabilities		Logos
1.	Motor Disability	
2.	Visual Disability	
3.	Hearing Disability	
4.	Cognitive Disability	
5.	Hidden Disability	

**Figure 4: Proposed clustering for people with disabilities for accessible transport and tourism (logos for 4 & 5 are not standardized)** [Source: Bekiaris et al.’s (2018) elaboration based on the “Tourism & Handicap Labelling scheme of France”]

In order for the efforts to be fruitful research is needed and orientation towards specific characteristics of people in need, diving them into those with permanent and temporary mobility restrictions. There should be also sub-categories that involve psychosocial disabilities (DGTREN, 2003), as suggested (Figure 4) by the above-mentioned EU report (Bekiaris et al., 2018) coordinated by CERTH/HIT15 and The “rough clustering” targets to meet the needs for a limited number of accessibility signage across the sector; whereas still highlighting that accessibility in transport and tourism concerns a much broader social group with respective needs, than limitedly focusing on persons with wheelchairs and/or blindness. Such efforts could be disseminated through campaigns in order to spread and create a voice for the social demand to include all citizens. A nice opportunity could be the program of private agency ECOCITY<sup>16</sup> “Free mobility” where different educational entities take part in competition by creating projects illustrating their everyday struggle to mobility. For example, a mission of the Special Vocational

<sup>15</sup> Hellenic Institute of Transport of the Centre for Research and Technology Hellas.

<sup>16</sup> Source: [www.ecocity.gr](http://www.ecocity.gr)

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Education and Training High Schools (EEEEK) of Serres, Greece reached even the European Parliament to present its work on inclusive mobility and to be heard.

## **2.6. Needs, identifying the primary and secondary needs for these families**

In Greece there are founded public services for identifying primary and secondary needs for these families:

- a) Educational and Counselling Support Centres (KESYs) and Sustainability Learning Centres (KEAs) have been established at regional level to support families with disabled children at schools. KESYS assess special needs of child and family and support schools to develop specific curriculum to include them in school curriculum KESYS identifies the needs of families and give advises concerning how to support their child with disability. KESYS, although they could, they haven't developed specific curriculum or programmes for education parents how to support their children while they are travelling. Although KESYS are staffed with experts in inclusive, special education, social workers, psychologists and they really know the difficulties a family faces even for the everyday trips and transportations they haven't designed specific curriculum addressed to these difficulties.
  
- b) Mental Health Centres with the support of Psychiatrists, under the Hellenic Centre for Mental Health and Research (HCMHR) The Hellenic Centre for Mental Health and Research is a private-law public benefit organization that provides mental health services to children, adolescents and adults, serving the principles of community-based psychiatry, as shaped by clinical and theoretical experience, both in Greece and in Europe. It was founded in 1956 in Athens by the Royal National Foundation as a Mental Health Section. In 1964, based on no. 20173 / 17.1.64 of the founding act, was instituted as a Legal Entity under Private Law, called the Center for Mental Health and

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Research. On September 12, 2017 Decision No. A4b / GP67300 "Organization of the Hellenic Center for Mental Health and Research" (Amendment-Addition to Decision no. C3b) was published in the "Government Gazette" (No. 3192). 23902- Sheet No. 1192 / 9-4-2019, Issue Two). Today EKE.Y.E. is sponsored and supervised by the Ministry of Health and managed by a seven-member Board of Directors designated by the Ministry. It is the largest provider of outpatient mental health services nationwide.

- c) Medical Centers inside Public Hospitals These centres support families with children with disabilities. And identifying their needs primary and secondary.

These needs as families form “Include” described and depending on the personality traits of each individual child the family needs and their prioritization can obviously vary, are presented below:

- a) Due to this variability of needs, sensitivities, possible triggering stimuli and anticipated reactive behaviours, it would be more practical to offer parents and guardians a tool kit of assistive interventions rather than a pre-decided course of action.
- b) Specialized travel and special education professionals could then use this tool kit and advise parents on how to set up a pre-emptive travel plan, including contingency planning in case adverse reactionary behaviours do occur.
- c) Family needs are the driving factor behind the variability of need for possible assistive interventions.
  - Adequate time to prepare for travel including
  - Brief preparatory consultation of parents with experts
  - Preparatory work performed by the parents or special education experts with the child



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- Contingency planning
- d) Minimization of the amount of time spent in travel terminals while waiting to board, after disembarkation and during transfer between modes of transport particularly time spent waiting standing in queues
- e) Minimization of the exposure of special needs children to possible sources of stimulation overload
  - Sounds
  - Smells
  - Crowds
  - Flashing lights and colours
- f) Travel company personnel who has been trained to assist families with children with behavioural disturbs, to escort the family through security checks and until they find their seats. For any waiting time which is absolutely inevitable, special uncrowded, relatively quiet waiting rooms, with comfortable furniture where a child can relax, play and lower stress levels
- g) Some discreet symbolism (e.g. special lanyard passes that a parent can choose to wear around their necks) that signal to other passengers that there is a health reason for bypassing queues, without stigmatizing the child or the family. This is particularly important because behavioural disturbs are not always apparent, especially for high-functioning individuals
- h) Special preparation for giving explanations and descriptions concerning the child’s specific difficulties in the language of destination. Talking about child’s special needs in local language would be difficult. Knowledge of specific terminology of the child’s special needs it will be useful while they are travelling. In particular, special physical or



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mental needs, special equipment, medicine etc.. They would also be prepared to talk about allergies, special diets (vegan, vegetarian, soy-free, gluten-free, etc.). It is, also, recommended to use an online translation service to print out explanations of family’s needs in destination’s local language. The use of cards in both English and the local language it is also recommended. Giving these cards to hotel staff, to the waiter at a restaurant, or anyone else who needs to understand your special needs and characteristics of the child and families, families will easily communicate the needs of their child. Clear explanations can ensure that the family gets the treatment they need and no one has to experience the discomfort of trying to explain a problem with hand motions or funny faces. □ If families are travelling to several countries with different languages, they may need a few sets of cards for each language.

- i) Prevention of possible illness of the child with behavioural difficulties during travelling. Parents need to be prepared to make the sick child feel better as quickly as possible. It’s always a good idea to take a few over-the-counter medications while travelling. Over-the-counter medications may include:
- Headache medicines
  - Allergy medicines
  - Medicine for upset stomachs
  - Motion sickness prevention medication
  - Other medication that might apply to your family or the specific trip
  - If the child is taking prescription medication, parents are recommended to be sure to bring it along. Whenever possible, take medications in their original packaging, especially prescription medications.
  - If the original package cannot be taken, a copy of the prescription from the doctor



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would be taken so they can show exactly what the prescription is and why they have it for border crossings and if the luggage is searched.

- j) Before the trip, regulations for the destination recommended to be checked and confirmation that the specific medication it is allowed to enter the country without filling out additional paperwork or getting special permission.
- k) Providing the child with some level of familiarization with what is about to happen can generally be beneficial, especially if it is offered in a personalized fashion, based on methodologies that have been proven to work in the past. For instance, some children can optimally absorb information and accept a new experience using
- repetitive narration and instruction
  - social stories based on multimedia and narration
  - simulated mock runs of the experience (or parts of it)
  - theatrical re-enactments of the experience (or parts of it)
  - timely introduction to accessories or equipment that filter or direct their attention (e.g. ear plugs, ear phones, toys, electronic devices, etc)
- l) Contact information should be written in a an obvious point so that easily somebody could read them in the case the child be lost. Contact information includes the following items for all of the adults on trip so multiple opportunities for help locating your child could be found. Name, Phone number, Email address, Local address
- m) A small GPS tracker attached to child shoes or belt is strongly recommended. The tracker will alert the parents if the child gets too far away and will let parents track it to see exactly where the child went.
- n) During the trip the time between meals will get extended. It could be a delayed flight, unexpected traffic getting to your hotel, or a tour that takes a bit longer than you thought



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it would. The food at your destination may be quite different than what your kids usually eat. It doesn't hurt to have child's favourite snacks.

- o) Plenty of apps, movies, or TV shows downloaded and ready to use are recommended.

**2.7. Stakeholders, identifying the key stakeholders and their role in supporting these families.**

- Regional Health Services: Mental health and special education professionals who would advise the parents and help prepare the child with special needs for travel Specialized mental health and special education professionals who may be embedded in traveling institutions (e.g. an airport) Public social and health insurance institutions
- Regional Tourism public and private Services: Travel companies and personnel, including personnel specially trained to assist with behavioral special needs. Travel facility companies and personnel Ground crew at an airport/bus/railway terminal, security personnel, drivers, pilots, cashiers, baggage handlers, etc.
- Catering companies and personnel
- Travel and health insurance private companies
- Parents associations
- KESYs and Educational regions
- Municipalities

**3. Conclusions – Recommendations**

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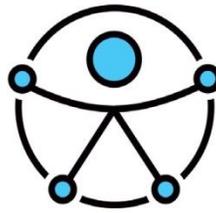
First conclusion is that no matter the commitment to EU regulations, there is still a lot to be done for equity in travelling in Greece. The investment on disabilities differs and mental ones seem rather neglected. What also seems to be underestimated is the broader impact of the prevalence of a disability on the close entourage of the disabled individual. Behavioral disturbs need to no longer consist a social issue affecting the minority of relevant scientists and families concerned. This requires state funding for research and the enhancement of the educational and health system with appropriate supportive structures, early diagnosis procedures, training programs for teachers and parents, unified and structured awareness campaigns, and a proper “coaching” for parents reluctant to accept the condition of their children and step forward. The need of more investment to fund initiatives in multiple sectors like research or legislation for such disabilities and the appropriate awareness and activation was broadly advocated during the multiple contacts undertaken within this research. Short telephone or face-to face interviews as well as e-mailing with public officers, specialists, associations for disabled persons or parents of children with such disturbs really added a different perspective: the surprise of the people contacted (some of those listed at the end of the report) was indicative at the hearing of our request on mobility experiences and provisions for such families in Greece. What has to be stressed is that such disabilities are considered hidden and somehow neglected and families or care-givers of such children are used in coping with problems in their own... travelling from a middle-sized Greek city to Athens for the special Olympics was feasible thanks to the courage and the inspiration of accompanying adults, specialists and parents. Efforts should constant an interesting training was held addressing professionals in the public transport sector on the occasion of Olympic Games in Athens in 2004, however never repeated since. The training was focusing on how to handle incidents and the needs of persons affected by behavioral disturbs. Mobility and tourism involve issues of “hidden impairments” and a concise strategy is required in many sectors. UN Committee recommends that Greece ensure that providers of services to the public, particularly public broadcasters, telecommunications operators and public libraries, progressively provide information for persons with disabilities in accessible and easy read formats and captioning,

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based on an established and monitored action plan. It also recommends that Greece adopt effective measures to facilitate the use of appropriate formats with the active involvement of the relevant organizations of persons with disabilities (UN, 2019).



