Autism Europe aisbl

Fostering a barrier-free society for people on the autism spectrum

Testimonies collected within the framework of the World Autism Awareness Day campaign "Break barriers together for autism – Let's build an accessible society"

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How to foster a barrier-free society for people on the autism spectrum

Europe counts an estimated 7.4 million people on the autism spectrum (1% of the population according to prevalence studies). This is more than the entire population of Bulgaria. Autism is therefore by no means a rare condition. However, the diversity of the spectrum and the fact it is a largely invisible condition, means that it can be quite easy to overlook the difficulties experienced by autistic people.

Although they might not always be obvious, the barriers autistic people and their families find themselves confronted with are numerous. Autism-Europe conducted a survey across Europe in 2017 to assess the main challenges faced by autistic people. It appears that in all countries, at varying levels, autistic people and their families have similar difficulties in accessing a diagnosis, inclusive education adapted to their needs, employment, person-centred and life-long support, and lack services to assist them in moments of transition throughout their lifespan. As a result, many autistic people are deprived of the right to enjoy life in the community.

As part of our campaign "Break Barriers Together for Autism", we would therefore like to share a selection of personal testimonies, to illustrate some of the main barriers autistic people and their families face in their everyday life, as well as examples of good practices that can foster a more inclusive society.

When reading this document, it is also important to keep in mind that every autistic person is different which entails that accommodation and support must be person-centred and individualised to respond to the person's aspirations and needs.

These testimonials are a poignant reminder that the EU and its Member States still have to address many structural obstacles that have a significant impact on access to rights and ultimately the quality of life of autistic people and their families. At Autism-Europe, we strive to shape policies and practices that will make society more autism-friendly and barrier-free, in accordance with the United Nations Convention on the Rights of Persons with Disabilities UNCRPD). This document is also an opportunity to highlight some key recommendations for the promotion of the full realisation of the rights of autistic people.

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1- Improve access to early diagnosis and to diagnosis for adults age

Claude Schmit

Luxembourg

Father of a person on the autism spectrum, on the barriers to getting an early diagnosis.

"The waiting time is excessively long due to massive demands and the limited means"

"The access to a quality diagnosis remains difficult. Parents with children on the autism spectrum often fight for years before a valid diagnosis is established. Many of them turn to the (small) diagnostic service at the *Fondation Autisme Luxembourg*, where the waiting time is excessively long (around one year) due to massive demands and the limited means.

"The same foundation also provides support to people who wish to obtain a diagnostic assessment when they suspect that they or a member of their family have autism. Unfortunately this service is so popular that the waiting list is considerable and the waiting time to enter the diagnostic process is excessively long. "

Jan Verhaegh

The Netherlands

Person on the autism spectrum from the Netherlands, on barriers faced by being diagnosed later on in life.

"I was 63 years when my daughter, a psychologist, discovered that I was autistic"

"The official mental health institute did not see that I have autism. I was 63 years when my daughter discovered that I was autistic. At that time (ten years ago) there was less information about autism.

There are people who are good in autism support. There are autism information centres, in which parents and patients are active as volunteers and who give information about autism to everybody who wants it."

Irena Lozana

FYR of Macedonia

Mother of a child on the autism spectrum, on the barriers to getting an autism diagnosis in her country.

"There is a very limited number of people in our country that can do a proper diagnosis"

"We have faced difficulties from the beginning of our journey with my son when he was 2.5 years old. We have a mental health institute for young children, which is the only institution that treats every child in our country, and they couldn't offer us a diagnosis for almost four years. The way of working and communication was not following state of the art science [...] No centralised information is flowing through this institute, whereas it should be.

"The parents are just being shovelled through the system and then left on their own to make do with whatever they stumble upon. This institution should also take care of the registration of all the autistic people in the country and use the registers to spread information for help.

"A positive experience for diagnosis is the one that we had just recently from a doctor who was working in the institute, but who is now working for a private hospital. The fact that this positive experience relied on one sole person shows that there is a very limited number of people in our country that can do a proper diagnosis, which is a disaster for the system.

"Ways to improve diagnosis could include providing training to staff in the institute mentioned above. More training to the school staff and paediatricians is also needed."