**Figure 5: New symbol of Disability (proposed by the United Nations)**

[Source: OneWorld, 2018]

Aiming to make the country attractive to foreigners but also facilitate local families' life, good practices tested abroad can be introduced to local conditions. New signs or new equipment addressing people with disabilities beyond the traditional ones solely referring to kinetic disabilities can be introduced in the Greek context. For instance, the new symbol of disability developed by the United Nations (UN) which may be used to signify accessible services for persons with disabilities. This symbol is used at Heathrow Airport to indicate services for persons with reduced mobility.

Another good practice, supported by charities in some EU countries and beyond, is a sunflower lanyard, worn around the neck, lets others know that you have hidden disabilities. Sunflower lanyards can be worn by individuals with hidden disabilities as a way of discreetly letting others know they might need extra assistance in certain situations. The Hidden Disabilities Sunflower purpose aims to help others identify when support may be needed for those with disabilities such as autism, dementia, anxiety, or other conditions that may not be immediately obvious to other people.

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Today, the fast-growing sunflower lanyard initiative is helping adults and children with hidden disabilities experience more support in airports and supermarkets by acting as a discreet sign for staff that additional support or help may be required by the wearer of the lanyard. The lanyards, which are bright green in colour and decorated with a sunflower design, are free of charge, and help identify people with additional needs and their families navigate their way through busy airports without having to specifically ask for assistance. The scheme is a simple way to enable staff at airports to identify those who may need extra support.



**Figure 6: The sunflower lanyard**

[Source: <https://www.disabled-world.com/disability/awareness/sunflower-lanyard.php>]

Last but not least, Information and Communication Technologies (ICTs) should be exploited the most as they have considerable importance for transportation: they offer access to travel information, planning trips, opportunities to share transport modes, to compare transport modes'

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costs, make bookings and payments, as well as to communicate travel plans. Over the past years, there has been a massive development of transport ICT through, for example, smartphone applications. ICTs have profoundly changed the way transportation systems (both local and long-distance) and it is high time this was done for those who mostly need it. As regards persons with cognitive disabilities, as users they require user interfaces with minimal complexity, to be able to use advanced vehicles. The vehicle’s ability to provide supervision and tracking in the form of video cameras and GPS would also be helpful for caregivers responsible for their safety and well-being. For example, if one’s family can help the individual into a vehicle, the system may help ensure the individual is not lost or in danger, which may ultimately provide more independence (Ruderman Family Foundation , 2017).

To conclude, situation for families travelling with children with disabilities in Greece is not something to be satisfied about. It is crucial to take advantage of the rich potential the country has in science and research and take steps forward given its people’s demonstrated empathy and in respect to Greek values of democracy and social equity.

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## Pictures

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Cover page <https://pixabay.com/illustrations/people-kids-children-group-2129933/>

## 5. Useful links

- <https://www.aia.gr/traveler/travellers-info/special-assistance/>
- <https://www.un.org/development/desa/disabilities/>
- <https://autismhellas.gr/en/>
- <https://www.disabled-world.com/disability/awareness/sunflower-lanyard.php>
- <http://www.trainose.gr/en/passenger-activity/passenger-services/disabled/>
- <https://www.snf.org/en/>
- <http://www.ecomobility.gr/>
- <http://www.amillionsenses.com/articles#>
- [www.aglaiakyriakou.gr](http://www.aglaiakyriakou.gr)
- <http://www.autismaroundtheglobe.org/countries/Greece.asp>
- <http://autismpraxis.ning.com/>
- <https://www.autismgreece.gr/nea-ekdiloseis/anakoinoseis/512-syriop.html>
- <https://www.european-agency.org/country-information/greece/>
- <https://www.ohchr.org/EN/countries/ENACARegion/Pages/GRIndex.aspx>
- <https://www.birmingham.ac.uk/generic/transform-autism-education/greek-team/terminology.aspx>
- [www.autismspeaks.org](http://www.autismspeaks.org)
- [www.aspergerhellas.org](http://www.aspergerhellas.org)
- [www.parentingaspergers.com](http://www.parentingaspergers.com)
- [www.noesi.gr](http://www.noesi.gr)
- [www.4family.gr](http://www.4family.gr)
- [www.AutismResearchInstitute.com](http://www.AutismResearchInstitute.com)
- [www.eas.asu.edu/~autism/](http://www.eas.asu.edu/~autism/)
- [www.disabled.gr](http://www.disabled.gr)

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- [www.specialeducation.gr](http://www.specialeducation.gr)
- [www.parents.gr](http://www.parents.gr)
- [www.pecs-greece.com](http://www.pecs-greece.com)
- [www.ldam.org/default.html](http://www.ldam.org/default.html)
- [www.european-agency.org](http://www.european-agency.org)

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## **7. Appendix I - Extract from Legislation Updates 2019 report elaborated by the European Agency for Special Needs and Inclusive Education**

### **GREECE**

#### **Re-organization of support structures of primary and secondary education (Law 4547/2018)**

##### **Overview of the new law or policy**

Law 4547/2018 refers to the reform of educational structures, with a view to gradually decentralizing the education system and responding to all learners’ diverse needs. The text below reflects the implementation of Law 4547/2018, which may be subject to review by the current Ministry leaders. Therefore, some of its content may change.

##### **Focus and aim of the law or policy**

###### *Regional Centres for Educational Planning*

Regional Centres for Educational Planning (PEKES) are being established at regional level. PEKES primarily aim to:

- plan, monitor, co-ordinate and support the educational task of public and private schools, and Vocational Education and Training (VET) Workshop Centres;
- co-ordinate the Educational and Counselling Support Centres (KESY), Sustainability Learning Centres (KEA) and Natural Sciences Laboratory Centres (EKFE) of their area of competence;
- support teachers in both the public and private sector in scientific and pedagogical matters;
- organise training programmes for teachers (including introductory training) on scientific, pedagogical, teaching and evaluation matters;
- promote sharing of good practices among schools and teachers, design co-operation programmes among schools, KESYs and KEAs, and with the higher education institutions in their area;
- support the planning of and self-reflection on schools’ educational work at regional level.

Each PEKES has its own group of educational co-ordinators, each of whom is responsible for different subjects and fields. These include Co-ordinators of Special and Inclusive Education Matters, with their respective responsibilities.

###### *Educational and Counselling Support Centres and Sustainability Learning Centres*

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Educational and Counselling Support Centres (KESYs) and Sustainability Learning Centres (KEAs) are established at regional level and operate at local level. KESYs replaced the previous KEDDYs (Diagnostic Assessment and Support Centres). KESYs have a wider role and mission, not limited to special needs education, but with a more inclusive focus. In particular, KESYs aim to support school units and VET Workshop Centres to ensure equal

access to education and to safeguard learners’ appropriate psycho-social development and progress.

KESYs explore and evaluate educational and psycho-social needs, difficulties and obstacles to learning and barriers to education that all learners in the school community face, including learners with disabilities and/or special educational needs. In this context, KESYs make proposals on issues of differentiated learning, assistive technology and service provision. They also make proposals for formulating the main pillars of individual education plans (EPE).

Their other competences include:

- planning and implementing educational and psycho-social interventions, vocational guidance actions for learners, and counselling support for teachers and parents;
- supporting the overall goals of schools and VET Workshop Centres;
- providing information and training to the school community to promote inclusive education;
- raising awareness of the community by promoting partnerships among schools, families, scientific and social institutions, local authorities and universities on issues of diversity, psycho-social health, career guidance and transition to the labour market.

In addition to the above, PEKES co-operate with KESYs to:

- ensure that remedial educational programmes are implemented to tackle issues like school failure, school drop-out and bullying;
- combat any form of exclusion or discrimination by supporting teachers through training to promote inclusive education;
- plan training courses for parents to inform them on matters that are relevant to their parental role and their co-operation with teachers and the various local support bodies.

PEKES also co-operate with KEAs to support the planning of innovative school activities on environmental, cultural and healthcare matters. These are in accordance with educational policy priorities and the needs of school units and VET Workshop Centres.

### ***School units***

At school unit level, the networking of groups of schools is being promoted through the establishment of School Networks of Education and Support. The pedagogical autonomy of each school unit is also being promoted.

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### **Likely impact of the law or policy**

Law 4547/2018 aims to re-organise the education system’s supportive structures with a more inclusive focus. It emphasises effective support for the whole school community, learners and their families.

From this perspective, it sets the scene for:

- the necessary mentality shift towards inclusion among all stakeholders and practitioners;
- building mainstream schools’ capacity to respond to the diverse needs of all learners, including those with disabilities, refugees, learners with low achievement, learners from underprivileged backgrounds and learners from vulnerable social groups;
- taking a further step towards realizing the principles of the United Nations Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

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## RTA report

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## INTRODUCTION

All children misbehave at one point or another. Although getting into trouble occasionally is a normal part of growing up, some children have behaviors that are extremely difficult to deal with and are not common for their age. Behavioral disorders refers to a category of mental disorders that are characterized by persistent or repetitive behaviors that are uncommon among children of the same age, inappropriate, and disrupt others and activities around the child. <https://study.com/academy/lesson/behavioral-disorders-in-children-definition-symptoms-quiz.html>

Mental health problems in children and adolescents include several types of emotional and behavioral disorders, including disruptive, depression, anxiety and pervasive developmental (autism) disorders, characterized as either internalizing or externalizing problems. The age and gender prevalence estimation of various childhood behavioral disorders are variable and difficult to compare worldwide. Childhood behavioral and emotional problems with their related disorders have significant negative impacts on the individual, the family and the society (Michael O Ogundele. 2018).<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5803568/>

Children and young people with undesirable behaviors, deficiencies and annoying behaviors have always been present in all societies. The degree to which they have been striking and the environmental response to them depend on cultural, religious ethical, economic and social conditions. These reactions have changed dramatically over the centuries and have evolved from diverse forms of corporal punishment in the European Cultural Area to a full understanding of socially adequate development (Myschker, 1992).

The term "behavioral disorders" is usually understood to mean difficulties in upbringing and violation of socially accepted norms in human relationships. These difficulties and norms may depend on each individual person encountering them. Some consider behavioral disorder as

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a behavioral disorder and associate it with aggressive behavior. Little attention is paid to passive activity and depressive states as behavioral disorders, although they affect one's own life and successful integration with others (Bethere D., Līdaka A., Plostniece A., Ponomorjova J., Striguna S., 2013).

Behavioral disorders are related to the age of the children:

- childhood-onset CDs (~ 7%) (more common in boys) show more aggressive behavior, disproportionate delinquency, and persistence as the child grows.
- Character remains the same as other options become available as they grow (Patterson, 1993).
- Adolescent disorders (same for boys and girls) = less aggression, the disorder decreases with increasing adolescence (Waldman, Lilienfield , Lahey, 1995; Lahey, Goodman et al., 1999).

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## 1.

### 1. TRAVELING WITH CHILDREN WITH BEHAVIORAL DISTURBS IN LATVIA

#### 1.1. Issues in traveling for families with children affected by behavioral disturbs, in Latvia

Investigating human behavior and timely detection and prevention of negative behaviors can be considered essential in any society. This is particularly important for countries facing socio-economic crises, as is currently the case in Latvia. In Latvia, the issue of reducing the negative manifestations of behavior is topical, as they significantly influence the educational attainment of students and the quality of their upbringing or preparation for life in society. Currently, researchers in different countries (*Bethere D., Līdaka A., Plostniece, A., 2013*) characterize the causes of negative behavior and classify them by focusing on the functional manifestations of behavior. At the same time, the basic component of the effectiveness of using behavioral research results in different situations is unjustifiably neglected.

<https://visc.gov.lv/specizglitiba/dokumenti/metmat/esfpr/VISC%202.2%20%20metod%20mater%20pedagogiem%20-%20uzvedibas%20traucejumi.pdf>

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We can understand child's actions and get an answer to the question, why he/she is doing so, only through conversation. Often children say that they are the biggest fools in the world and there is no point in trying. Typical negative behavior has a lot of reinforcements, also called coercive behavior, because the child is forced to do what he/she does not want to do. If not otherwise, screaming is the next step. There is little reinforcement of positive behavior, appreciation, tangible rewards for doing something good, which reduces self-esteem and makes a child with a negative self-image become more aggressive.

[https://izglitiba.riga.lv/lv/izglitiba?target=news\\_item&news\\_item=berna-uzvediba-ir-aisberga-redzama-dala-1828](https://izglitiba.riga.lv/lv/izglitiba?target=news_item&news_item=berna-uzvediba-ir-aisberga-redzama-dala-1828)

It is important to start dealing with behavioral problems as early as possible, the sooner one start solving them, the easier it will be to deal with them. If behavior problems start before the age of 10, they are unlikely to resolve themselves. However, massive behavioral problems are costly for both parents and society; if the problems are being dealt with in older age, the more expensive and less effective support programs are. Adults, who have not solved behavioral problems in childhood, often end up in closed-type correctional facilities, where the state has to take care of them.

Parents also need support to raise their children fully. For example, parents often get tired at work and at the same time feel guilty for not being able to pay enough attention to the child. In addition, parents not once feel socially isolated with their problems. State and municipal institutions frequently pay a lot of attention to families with high social risk, but parents who are not in the daily view of social services also need support.

<https://www.la.lv/ja-uzvedibas-problemas-sakas-lidz-10-gadu-vecumam-tas-visticamak-pasas-neparies>

Specialists believe that human behavior is based on five personality traits: hereditary temperament, age, stress, emotional factors and value system, so it is important to distinguish and separate behavioral problems from disorders. Behavioral problems are violations of behavioral norms such as disobedience, noise, brawling or name-calling; behavioral disorders are

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clinically based disorders that require medical diagnosis and treatment. It is usually difficult for parents to accept that their child's behavioral disorders may be due to mental health, neurological or other causes. Parents refuse to seek the help of a neurologist, psychotherapist or psychiatrist; they look for other children or educators to blame.

<https://jauns.lv/raksts/sievietem/71885-sabiedriba-aug-satraukums-par-bernu-slikto-uzvedibu-skola>

Children with behavioral disorders - these are all minors with problems with self-regulation and/or social interaction with adults and peers. (Sociālā darba terminoloģijas vārdnīca. (2000) Rīga, SDSPA "Attīstība“).

Children with behavioral disabilities are usually classified as people with special needs. SUSTENTO, the Latvian organization for the co-operation of people with special needs, points out that the barriers and limitations of traveling for such people are not only to be found in the environment, but also in the person itself. Although it is not possible for tourism service providers in Latvia to address these barriers directly, it is important to take them into consideration when designing a service marketing plan to offer it to this specific target audience. People with disabilities need a significantly longer period of time to plan their trip. Lack of information on tourism availability is one of the most important factors that reduce the number of potential travelers. Incomplete and inaccurate information misleads travelers and the resulting negative experience discourages them from traveling one more time.

[https://www.daba.gov.lv/upload/File/Publikacijas/BRO\\_14\\_Zalie\\_marsruti\\_turisma\\_uznemejiem\\_LV.pdf](https://www.daba.gov.lv/upload/File/Publikacijas/BRO_14_Zalie_marsruti_turisma_uznemejiem_LV.pdf)

When traveling with the child with behavioral disorders, parents should be prepared for and react to unusual situations, as the child may have a variety of manifestations:

- extreme activity: frequent, rapid and aimless movements;
- distracting behavior during the travel - leaving the place, harassing others, playing and making noise;
- aggressive, victim-oriented behavior with intent to harm;



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- attempts to hurt himself/herself or others;
- criminal behavior - theft, lying, breaking the law;
- thought disorder (strange ideas);
- seclusion, avoiding social interaction, drowning in sleepiness;
- playing alone, being unable to cooperate with others upon invitation;
- sudden changes in behavior or mood for no apparent reason;
- monotonous, crippled or exaggerated emotional reactions.

Every child must be included in the community and environment, in which he/she is entitled to appropriate care and education, but the most important part of a child's development is the family and environment, in which he/she is present. The guidance and love of adults plays an important role in the child's development. If the child has behavior manifestations, it should not be an obstacle to refusing to travel. Young children require special care on long journeys. Children with behavioral disorders at all ages, on the other hand, require increased attention, support and sensitivity from parents, accompanying persons and society as a whole. Disability makes them particularly vulnerable to the general public. People with disabilities should know their rights, as well as their representatives - parents, guardians - should know these rights and obligations. In this way, the responsibilities of parents/guardians in relation to children with disabilities in Latvia include the following:

- an obligation to act in the best interests of the child;
- the right to non-discrimination;
- consideration of the child's ability to develop;
- the right to participate and the right to be heard;
- the right to be free from violence;
- the right to family life;
- the right to assistance;
- the right to education, including inclusive education.

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## **1.2.Regulations available to support the travel needs of these families**

### **Law on Protection of the Rights of the Child has been officially approved in Latvia.**

The rights of the child shall be protected in order to achieve the following objectives:

- 1) formation and consolidation of the value orientation of the child in accordance with the public interest;
- 2) child's orientation to work as the only source of the means of subsistence and well-being supported by morality;
- 3) orientation of the child to the family as a fundamental value of the organization of the society and one of the main values of the society and the individual;
- 4) orientation of the child towards a healthy lifestyle as an objective precondition for the survival of the people;
- 5) safety of the child, as well as the maximum protection of his/her health and life, paying particular attention to them during public events or children's public entertainment, sports or recreation events, armed conflict, fire or other emergencies (floods, storms, increased radiation levels, etc.). <https://likumi.lv/ta/id/49096-bernu-tiesibu-aizsardzibas-likums>

Latvian legislation and Cabinet regulations govern actions, rights, etc. only if the child has a disability, but not behavioral disabilities:

- free public transport;
- parents do not have to pay a vehicle operation tax for 1 car;
- access to social care and rehabilitation;
- an assistant available at an educational institution;
- technical aids are paid by the state;
- there are exemptions from state fees and discounts;
- discounts in museums.