UNCRPD Article 25 - Health

State parties should provide "those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons".

Autism-Europe thus recommends cooperation at the EU level to:

- Develop and adopt EU guidelines on gold-standard screening and diagnosis instruments and criteria across all EU Member States;
- Promote adequate screening and foster access to diagnosis, including by promoting access to adequate resources for professionals;
- Take steps to harmonise intervention protocols for autistic children across the EU;
- Introduce compulsory training on specific and evidence-based habilitation strategies for autism, as well as on ethical issues in the curricula of all the habilitation professionals;
- Promote access to early and evidence-based intervention for autistic children.

2- Promote training of professionals and parent education programmes to foster a positive approach to autism

Gregor Ziebarth

Germany

Gregor is a young man on the autism spectrum who sadly took his own life in 2015. This testimony is written by his mother Sonja and highlights difficulties linked to lack of understanding of autism and bullying.

"He suffered harassment throughout school and further education"

"Neither psychiatrists, (ergo) therapists, psychologists, psychotherapists (doctors), pedagogues, nor institutions for children or schools knew about the phenotype of "high functioning" autism. My son had an ADHD diagnosis since his second year of school, at the age of 7 years.

"He suffered harassment throughout school and further education.

"I have witnessed the positive engagement of the social workers in school and the social work schools can do (mostly special schools). However, pediatricians, psychologists, doctors, therapists and psychotherapists need training on autism. There also needs to be funding for the screening for neurological conditions and early intervention for young children (aged 0 to 6).

"It should be taken into consideration that there are some peculiarities linked to an autism diagnosis, such as eating behaviour. My son had a very selective eating behaviour and developed eating disorders. It is also key that information is given to parents."

UNCRPD
Article 8 - Awareness raising

This article provides that States Parties should undertake to adopt immediate, effective and appropriate measures to raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities.

AE strongly recommends cooperation at the EU level, and that:

- Parent training and curricula should be developed and delivered locally to meet the needs expressed by families and autistic people, offering practical solutions and strategies to cope with the evolving challenges they face across their lifespan;
- They should adequately reflect the diversity of people on the autism spectrum (e.g.: with and without a learning disabilities) and of their support needs, and autistic people should be involved in their design and delivery;
- Parent trainings must be accompanied by the development of multi-sectoral support services in the community, both for autistic people and their families (e.g.: diagnostic, early evidence-based intervention, education taking into account their support needs, life-long support, etc.).
- Further develop the training of a wide range of professionals in Europe across relevant sectors, including for teachers and educators.

2- Foster more accessible, inclusive and flexible educational settings and systems

Zsuzsanna Szilvasy
Hungary

Mother of a person on the autism spectrum, on the barriers to inclusion and support.

"Schools are not accepting kids with autism or do not even want to include them, because they have no idea what autism means"

"More than 10 years ago I started to advocate for the rights of my autistic child, because we couldn't find a school for him, and I thought that was nonsense in the 21st Century.

"I realized that the decision-makers were trying to mould my child to fit into the existing education system and that they did not even think about reforming the system so that it could also fit my child, and many other children with autism.

"To find a way into this system was already hard, but to keep my son in, and force the decision-makers to provide autism-specific support was even harder.

"We faced discrimination on so many levels: the decision-making level, the service-provider level and, unfortunately, in the school among his peers.

"When young adults with autism leave school, the future is uncertain. They are faced with just a few job and housing possibilities. Many of them go back to their parents' house, doing nothing and losing all the skills they developed during their education.

"In 2013 the Hungarian Ministry of Human Resources issued a decree on the inclusion of children with special needs in mainstream education. The resolution is very good, focusing on tailor-made education for all kids with special needs.

"Unfortunately the schools themselves are not always aware of this decree. The NGOs are raising awareness of its existence and forcing the service providers to implement this legal tool".

"I think we are always are afraid of things that we don't know. I see many times, in our life and in the case of many other families with an autistic family member, that schools are not accepting kids with autism or do not even want to integrate them, because they have no idea what autism means. They are simply afraid.

"I believe in awareness raising. We still have long way to go, to convince the whole of society that persons with autism are not dangerous. They have another mind set, but we have to accept it. We have to give them the possibility to be who they are. In this way they can also reach their full potential and contribute to society."