<https://lvportals.lv/skaidrojumi/252629-atviegljumi-berniem-ar-invaliditati-2012>

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One of the main tasks of the tourism industry in Latvia is to facilitate the granting of benefits for the tourism of pensioners, the disabled, young people and children. (Section 3 Paragraph 7 of Tasks of Tourism Industry)

<https://likumi.lv/ta/id/50026-turisma-likums>

For example, the European Parliament and Council Regulation No. 1107/2006 concerning the rights of disabled persons and persons with reduced mobility when **traveling by air**: disabled passengers and persons with reduced mobility requiring assistance, as well as the legislation require action:

- if the passenger is blind or partially sighted;
- if the passenger is deaf or hard of hearing, with speech impairments;
- if the passenger is blind and deaf, and who can only move with the assistance of an attendant;
- if the passengers have intellectual disabilities or developmental disabilities, who require support.

This applies to the passengers suffering from, for example, Alzheimer's disease or Down syndrome, etc. However, Latvian legislation does not regulate the behavior of passengers, including children, with behavioral problems. The Administrative Procedure Law of the Republic of Latvia or the Law on Administrative Liability does not determine norms of behavior. Each municipality can adopt its own binding rules that regulate behavior in public places, such as a ban on sitting on the lawn, etc., but not when parents traveling with children.

<https://likumi.lv/ta/id/55567-administrativa-procesa-likums>

In Latvia, the rights of a natural person, who has not reached the age of 15 or whose legal capacity has been restricted by a court, or a minor has violated a rule or law, are legally represented by parents. However, the first institution dealing with such issues, including behavioral problems, is the Family Court, which operates in each municipality.

<https://likumi.lv/ta/id/49096-bernu-tiesibu-aizsardzibas-likums>

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Latvia is also implementing the European Social Fund project "Improvement of Support System for Children with Communication Difficulties, Behavioral Disorders and Domestic Violence". The Latvian Sustainable Development Strategy 2030 identifies long-term investment in human capital and quality and accessible education as a separate line of action in order to preserve the basic value of Latvian human capital and increase its productivity. The National Development Plan of Latvia 2014-2020 also includes the development of psychological stability in childhood among the tasks, providing a solid foundation for development, assistance in crisis situations and parents' education, which would reduce the risk of inappropriate behavior in children.

[https://www.pkc.gov.lv/sites/default/files/inline-files/ZINOJUMS\\_berni\\_01X2018.pdf](https://www.pkc.gov.lv/sites/default/files/inline-files/ZINOJUMS_berni_01X2018.pdf)

### **1.3.Recommendation and advice available for these families**

Behavior therapy and corrective behavior are always taught (socially desirable or undesirable) by imitation and/or reinforcement. Children get some form of benefit with aggressive behavior, disobedience, resistance to adult demands. The behavior to be changed shall be described precisely when conducting a behavioral analysis; the situation immediately before and immediately after the behavior should be described. Problems of behavioral therapy and correction in Latvia are dealt with by social educators, psychologists, psychotherapists, social rehabilitators by implementing diverse and widely available correction programs and recommendations for parents.

<https://visc.gov.lv/specizglitiba/dokumenti/metmat/esfpr/VISC%202.2%20-%20metod%20mater%20pedagogiem%20-%20uzvedibas%20traucejumi.pdf>

[http://www.lm.gov.lv/upload/berni-b/vp\\_2017\\_groz\\_2\\_pub.pdf](http://www.lm.gov.lv/upload/berni-b/vp_2017_groz_2_pub.pdf)

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Information related to behavioral disorders during travel is minimal, for example, Broka O., (2015) recommends that children with aggressive behavior have muscle cramps, so relaxing exercises are useful for the relaxation of face, arm and body muscles.

30% of Latvian residents choose to travel with their family, according to a survey conducted by travel agency "Latvia Tours" Ltd. at the beginning of last year.  
[http://epadomi.lv/celosana/padomi\\_celotajiem/29082017-padomi\\_ertakai\\_celosanai\\_kopa\\_ar\\_berniem](http://epadomi.lv/celosana/padomi_celotajiem/29082017-padomi_ertakai_celosanai_kopa_ar_berniem)

Therefore, parents should be aware of the problems they may encounter while traveling with their child:

- The child becomes unsafe when there are no parents or other adults nearby.
- The child does not accept changes (other clothes, new toys, food, etc.).
- The child is running or climbing in unauthorized situations.
- The child is unable to rest (moving his/her hands and feet uneasily, swinging on a chair, being too active, moving, even when asked not to do so).
- There is an impression that the child does not hear what is being told.
- The child can only perform the task if the instructions are repeated several times.
- The child finds it difficult to engage in activities that require compliance with the rules.
- The child tries to avoid common games, plays alone for a long time and does not want to be disturbed
- The child is too sensitive to reprimands (screaming, falling down, kicking, tearing things apart, running away, getting agitated and hard to calm)
- The child behaves apathetically, indifferently.

When traveling with a child with behavioral disorders, preparing for the trip should be started early.

During the trip planning phase:

**1. The choice of vehicle should depend on the specifics of the trip**



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- 1.1. **A personal car** is a convenient vehicle as you can take everything you need and feel free to plan your trip. This type of travel is suitable if you do not have to travel long distances.
- 1.2. If **a bus** is chosen as a means of transport, it has to be taken into account that you will have to adapt to the route and the wishes and interests of the other travelers.
- 1.3. When choosing, for example, **the group excursion**, you should pay attention to the travel program and assess whether it is suitable for traveling with a child with special needs. It is important to find out how often rest breaks are provided and what amenities are available in the vehicle. Of course, in this case too, light snacks, drinks and necessary hygiene items must be packed with you.
- 1.4. When traveling by **waterborne**, you must pay particular attention to safety -children cannot be left unattended. Before traveling, it is also advisable to familiarize yourself with the weather forecasts and pay attention to appropriate clothing.
- 1.5. **Public transport** in the city. Within the territory of the Republic of Latvia, children with Group I disabilities and their companion are entitled to free public transport. When traveling to another country, it would be useful to find out what the situation is in the country where you plan to stay.
- 1.6. **An airplane** is the best choice if you plan long distance or need to get to your destination quickly. It is clear that the child is energetic and needs to be employed during the flight. At the same time, children can get tired faster than adults. Therefore, it is important to think about possible games, light snacks, including suitable drinks and hygiene items before your trip.

## 2. **The list of things to bring with you is well thought out**

Before traveling, think carefully about what you will need for your trip (from IDs to hygiene items). It is also a good idea to take advice, extracts, if any, from mental health and special education specialists, and to collect in advance the experiences of other families with



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children with behavioral disabilities, who have ever traveled. It is worth remembering about the vaccination passport, as well as the vaccines to be taken when traveling to an exotic country. It is useful to discuss the parts of travel with the child with behavioral disorders that can cause anxiety and sensory overload, for instance, security checks, waiting in queues, climbing escalators, sitting in various means of transport, hotel lobbies, etc.

### **3. When traveling with family, it is recommended to choose family-friendly hotels**

Before booking a hotel, it is advisable to familiarize yourself with the types of rooms available at the hotel and the terms and conditions of their reservation, and it is worth inquiring whether the chosen hotel is "family friendly", including discounts or special services for children. There are various rules regarding accommodation, which you should consult with the hotel or your travel consultant beforehand. Not all hotels are family-oriented. Sometimes a family room or two connected rooms can be found in the range, which are also suitable for family. It is advisable to pay attention to the equipment of the room and evaluate its suitability for the requirements.

- 4. Catering** is an important ingredient for a successful trip. A child with behavioral disorders may be aggravated by a lack of food. This may cause an adverse reaction. Parents are advised to bring light snacks, non-perishable products so that the child can have a small meal and soothe hunger when needed.
- 5.** There are quite a lot of **information stands** placed for tourists in Latvia to reflect the information. Most of the information is in Latvian, Russian and English. Persons with disabilities, such as wheelchairs, may find it difficult to access information, especially in the public sector, also due to the lack of documentation in accessible formats and sign language.
- 6.** When buying **insurance**, it is obligatory to insure the child, because it is difficult to predict, how they will react to food and climate change. Without insurance, even an ordinary visit to a doctor can be very costly.

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7. Depending on the age of the child, a stroller, a special cot or other means may be needed, so **renting the equipment** must be identified in advance of travel. It is often the case that it is cheaper to use rental services than to transport the equipment by air.
8. **Suitable clothing.** When traveling, you have to expect different weather conditions. The child with behavioral disorders may react differently to new situations, including getting dirty and spilling on. Clothing must be in reserve.
9. **Medication.** If your child needs to take certain medications, they should be definitely packed with you while traveling.
10. **Start travelling with children as early as possible.** Do not wait for the "child to grow up" - it will never be the right time. Plan your trips carefully, talk to experienced friends, read articles online, and a vacation with your child will be an experience that will strengthen your family.

#### **1.4. Good practices, illustrating initiatives that have been realized to sustain these families**

There are many travel agencies in Latvia, the most popular of which are Kolumbs (www.kolumbs.lv), Impro celojumi (www.impro.lv), Ozolciems ture (www.ozolciems.lv), Novatours (www.novatours.lv), Atlantic travel (www.atlantic.lv), etc. It is the only source of minimal information about traveling with children with special needs, but not behavioral problems.

The articles about family experiences concerning traveling with children are available in Jekabs' travel blog "How to Make A Travel with a Young Child a Mission Possible. 10 Inspirational Tips" <https://blogs.jekaba.lv/ka-celojumu-ar-mazu-bernu-padarit-par-iespejamo-misiju-10-iedvesmojosi-padomi/>

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If traveling to the so-called 'near abroad' took several days in the beginning of the 20th century, today, thanks to technological advances, it is possible to reach further corners of the globe in about 24 hours. Traveling has also become much more comfortable, so parents are increasingly traveling with their children. It is important to plan all the nuances for such trips and avoid unnecessary incidents, so there are some tips known in Latvia on how to travel easily with children.

**Good practice stories** and personal experience tips are shared by parents who often travel with their children:

1. **Plan and pay attention to details.** Every trip with children is special, so careful planning is the key to success. For babies, the key is not to disturb their daily rhythm, to ensure good sleep and regular meals. Traveling with older children is a bit more difficult, because they already have specific desires and needs, for example, the child is hungry and does not care if you are running late for transport.
2. **Use travel insurance, because you never know what might happen.** Travel insurance is always on the list of things to take with you, as it is not worth to risk during the trip. It is easier to protect yourself, your children and your luggage in advance.
3. **Think about activities for children.** Traveling with children is an established tradition for families. When planning a trip, it is important to consider the wishes of children and organize activities specifically for them. The options are different. You can play different games both during your trip and at the destination.
4. **Travel with other families.** This model of traveling helps you to divide your responsibilities and prepare for your trip better, making it more successful.
5. **To create joy of traveling in children.** It is important to raise awareness among children that traveling and exploring the world is of great value, as it also helps to harmonize the trip and creates lasting memories.

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<http://www.aprinkis.lv/index.php/atputa/3984-ka-celot-ar-berniem-viegli-pieredze-dalas-sabiedriba-zinamas-mammas>

### **How to entertain a child on long journeys:**

- Always make maximum use of all available space on the plane.
- If your baby is very small, make sure you have ordered a special cot before the flight that is comfortable for him/her to sleep and play in.

Traveling with young children is definitely not a relaxation, but it still brings pleasant emotions and memories, and it is worth it.

### **Best practice stories for traveling with children: in the car**

Sometimes parents are not sure if their child is ready for traveling. Although it is individual, it is considered that three months is the threshold, when you can start planning the route. When planning a trip in the summer, it is advisable to be careful of visiting hot regions. The journey will take longer, as you will need to stop more often to feed the baby, change diapers and breathe in the fresh air. Children aged between 3 and 12 months should not be held in the seat for more than two hours. If it is not possible to avoid continuous long distances, it is better to plan the route in a way that the long distances can be driven at night, when the child is asleep. When choosing hotels, it is important to give priority to kid-friendly places, where there is no charge for overnight stays up to a certain age. It should be remembered that there should be no draughts or excessive heat in a car, so it should be ensured that the child's clothing is suitable. To avoid getting sick during the trip, it is advisable to cover them with a blanket to protect them from draughts when opening the door. Side windows should preferably be covered with a sunshade.

**Legislation.** Just like adults, the child will need a passport or ID card when traveling. If you plan to travel outside the Schengen area, you will need to complete the child's travel authorization in addition to these documents. It is also worth asking in advance how long the passport should be valid in the countries you want to visit, as it will take some time to renew the documents.

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<https://www.santa.lv/raksts/mansmazais/berns/padoms-vecakiem/ieteikumi-celosanai-automasina-kopa-ar-berniem-7148/>

### **Parents' experience of traveling by bus:**

Parents assess when their child is ready for a longer bus trip. Two and three-year-old cozy travelers are also encountered, but mostly children begin to appreciate travel as a pleasant pastime around the age of five or six. At this age, the child is able to withstand and even interestingly spend a long sitting in the bus. It is important that they do not spoil the trip for themselves or for others, since they also go to rest and do not want anyone screaming along the way. The child is able to endure and hurry when asked to do so. After all, he/she is already interested in many things, and the trip is a joy to him/her.

For the sake of safety, perhaps the first trip should not be chosen all over Europe at once. One day trip around Latvia will be useful for the trial. It will show how a child feels in a strange company.

### **Pros of traveling by bus:**

- The opportunity for the family to travel together without anyone having to work as a driver.
- This is one of the cheapest ways to travel.
- Like other forms of traveling, it is an opportunity to explore the world and yourself.

### **Cons of traveling by bus that can be turned into pros:**

- The pace of group travel has to be reckoned with; usually it is quite tense and hard to influence.
- Long journey. However, it can also be seen as an opportunity to be together all day and talk to the child.
- For parents, this will definitely not only be a recreational trip, but also an extra effort to get on time, keep the little traveler in a good mood, and so on. You may also need to become a peculiar interpreter, who interprets the guide's adult narrative into a child-friendly and engaging form, but it is gratifying if everything goes well.

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## **JKPU report**

MAREK KAWA Ph D

Report: „ **Tourism of families with the disabled children or with special needs in Poland**”

### ***1. Issues in traveling for families with children affected by behavioral disturbs, reporting the studies, investigations.***

There are currently around 650 million disabled people in the world, of which around 4.5 million in Poland. Due to the difficult financial situation of families, most often caused by the fact of staying with a disabled child in the home of one of the parents, the vast majority choose domestic trips. According to research by T. Skalska, around 21% of people with disabilities travel in Poland, while according to our research, at least once a year, 60% of families go away, and only 12.7% twice. Most often these are trips within the voivodship, travels abroad are declared by about 10% of respondents.

In relation to healthy Poles, the disabled travel more than three times less often. Their participation in international travel is fourteen times smaller (Analiza...2007). For many people, a rehabilitation trips remains the only chance to see the Baltic Sea, Mazurian lakes or the capital of the Tatra Mountains - Zakopane. There is no publicly available statistics on travel in Poland people with disabilities, and tourism preference studies are carried out sporadically and to a narrow extent, which makes it difficult to generalize the issue.

People with physical disabilities should be constantly rehabilitated. Parents of such children must take care of the most common breathing and relaxation exercises, equivalent or improving, to facilitate the functioning of healthy people in the world. Exercise in water or an hippo therapy, which often takes place outside the place of residence, usually during the vacation, can be helpful in rehabilitation.

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Already for 40 years has been trying to help disabled people to fulfill their sightseeing and tourist dreams, offering various forms of touristic activity. It is tourism that builds emotional bonds with the landscape, with Poland, with people who wander and people inhabiting the regions you visit. On the tourist route, everyone is equal in the face of nature and other people. It facilitates the integration of the disabled with all the society and necessitates the elimination of all barriers already for 40 years has been trying to help disabled people to fulfill their sightseeing and tourist dreams, offering various forms of touristic activity. It is tourism that builds emotional bonds with the landscape, with Poland, with people who wander and people inhabiting the regions you visit.

## ***2. Regulations available to support the travel needs of these families;***

On the tourist route, everyone is equal in the face of nature and other people. It facilitates the integration of the disabled with all the society and necessitates the elimination of all barriers.

The Polish Constitution states that:

The Constitution of the Republic of Poland of April 2, 1997, Art. 32. 1: Everyone is equal before the law. Everyone has right to equal treatment by public authorities 2. No one may be discriminated against in political or social life or business for any reason; Art. 47. 1: Everyone has the right to the legal protection of private and family life, honor and good name and to decide about your personal life; Art. 68.1: Everyone has the right to health protection....

According to resolution 58/168 (z 19 grudnia 2001 r.) the Committee on a Comprehensive and Integrated International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities). The Convention on the Rights of Persons with Disabilities was adopted on December 13, 2006 by the United Nations General Assembly and will enter into force after ratification by at least 20 of 192 member countries, including Poland.

Also Poland accepted Charter of the Rights of Persons with Disabilities of August 1, 1997 (MP of August 13, 1997, No. 50, item 475), which states that "Disabled are persons whose physical,

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mental or mental fitness permanently or periodically hinders, limits or prevents daily life, education, work and social roles in accordance with legal and customary standards”.

Many years ago in Poland there was implemented the Legal Act which was in some parts referring to the required conditions for the all groups of disabled people which would ease and help the functioning better in society. It was called: The Act of 27 August 1997 on professional and social rehabilitation and employment of disabled persons (Journal of Laws of 1997, No. 123, item 776, as amended):

Relating to children with some degrees of disabilities in Poland there was implemented on January 1, 2002, a disability certificate for children under 16 for the purposes of obtaining nursing allowance, permanent allowance for caring for a disabled child from social assistance, for rehabilitation and treatment purposes. The disability certificate contains indications regarding, among others, the need to supply orthopedic items, auxiliaries and technical aids, facilitating functioning, the need for permanent or long-term care or assistance of another person in connection with the significantly limited possibility of independent existence, the need for permanent participation in every day the child's guardian in the process of his treatment, rehabilitation and education, meeting the conditions specified in art. 8 clause 1 of the Act of 20 June 1997 Road Traffic Law (Journal of Laws No. 98, item 602). Such an assistance should include also help during the movement because of the touristic causes.

There are also in Poland some others more detailed documents referring to this special group of Poles, an example of such a solution is, for example, the Regulation of the Minister of Economy and Labor of 2004 devoted to giving categories to hotel facilities. This document introduces, among others rules for making such facilities available to people with disabilities.

The problem of tourism of people with disabilities is also raised, albeit only to a small extent, as part of the draft Tourism Development Strategy for 2007–2013. Written into the broader concept of the National Development Plan, the document prepared by the Tourism Department of the Ministry of Economy sets directions for the harmonious and coherent development of tourism as one of the branches of the national economy.

By the way regulations of such areas in Poland as public transportation there are some references to situations of the disabled like in the Act no. 02.179.1495, with further amendments “Regulations of the Minister of Infrastructure of 25 October 2002 on the types of documents confirming the right to use concessionary public transport services”. Poland also accepted the Regulation (EC) of the European Parliament and of the Council EU No. 1107/2006 of 5 July 2006 on the rights of persons with disabilities and persons with reduced mobility traveling by air.



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Many issues regarding the provision of buildings and spaces for the disabled in Poland are governed by the provisions of the construction law and the law on spatial development. However, people with limited mobility themselves specify the requirements that their environment should meet to remove barriers. For last years the majority of public buildings (including schools) have been adjusted to such motoric requirements of the disabled people including students and kids.