Ari Ingólfsson
Iceland

Father of an autistic person, on how education needs to adapt to remove barriers for autistic pupils and students.

"Instead of pushing everyone into the same mould or form of educational blocks, there should be room to allow the differently talented ones to grow into the form they are capable of"

"The main difficulties I have faced is finding suitable ways to accommodate the schools' curriculum or agenda to suit the different needs or abilities of autistic persons, so they can achieve their suitable educational degree and move on to higher education in their field of interest, where they have less or no difficulties focusing on that specialty.

"With common side disorders like dyslexia and dyscalculia often being misdiagnosed and therefore not compensated for in their education program, they tend to eventually fall out of class and fail to complete their education, leaving them with no viable option to seek higher education, and thus will not reach their full potential in becoming officially educated specialists or experts in their field of interest.

"I have witnessed very good efforts of educational staff and support professionals, doing their best in finding ways to support and accommodate the environment for individuals with special needs.

"However the main school schedule is not flexible enough in substituting classes or even subjects to allow these individuals to graduate properly.

These schedules need to be seriously amended to truly offer educational support as well as the social and environmental support provided.

"All students go through same middle and high schools with no adapted curriculum to meet the needs of students with disabilities.

"The creation, acceptance and implementation of such a curriculum for students is needed, where the focus can be shifted from the weaker points to the stronger ones and allow for subjects to be exchanged quite individually for each student, and thus allow them to reach their full potential and level of education possible.

"Better screening of learning disabilities such as dyslexia and dyscalculia is needed in the early stages so they can be compensated for and treated as early as possible.

"Instead of pushing everyone into the same mould or form of educational blocks, there should be room to allow the differently talented ones to grow into the form they are capable of and further their educational ventures based on their strengths and interests, allowing them to actively enrich our society with their special skills."

Breaking barriers

The Dublin City University (DCU)
Ireland

The world's first autism-friendly university

Dublin City University (DCU) was recognised as the world's first autism-friendly university by autism advocacy charity AsIAm, at a ceremony held on the 22 March 2018.

The university achieved this status by addressing eight key principles, established as part of a research study into what makes higher education studies accessible for people on the autism spectrum.

The principles include implementing complementary academic and social supports as well as supports in areas such as: communication and socialisation, provision of quiet spaces or quiet times at events, life skills, navigation of the physical campus, and securing internships and employment.

Autism-specific training and awareness among DCU academic and support staff as well as the general student body, including class representatives and student ambassadors, has been focused on too, and is set to increase even further.

The DCU is understanding of the needs of autistic students, open to making adaptations to be more accessible, and has a positive, celebratory culture towards autism. Fostering autism-friendly educational establishments will not only ensure that autistic students can thrive while studying, but also serve as a springboard to employment opportunities after their studies.

Monique Post
The Netherlands

Person on the autism spectrum and professional in the Netherlands, on her experience of barriers to accessible education.

"[In the absence of education] you build many failure experiences which can prevent children from getting back into a learning setting"

"Inclusive education is a concept which is a basic human right but sadly is not yet fully integrated within every education system on a national level. Making exceptions should be the norm for all children, not just children with a diagnosis.

"Parents are forced to fight for the rights of their child to education and in the meantime the kids are often stuck at home.

"Education and healthcare do not work well together and there is often a fight between authorities concerning what should be paid for by the education budgets and what should be for the healthcare budgets. Barriers exist. The only person in this who is harmed is the child or young person who, in that time, is stuck without any education. The longer you are out of the system, the more difficult it is to find your place. [In the absence of education] you build many failure experiences which can prevent children from getting back into a learning setting […].

"Children with autism have a delay in social/emotional development and are so often under-stimulated to develop in this area. On the other hand, they are often accelerated in their cognitive development but are often scaled into level of education below their ability, and are thus under-stimulated on a cognitive level too.

"In the Netherlands children are faced with 2 big challenges. At the age of 12 they are forced into a level of education based on a test (CITO). You are judged on your worst subject and this essentially decides the level of education you are allowed to go for in your next school.