The problem of disabled people's tourism, though, appears in the most important document programming Polish development tourism for the coming years, however, it does not treat it as a separate one areas.

***3. Needs, identifying the primary and secondary needs for these families.***

In turn, M.A. Devine has shown that 28% of the US population of people with disabilities travel outside their own territory. The distances that disabled families can get through for tourism depend on the type of child dysfunction. M. Milewska showed that 20% of people with physical disabilities travel in the country, which is 8% from the received in this job. A much larger difference occurs in the case of mentally ill people, because according to M. Milewska they travel the least often, which was not confirmed in the presented work.

Needs of the disabled they are generally the same as for the healthy part of the population, but they require support to in a creative way fulfill specific social roles to the best of their abilities. It is widely believed that people with disabilities are one of the most in Poland marginalized groups and are constantly experiencing restrictions on access to any field social life.

The level of participation of disabled people in tourism is also marginal, despite its undeniable values and positive rehabilitation effects.

Disabled adult people are active participants society, making a significant contribution to its development. Medical model instead, it defines disability through the lens of health, perceiving it as a disease, which is under the control of doctors and rehabilitation specialists. Among adults disabled people declaring their stay outside the place of residence, only 30% took part in tourist and leisure trips, 28% in health care, while most trips concerned visits of relatives and friends.

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Due to the type of disease, people with cardiovascular diseases travel most often (21%), while the least people with mental retardation and mentally ill (15%), as well as people with hearing impairment (Milewska 2008).

Tourism of disabled children should be treated as part of the rehabilitation of disabled people, whose main goal is to restore maximum physical, mental, social and professional fitness and adapt to normal life. Tourism of people with various disabilities should be treated not only as active leisure, but also as therapeutic and educational measure, enabling you to try your hand at various, often harsh conditions.

Some data from table no. 3 referring to question about the means of transportation during such touristic trips indicate that respondents definitely most often choose a car and then rail as a means of transport during travel. Parents of children with physical disabilities do not use buses and planes at all, choosing trips within a given region of Poland (Poland is divided into administrative regions which are called by term of a voivodship) most often (51.7%). A similar destination is preferred by parents of children with multiple disabilities (65.4%), while parents of blind or deaf children travel throughout the country (over 60% of respondents). Probably for financial reasons, the vast majority of Poles go with the child only once a year. For parents of mentally handicapped children 43.8% declare that they travel less than once a year (Milewska 2008).

According to the results in (table 4) parents, regardless of the type of child disability, most often decide on trips organized on their own. Organized travel is popular among families with a blind child (18.5%), while specialized camps among children with physical disabilities (17.9%). Active recreation is preferred by families of deaf (60%) and mentally retarded children (51.4%), while most families passively rest with children with motoric dysfunction (71%) and multiple disability (65.4%). A popular form of recreation among families blind children are visited (35.7%) (Milewska 2008).

Data from (table 5) indicate that parents of disabled children most often use the offer of private accommodation. Guest houses are also popular. Parents of deaf children choose to stay in holiday homes and campsites (20% of parents surveyed each), while parents of blind and disabled children use hotels (24.1% and 15.2%, respectively).

Most obstacles related to the lack of infrastructure adaptation during trips are declared by parents of children with physical disabilities (80%), multiple disabilities (63%) and blind children



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(44.4%). The problem of parents with a mentally retarded child is usually intolerance (56.3%). For parents of deaf children, 60.0% have no objections when traveling (Milewska 2008).

Rehabilitation visits are most popular among families with children with motoric dysfunction (92.6%) and multiple disability (76.9%). In the case of deaf children, 80.0% do not use the option of going to such visits.

Another factor hindering the tourism of children with hearing impairments is the problem of focusing attention, arousing curiosity, eyes arousing interest. Camps or other forms of organized tourism for children may not be suitable for deaf children because it is more difficult for them to make any interpersonal contacts. They often have egocentric habits that make it difficult to function in a group.

Vision disability, according to (Kędzińska 2003), has a medical, social, psychological and didactic dimension. The sight itself should be considered in the categories of cognitive, practical activity, spatial orientation, emotions and interpersonal communication. Tourism adapted to the needs of the blind is a big challenge for the organizers. In the case of blind and partially sighted children, it should be taken into the consideration that any form of activity should be combined with rehabilitation that will facilitate their efficient life in society.

The tourist accommodation must meet the following requirements for persons, including families with blind and visually impaired children:

- open spaces and paths free of obstacles,
- explicit and accurate descriptions of the environment to help experience surroundings and obstacles,
- well-lit and high contrast marking,
- the possibility of touching objects in the immediate surroundings,
- acoustic signals for obstacle or dangerous determination place
- the use of documents and forms in Braille,
- information on CDs, DVDs, floppy disks etc. or in the alphabet Braille,
- an assistant available to assist you in special cases.

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Due to the fact that tourist information is often distorted, most respondents individually organize their family trips (over 81%). The obtained results indicate that the goal of 50% of travel was passive rest, while active holidays were declared by 29% of respondents. The most therapeutic, from the point of view of rehabilitation, is the form of active tourism that has a positive effect on health, develops physically, aesthetically and morally. According to the research of K. Kaganka and H. Stanuch, the most favorable for people with visual disabilities is the cognitive factor, which is confirmed by the results of the study. 35.7% of respondents declared "visiting" among families with blind children (Kaganek, Stanuch 2005).

There are many wrong ideas about deaf adults and children in society. The consequence of this is to avoid hearing contact with hearing impaired people and vice versa. This reluctance of the sides is due to the stage fright and fear of talking to someone who does not know the language of the other person. People who are deaf and hearing-impaired, despite the accepted opinion, are disturbed by noise as much as hearing people. The deaf person with a damaged middle ear is sensitive to noise and vibrations, and the hearing impaired people do not have good sound selection skills and may pick up the wrong sounds in noise.

The time of hearing loss has a huge impact on the socio-psychological situation of people with hearing disabilities - apart from the popular stereotypes. Children who have lost their hearing after the age of 5, i.e. after completing language learning, are able to use audio speech. Those who have lost their hearing in old age but have not mastered sign language are suspended between the world of hearing and deaf people. They do not identify with any of the groups. Deaf from birth, called culturally deaf, they create instead own social group. They easily make contacts with each other, they exchange information, and because of different communication they think specifically. This, in turn, is the reason for their perception as a mentally retarded group. This reasoning is wrong.

Hearing impaired people are sometimes treated as nervous and aggressive ones. They often give the impression that they are disregarding the interlocutor. These include those who communicate effectively with hearing people by reading speech from their mouths. They make breaks in the conversation because they are no longer able to focus their eyes and attention on the interlocutor's lips.

All this makes deaf people feel better in a similar environment. The conversation does not require much effort from them and is more pleasant. This approach further isolates this group of

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disabled people from the rest of society. Integration of the deaf and hearing impaired should therefore consist in accepting the need to have their own environment, and rehabilitation should lead to equal opportunities for hearing-impaired people.

People with intellectual disabilities, often showing intellectual retardation, must learn basic life activities, cannot play, often have to learn to live together and work with peers, hence the important role of rehabilitation stays or integration camps.

It should be remembered that children/adults with intellectual disabilities in their environment expect friendly guides, guardians and visual signals that will diversify their impressions. The most dangerous for this group of disabled people is noise - disturbing, distracting and disrupting the reception of signals coming from the environment.

However, sport and tourist activity of the disabled faces a number of barriers. Research conducted in a group of people with various dysfunctions shows that one of the most important barriers to tourist activity are organizational difficulties and lack of information (Skalska 2004). Among dozens of travel websites operating on the Internet, none treat people with disabilities as customers with different needs. They are missing in them also information on travel amenities and the availability of hiking trails.

On the other hand people with disabilities can increasingly engage in water sports, such as canoeing and sailing, and winter sports (trekking, ski-mountaineering). Little is known about this, but people with disabilities have been practicing even the most difficult types of qualified tourism in Poland for many years: skydiving, diving, sailing or canoeing (Szczuciński 2005).

Many researches done in Poland throughout the period of 2007-2015 among adult people with disabilities indicate similar group of answers. For instance the vast majority of respondents do not feel the fear of those around them that could be another barrier in tourist and recreational activity. A significantly higher percentage of the unemployed and inactive in the study group in relation to the group of working people considered communication difficulties as a serious limitation (Żbikowski, Soroka 2011). Factors such as: fear of people, lack of help on the part relatives, the lack of facilities associating people with disabilities do not significantly discourage people with disabilities especially in the Lublin region ((the south-east part of Poland) from tourism and recreation (Żbikowski, Soroka 2011). To sum up research made in this particular region of Poland (Lubelskie Region) we may conclude that: the largest percentage of respondents do not feel fear of people with whom they would come into contact during travelling, sport and recreation, which indicates the openness of disabled people and the desire to

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make new contacts during active rest. The attitude of people with disabilities should be assessed positively, which is characterized by great interest in tourist activity and recreational, and the possible lack of help from loved ones is not an obstacle in their intentions to implement real actions. Disabled people living in the Lubelskie Voivodeship (the south-east part of Poland) considered as insignificant or insignificant the barriers to participation in tourism and sport and recreational activities identified during the research. This is a phenomenon optimistic from the perspective of the development of the tourist and recreation market, which should focus its offer more on the segment of the disabled market.

#### **4. Good practices, illustrating initiatives that have been realized to sustain these families.** Propositions of improvements

In Poland mostly a third sector of NGOs is trying to response to challenges of social tourism. Also implementing a results of the EU pro-social projects. For example: Project "In the world beyond Silence and Darkness" In 2012, the "Zdążyć z Pomocą" (“Be on time with help...”) - Foundation for Children in cooperation with PTTK (“The Polish Society of National Tourism”) became the organizer of anti-discrimination training for tourist guides. project "In a world outside of Silence and Darkness" is not only raising qualifications and acquiring new ones skills, but also broadening the guides' view on the problems of the blind and visually impaired.

There are some proposals of sustainable development of disabled tourism through individual elements of travel in Poland:

Elements of voyaging	Now	Needed to do/ Future
Access to touristic information.	city guides, internet, folders, leaflets	more details on the maps, more widespread.



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travel preparation	specialized travel agencies, organizers	increasing the number and scope of activities
external communication	good and bad situation	increasing accessibility to railways, ferries, bus transport and aviation
Internal communication	depends on personal and local circumstances	this element requires enhancing
travel destination, (open air, museums, monuments)	it depends on type of disability	more detailed information
accommodation, housing	variety of offers	more detailed information on special equipment in accommodation
feeding	good conditions	there is a need of detailed information
functionality	barriers and limitations in connection with a particular type of disability	abolition of barriers and limitations

So far in Poland have been completed some programs dedicated to disabled families. For example:

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"Tourism for All" implemented by the “Polish Tourist and Country Fans' Society” with the support of the Government Program of Civic Initiatives Fund. As part of the pilot project carried out in Łódź City, the Masovian Region and the Podlaskie Region, the availability of various types of facilities is checked: accommodation, catering, cultural, sports, but also tourist routes, national and landscape parks or means of transport. An important element of the project is a website containing lists of facilities adapted to the needs of people with disabilities, which can be searched in terms of their location or type of amenities offered (Grabowski, Milewska, Stasiak 2007).

Another example of internal institutional initiatives in Poland - the project called „Let's take the first step” was run and implemented by the State Vocational University of John Paul II Named in Biała Podlaska City a training system for the environment cooperating with disabled people. One of the main goals of the project is:

1. to break stereotypes in perceiving the role of people with disabilities in society by carrying out information and education campaigns that promote a change in the way people with disabilities are perceived as defective citizens;
2. preventing social exclusion of people with disabilities by overcoming problems associated with limiting access to public services and restrictions on the possibility of professional activation. Although the project is mainly aimed at improving the situation of people with disabilities on the labor market, its impact on other areas of life of people with disabilities cannot be excluded (Grabowski, Milewska, Stasiak 2007).

There are also some infrastructure improvements widely introduced in Polish hotels like for example for adults and kids with motoric disability especially using wheelchairs.

Internal exit in the "Delfin" indoor swimming pool in Ustrzyki Dolne, Podkarpackie Region (more popular touristic area of South-East Region of Poland):

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Access to restaurants and lobbies of hotels not only for adults and kids with motoric disability especially using wheelchairs but as well for families with vivid and small kids using trolls. Like an entrance to the restaurant at the Park Hotel in Olsztyn adapted for them.



In these days majority of Polish public transport must have a special area for those with special needs.

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In addition, people with limited mobility can also in cities use cabs (taxi). Vehicles specially adapted for them are available to this group of people, however, the fact of disability should be reported at the time of ordering. Many privileges for a disabled person give possession of card parking. It is a document that all countries belonging to the European Union recognize, and which allows parking in designated places and inaccessible to disabled persons. However, in individual countries the parking card entitles you to other types of concessions and when you are abroad, you must comply with the regulations in force in that country.

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Some advices for young, children and their families who deal with some problems during travelling:

- when giving directions, do not use terms that are understandable only for the sighted person;
- always turn to the blind person and not to the person accompanying him;
- when in a room with a visual disability try to put all objects in their place or inform them about any changes;
- express your gestures in words, e.g. willingness to shake hands (do not grab the hand beforehand);
- warn you willingness to help;
- choose the option of help accepted by a blind person; when you're in a hurry, don't offer your help so that you don't have to leave her unattended;
- helping the blind, warn about obstacles, change of direction;
- giving a chair, do not place a blind man on it, but place his hand on the backrest;
- plan your time well, without leaving too much for unorganized activities - blind people in a new place feel insecure.

Another large group of the disabled are deaf adults/children. Their activities should be supported, unrestricted access to mass media should be provided, and they should be provided with appropriate technical means supporting the hearing process. However, they must not be forced to teach speech and make deaf people like hearing people. It is also necessary to prepare social services for contact with deaf people, e.g. by learning sign language (Grabowski, Milewska, Stasiak 2007). For example access to such tools as a receiver with induction loop should be European standard:



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The tourist base should be properly technically prepared to support the hearing impaired and deaf people and use such solutions as (Budny 2003):

- information in writing (brochures, guides, guides) on the adaptation of the facility to service guests with hearing disabilities;
- phones with audio-visual function,
- facilities using Bluetooth technology, signaling devices and vibrations,
- alarm systems with audio-visual function,
- teachers - sign language interpreters,
- telephones, videophones with the teletext option,
- television broadcast with the option of sign language translation,
- textual information on all relays (devices) TV / Video.

Information for the deaf and hearing impaired guests should be mainly provided by means of signs, symbols, pictograms.

Into good practices dealing with deaf children, youngsters or adults belong also:

-if a hearing impaired person has a hearing impaired person, break the conversation from time to time and explain to a such person what has been said so far; in this way we free her from loneliness and isolation;



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- remember that reading from your mouth is more tiring than normal listening, especially for a kid; for this reason, take breaks while talking so that a person can relax from constant concentration;
- speak calmly, not too quickly, speak accurately; sentences must be short and unambiguous, and questions should contain interrogative pronouns (who, what, when, why, where, how much, etc.);
- make sure that the conversation is accompanied by natural gestures; appropriate facial expressions and gestures make it easier to understand or guess the meaning of our speech;
- do not approach the deaf person suddenly from behind so as not to frighten him;
- do not come too close when talking - the best distance is one meter;
- while talking, direct your face towards the deaf person so that he can read your mouth from the movement;
- participants should always be placed facing the object in question (during travelling the guide and translator are standing backwards);

For children with intellectual disabilities and some neurotic disorders intellectual disability may vary, depending on dynamics of nervous processes. Due to the many activities they perform routinely, may require assistance or a longer adjustment period in a new environment. During travelling is advised strongly to remember that some matters may be delicate. i.e.

- in catering also the menu card should be properly structured. If individual dishes are sketched or a photo is posted, the disabled consumer can easily choose the menu according to their preferences;
- an hippo therapy may be a very good form of recreation for intellectually disabled people. The use of appropriate positions and exercises during hippo therapy eliminates increased muscle tone. Contact with an animal teaches especially children sensitivity and friendship, affection and showing feelings.
- people with intellectual disabilities are unable to receive visual experience outside the bus window. For this reason, when we want to say something about a place, we should stop. Similarly to other disabilities, the position of participants on the bus should be planned for intellectual disabilities. Additional disorders such as epilepsy, anxiety, etc. are also included.
- there is important to encourage people with disabilities to carry on with their daily duties, help them focus their attention and mobilize them to act by giving very specific tasks to perform;

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## **NAMCB report**

### **Report objectives**

IO1 aims at modeling the various aspects which characterize travels of families with children affected by behavioral disturbs (months 1-6).

The main result of this IO is a descriptive model for Fair Traveling that represents the main features of:

- the typical behaviors of these families;
- their objective and subjective issues;
- the possible solutions (with the underlying theoretic references as well as best practices, constraints, and barriers).

### **Desk research**

Trips of families with children affected by behavioral disorders have the main characteristics of:

- the typical behavior of these families;
- their objective and subjective issues;
- the possible solutions;

The typical behavior of these families is associated with constant fears and doubts that something unforeseen and unexpected can happen. They can be summarized in the following groups:

1. Difficult mobility of the child and family
2. Lack of accessibility in the environment
3. Problems with the child's behavior in public places
4. Sensation of negative public response and lack of acceptance by the community
5. Child safety in public places

The objective and subjective issues and the possible solutions are also related to these 5 groups of problems.

Community action opportunities are listed according to the different levels at which they can be realized:

1. At the macro level: this is the level of government and local authorities. It adopts policies and votes on their funding at national and municipal level
2. At medium level: this is the level of regional institutions, local communities, neighborhood organizations.
3. At the micro level: this is the individual environment of the child at home, in the family, at school.

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The topics in preparation for the trip are:

1. Difficult mobility of the child and family
2. Lack of accessibility in the environment
3. Child safety in public places

Suggestions for overcoming barriers to the participation of children with disabilities and their families in the community in problem areas:

### **Mobility**

Macro level: Advocacy and support for policy development and provision of funding for the provision of adequate moving equipment in line with health and safety standards

Intermediate level: Advocacy and awareness-raising in schools, municipalities, neighborhood communities (and before developing such communities) and families on how to adapt the environment so that it is accessible (construction of ramps, lifts, sidewalk improvements, and etc.)

Micro level: adaptation of available equipment used for movement; assessing the interaction between the means of transport and the interior of the premises and making the necessary modifications to improve mobility. Improvement of moving equipment with appropriate materials and aids. If they are not available at the moment, make written recommendations and document their need. The availability of such documents at the micro level can lead to changes in policies at the macro level.

### **Environment accessibility**

Macro level: Advocacy, participation and support for policy development and provision of funding to build an accessible environment: ramps, elevators, pedestrian paths, etc.

Middle Level: Advocacy, working with schools, municipalities, neighborhood communities (and before developing such communities), families on how to adapt the environment to be accessible (ramps, elevators, sidewalk improvements, etc.) Surveys in neighborhoods and short reports that can support macro-level advocacy.

Micro level: Adaptation of available equipment used for movement; assessing the interaction between the means of transportation and the interior of the premises in real conditions and making the necessary modifications to improve mobility.

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Teacher and parent training how to change the environment to make it more accessible.