"You are also already expected to choose a direction at this young age! This is of course a crazy idea that a 12 year old can decide what they want to become as an adult […]

"If a child has been scaled into the Special Education system then you face the challenge of there being limited places in the highest forms of middle school level education (VWO) and if those places are full, then it is only if your parents can bring you to a school outside of your local authority (due to student transport being restricted and nearly abandoned on a national level) that you can study on that level.

"Otherwise you might be sent to a lower level of education because they have places, which is not right […].

"I have worked on a pilot project in the place where I live where the local authority has given a small subsidy to pay an experiential worker with autism (myself) to work with young people who have fallen out of education or are about to in order to see if I can find the challenges which are preventing inclusive and fitting education and help the young person think about potential solutions that they may have.

We found that taking your own experience with you can help make a connection between you and the young person, and not being a traditional healthcare worker opens doors in a situation that can be blocked for many years.

"Professionalised experiential workers with autism can support the guidance of kids with autism who get excluded:

1. Many young people who are at home have a form of autism. They go through a different development and if the school cannot respond to this, there is at risk of dropout/ exclusion. Care providers too cannot always connect well with the other order of development people with autism experience, resulting in even more negative experiences for the youngster.
2. An expert with knowledge of this alternative order of development within autism can:

• Help the young person to develop a better self-image by recognising the efforts of the young person (and his family) to function, but also offering stress reduction by helping the young person to gain insight into who he/she really is and reducing the pressure on adaptation.

• Provide insight into the reasons for school drop-out/exclusion. These causes are often not only at school, but in a combination with (radical) events in the life of young people and how they deal with these in a different way than their peers because of that alternative order of development. Insight into this can help to find appropriate solutions from the perspective of the child, who knows themselves the best rather than what the system thinks they can offer.

• Creative thinking about suitable solutions because the experiential expert works from the inside experiences of what autism can be and is often better able to speak about the younger person's own knowledge than a professional without autism could".

Some of the benefits of inclusive education can be the following:

- Students without disabilities made significantly greater progress in reading and math when served in inclusive settings. (Cole, Waldron, Majd, 2004)
- Students who provided peer supports for students with disabilities in general education classrooms demonstrated positive academic outcomes, such as increased academic achievement, assignment completion, and classroom participation. (Cushing & Kennedy, 1997)
- No significant difference was found in the academic achievement of students without disabilities who were served in classrooms with and without inclusion. (Ruijs, Van der Veen, & Peetsma, 2010; Sermier Dessemontet & Bless, 2013)
- Kalambouka, Farrell, and Dyson's (2007) meta-analysis of inclusive education research found 81% of the reported outcomes showed including students with disabilities resulted in either positive or neutral effects for students without disabilities.
- Time spent engaged in the general education curriculum is strongly and positively correlated with math and reading achievement for students with disabilities. (Cole, Waldron, & Majd, 2004; Cosier, Causton-Theoharis, & Theoharis, 2013).
- Students with intellectual disabilities that were fully included in general education classrooms made more progress in literacy skills compared to students served in special schools. (Dessemontet, Bless, & Morin, 2012)
- Students with autism in inclusive settings scored significantly higher on academic achievement tests when compared to students with autism in self-contained settings. (Kurth & Mastergeorge, 2010)

UNCRPD
Article 24 - Education

The aim of Article 24 is for States Parties to realise the right of persons with disabilities to education. "With a view to realising this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning." While ensuring that "Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion."

Autism-Europe recommends that the EU:

- Monitors the access to education of pupils with autism and collects data and statistics across EU countries on their access to mainstream education;
- Promotes the use of EU Structural Funds to support the training of school staff on teaching;
- Establishes common standards on the qualification of support teachers and assistants for autistic pupils and students;
- Develops and adopts guidelines on the prevention of abuses and bullying against children with autism in segregating and mainstream settings.

4– Improve access to employment

André Antunes
Portugal

Person on the autism spectrum from Portugal, on what is needed to remove barriers to employment.

"The team in the place where I used to work accepted me without prejudice"

"I believe the main reason why a lot of employers do not accept people on the autism spectrum is due to prejudice. It makes it difficult for those people on the autism spectrum to become employees themselves. Luckily for me, I managed to get access to a job related to autism, which made it easier for me to be accepted.