### **Management of the child's behavior**

Macro level: Provide your child with a behavioral specialist visit and be involved in programs that will fund these meetings. Provide such professionals or training in the field to local professionals. This can be done by applying to different EU programs or programs such as Fulbright, which ensure the visits of good professionals to specific regions.

Intermediate level: Provide training for the school and the community based on specific behavior management techniques, such as a picture day program, that is accessible to the child and outlines the expected behavior. Make sure you get the approval and support of the school leadership for applying these techniques at school.

Micro level: Use in your practice and demonstrate to parents and child how to implement behavior management strategies. Emphasizing the need for techniques to be applied regularly in order to be successful.

### **Acceptance from the community and support of the community's attitude to the child / family**

Macro level: advocacy and strategic government-level relations and policy-making in order to comply with the regulatory framework for the inclusion of people with disabilities and the exercise of their rights. A report may be drawn up or a complaint may be filed by people who believe that their rights are not respected. Public attention should be drawn to the needs and problems of people with disabilities through the media - newspapers, radio, television.

Intermediate level: Organize community-based events and activities that will enhance acceptance and allow for free communication. These could be celebrations, festivals, workshops. Create contact opportunities between different organizations working for the same cause, create the conditions for working together on projects such as organizing parent meetings, co-financing workshops and events. Partner with existing organizations to help teachers and students support school inclusion.

Micro level: Use the community and local organizations to create a supportive system for parents. The parent group is a very important structure that allows parents to help each other and to support each other when confronted with social pressures. Organize regular meetings for parents and support them in the group to become independent and self-employed. The group can focus on creating a contact list of all where to exchange phones, emails and other communication channels so that you feel comfortable communicating with each other. It is good for the group to

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make a list of key people and specialists, organizations, schools, politicians to be contacted when there is a need or a problem.

## **Safety**

Macro level: At policy level, make sure that environmental accessibility programmes and projects are in place in all institutions that take care of community development. The development of a handbook to raise awareness of the needs of people with disabilities, which is easy to read and disseminated among politicians and key actors, would help to raise awareness and strengthen advocacy at the level of local Power. The municipalities would have benefited from the disclosure of a regional Health Advisory centre or the inclusion of Professionals such as occupational therapists and other professionals working with people with disabilities in already existing centres. Budget funded projects related to construction and maintenance would benefit from obtaining information and training regarding the need for a specialised environment for people with disabilities and relevant accessibility and participation programmes.

Intermediate level: Assess the safety of the environment in school and in the neighborhood, including the journey to and from school and vehicles. Disseminate the results of the evaluation to people with safety concerns and may take the necessary measures to mitigate the risks.

Micro level: Talk to parents and discuss safety strategies: how can the environment be modified at home, at school, in the neighborhood. Teach the child to keep up and follow the safety requirements. Use in this process strategies that respond to the abilities of the child, work with him in an environment and contexts that are problematic for the child, at home and outside his home, until the child shows that he has mastered the relevant skills.

The topics during the tourist activity are:

1. Difficult mobility of the child and family
2. Lack of accessibility in the environment
3. Problems with the child's behavior in public places
4. Sensation of negative public response and lack of acceptance by the community
5. Child safety in public places

The list of the critical points is related to these five groups of problems.

## **Model definition (Deadline February 10)**

The available solutions to cope with the difficult mobility of the child and family are :

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- adaptation of available equipment used for movement; assessing the interaction between the means of transport and the interior of the premises and making the necessary modifications to improve mobility. Improvement of moving equipment with appropriate materials and auxiliaries
- advocacy and awareness-raising in schools, municipalities, neighborhood communities (and before developing such communities) and families on how to adapt the environment so that it is accessible (ramps, lifts, sidewalk improvements)

The available solutions to cope with the lack of accessibility in the environment are :

- adaptation of available equipment used for movement; assessment of the interaction between the means of transport and the interior of the premises in real conditions and the necessary modifications to improve mobility

The available solution to cope with the problems with the child's behavior in public places is:

- training of children in school and in the community (parents), based on specific behavior management techniques such as a picture day program that is accessible to the child and indicates his or her expected behavior

The available solutions to cope with the sensation of negative public response are:

- creating a support system for parents. The parenting group is a very important structure that allows parents to help and support one another when faced with social pressure. Organize regular meetings for parents and support the group to become independent and independent. The group can focus on creating a contact list of everyone to share phones, emails and other communication channels with so that they feel comfortable communicating with each other. The group should also make a list of key people and specialists, organizations, schools, politicians to contact when there is a need or problem

The available solutions to cope with the child safety in public places are:

- talking to parents and discussing safety strategies: how the environment can be modified while traveling, indoors, on the street. Preparing the child to keep safe and follow the safety requirements. Use in this process strategies that match the child's abilities, work with him or her in environments and contexts that are problematic for the child, at home and outside his or her home, until the child shows that he or she has acquired the appropriate skills

**Model discussion (Deadline February 29)**

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Partners will present and discuss the model in their country with a panel formed of four parents (two females and two males) and three educators.

Partners analyze the results and refine the model.

RTA performs the data analysis.

### **IO report (Deadline March)**

Ecoistituto prepares a report in English that partners translate into their country languages.

The model for Fair Traveling will be used to design the training module (IO3) as well as the toolkit (IO4) since it represents the behavior of the subjects involved in the different contexts of traveling (families, children, educators, social services, travel service companies).

### **Division of work:**

All partners carry out the following tasks:

1. collecting data;
2. collaborating in the model implementation;
3. creating a panel of parents and educators to evaluate the model;
4. interviewing the panel components;
5. realizing a short report;
6. collaborating to accomplish the final report.

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## **Conclusion**

Each partner performed an analysis of the critical points for families with children affected by behavioral disturbances when they are traveling.

The desk research showed that, in the partner countries, there are the same issues for these families.

In particular, emerged that no policies exist to support the need of these families in their travels but

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## **ANNEXED**

### **Fair traveling model**

#### **Premise**

This model is the result of desk research and surveys carried out by partners. It represents needs, issues, barriers that occur to families with children with ASD as well as the strategies to mitigate them.

#### **Model description**

A synthetic traveling model for families with children with ASD has been developed, identifying its most important dimensions, needs, and issues these families can experience in traveling. The model also refers to motivational, cognitive, situational, and dispositional factors that determine the interaction among subjects involved in traveling activities.

The primary components of the model are (Figure 1):

- Transportation
- Accommodation
- Restaurants
- Leisure
- Public services



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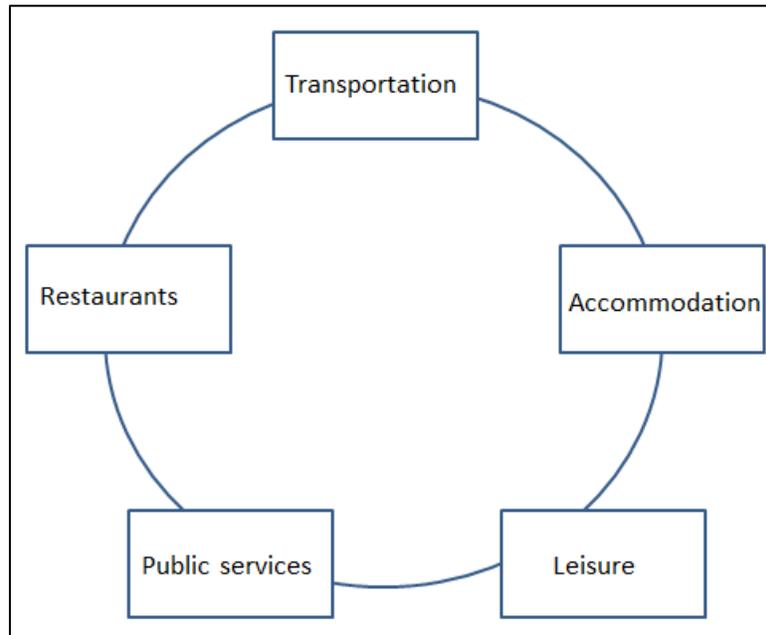


Figure 1. Traveling components

The key traveling relationships of families are with:

- Residents
- Other travelers
- Public services
  - Health-care services
  - Social services
- Traveling service providers
  - Travel agencies
  - Tour operators
  - Online accommodation bookings
  - Online flight bookings
  - Online public transportation bookings
  - Online private transportation bookings
  - Online leisure bookings

Note that families can take advantage of new technologies to access to services.

The relational issues include communication difficulties with:

- Residents: exclusion, due to the distrust and ignorance of the problems of people with ASD

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- Other travelers: exclusion, due to the distrust and ignorance of the problems of people with ASD
- Public services: lack of supportive policies and/or specific services
- Traveling service providers: lack of interest to create specific services

The main traveling impact/issues for families with children with ASD are:

- changes in routine
- tackling unexpected events
- Finding the appropriate accommodation structures
- Manage the children behavior
- Interacting with normal people
- crowd
- new noises and sights

Planning travel is an action that encompasses all the travel components and can be affected by traveling relationships. When a family plans travel should define a strategy to minimize the primary impacts/issues that can occur.

To achieve this goal, it is important to define travel in all its aspects. On this purpose, can be useful the following travel descriptors:

- trip origins
- trip destinations
- distance
- travel time
- travel duration
- trip purpose
- mode for trip
- number of persons

Lists of services that support families of children with ASD are also necessary.

Furthermore, the best practices to tackle the various issues should be identified. Best practices are also relevant to define the policies to support the traveling of families with children with ASD. The principles underlying good practice should form the conceptual basis for policies. Educational support is an important element of the model. Educational actions are needed to sustain families as well as to stimulate awareness and inclusion from “normal” people.

New technology plays a crucial role in providing information to families. Nevertheless, appropriate strategies should be identified in order to screen information available on the internet and select only reliable sources.