"Examples of good practice or positive steps I have witnessed are numerous. For example, the team in the place where I used to work accepted me without prejudice and the seminar and other events organized by the team (myself included) worked properly which showed others what people on the autism spectrum can do right in the world of work. The team where I was included was organized and helped me to become a better organized person at my job and also in my life. Finally my work actually left a mark in that place's history, given the fact that I became the first employee on the autism spectrum to work there.

"The suggestions I would give to improve the current situation are: the managers of companies should be more informed about the autism spectrum and help those who are on it. People on the autism spectrum should not be discriminated against purely because of their condition. Finally, people on the autism spectrum should have the same rights as the other employees who are not on that spectrum."

Kristýna Rungeová
Czech Republic

Hiring manager of person with autism as part of the SAP "Diversity & Inclusion- Autism at Work Program", on approaches to removing barriers to employment.

"A diverse and inclusive environment of the organization is a prerequisite to successful employment practices in the area of autism"

"There is a high importance of the support circle provided by the employer and NGOs/experts that are supporting people with autism. Close cooperation is an important piece for successful employment practice to support challenges of autistic people, leading to a successful and sustainable interview/ hiring/ employment process.

"The pre-employment support given to people with autism is very helpful to succeed in the corporate environment and interview process. The on-the-job coaching and mentoring needs to be a natural part of the whole employment lifecycle.

"An important factor is also the one related to building a pipeline of candidates whose skills, education and experience fit the job role, which is also deeply connected to the long-term struggle of people with autism to be employed.

"Awareness about autism and its specificities is a key part of the success of the whole employment process, together with a diverse and inclusive environment […].

"At the same time, I find it important to find a balance between acknowledging a person´s challenges with autism to make sure that the right support circle is in place and on the other hand to assure that this information is not publicly disclosed.

"Also, the public and private sector need to work together to make it happen. I believe the more companies and organizations that join to support the topic, the better the understanding and practices for people with autism and their peers will be […]

"An important example of good practice is our cooperation with various NGOs and experts on autism as well as creating an Enterprise Readiness Academy, currently available in the US, as a part of pre-employment support for autistic candidates who would like to apply for a position in a corporation like SAP.

"During the program, we have received a lot of positive stories where employment at SAP has had a very positive impact on people's lives.

"People involved in the program have grown significantly from a career as well as a human perspective. Focusing on the strengths of autism has brought us engaged, loyal employees on the spectrum and various perspectives, ideas and examples of innovation.

"As a part of the whole recruiting, on-boarding and employment process, we provide reasonable accommodation according to the individual needs of each autistic person, specifically during the interview process, which is adjusted. In terms of how the questions are asked, we also have the possibility of an accompanied interview where the autistic person is accompanied by an expert/coach with an autism certification to support them during the interview process.

"Similarly, on-the-job coaching and mentoring is also very useful during employment itself. Any person with autism, if for example they are sensitive to light or noise, receive a respective accommodation of their working environment in line with the possibilities offered by the building.

"Where possible, due to the character of the job and the interest of the employee, people from the Autism at Work program can also work from home, and tend to enjoy this opportunity very much […]".

SAP is a multinational software corporation with offices in more than 130 countries, and which has a goal of hiring 650 people on the autism spectrum. SAP's ground-breaking Autism at Work program integrates people with autism into the workforce.

UNCRPD Article 27
Work and employment

Article 27 reinforces the fact that States Parties should safeguard and promote the right of persons with disabilities to work, on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. It also includes giving equal opportunities and equal remuneration for work of equal value, and ensuring that reasonable accommodation is provided to persons with disabilities in the workplace.

Autism-Europe recommends that the EU:

- Monitors the employment, unemployment and inactivity rates of autistic people , and their access to vocational training programmes and traineeship opportunities;
- Supports awareness raising campaigns among employers and trade unions on needs for adjustments, abilities and potential of autistic people to work;
- Promotes training of employment services to enable them to match employment opportunities and work environments with the individual and particular skills and needs of autistic people.

5- Foster a person-centred approach and lifelong support in the community

Claude Schmit
Luxembourg

Father of a person on the autism spectrum, on barriers faced by autistic adults

"The public schools and even the specialised services for autistic people with lower support needs have a tendency to turn people away when their behaviour becomes too challenging"

"Most of the services run in Luxembourg are foreseen for people that do not have so-called "challenging behaviour". Only the *Fondation Autisme Luxembourg* takes care of people with behavioural issues, but its services are limited to people with high support needs. The public schools and even the specialised services for autistic people with lower support needs have a tendency to turn people away when their behaviour becomes too challenging. After being expelled, these people have to remain at home with no services. Some are placed in psychiatric services. The *Fondation Autisme* has been approached with demands from parents to open a service to address their needs, but has not yet found a possibility to finance it.

"Only very few people on the spectrum have jobs in the open labour market. Although there is a law setting a minimum quota to employ people with disabilities, most people on the autism spectrum have no chance of finding a job in the open labour market.

"Finally, when the parents pass away, the situation is worrying. If needed, a guardian will be nominated, but the role of the guardian is mainly to protect them from financial abuse. Other aspects, like medical questions or community support, are not considered to be an issue. In many cases the guardianship is given to the caretaking association of the person, which results in conflicts of interest and an external regulation becomes impossible.

"A group of parents set up a foundation, which offers services for autistic people. There are now two locations that offer residential and day care centres for people with high support needs and the environment is specifically designed to offer assistance adapted to their individual situation. They are the only centres where people can stay without being heavily medicated when they show challenging behaviour. This of course means that extra staff is needed to handle difficult situations. The government has understood this and has granted special funds to enable a setup that makes a dignified life possible.

"In order to help the families to keep their children at home as long as possible, the foundation offers rooms for short-term stays. The purpose of these rooms is:

- to host persons with autism so that their families can take a short break or have time to rest;
- to host persons with autism who have severe behavioural difficulties and occasionally require more intensive supervision than usual.

Heidi Thamestrup
Denmark

Mother of three children on the autism spectrum, on barriers to effective support to autistic people.

"The carers that achieve the best results work on building relationships"

"Autism is hard to explain and even harder to understand. Especially when adult autistic people are moving away from home, and are put in an apartment, all alone, with one or two visits a week from municipality care services. Why do we get surprised, when we visit, and find pizza boxes piled from the floor to the roof? If you do not have the ability to get in contact with other people, if you do not know how to commit with peers, then there is no chance you can grow a social life for yourself. But you can still want one.

"Often these autistic youngsters feel more and more distant from society and develop anxiety. With the anxiety they experience a loss of social strategies and become more and more isolated. Sleeping the day away but awake at night. Ordering food from delivery stores and never leaving home.

"We are great at compensating for physical disabilities. It's simple, with prosthetics and wheelchairs. It's also easy to understand - that you can replace an arm with a prosthesis or legs with wheels ...

"We are really bad when it comes to compensation for conditions such as autism. If you do not have the ability to create a network or form friendship and you cannot ask for help when you need it, you are severely disabled.

"The carers that achieve the best results work on building relationships. It is not enough to make relationships available. When a relationship is created, the professional who has the ability to create, maintain, and keep the relationship going must be responsible for taking it further.

"Professional relationships work best in teams. It is necessary to have more colleagues maintaining an extremely high ethical standard. It is important that the autistic person does not become dependent on one person, as then the set up will be too vulnerable.

"It is important that the support person understands that the work goes on in another person's home - it requires respect, professionalism, sincere interest and will."

Maria Wroniszewska
Poland

Mother of a person on the autism spectrum, on the barriers to accessing lifelong support.

"It's about quality of life"

"In Poland children and young people with autism have very comprehensive support and access to different kinds of education (special, inclusive, integrative). However the support stops at the end of school. There is no lifelong vocational and learning system, no day activity centres, no supported employment or group living facilities.

"The only possibility is to stay in the family home doing nothing or going to a big social care institution with over 100 people. For most parents, the future of their adult sons and daughters is the greatest problem, especially for autistic persons with the highest support needs.

"Parents have been trying to change this situation for many years and are using the possibility to introduce new solutions on the basis of projects. The aim is to show good examples to the authorities and insist on common implementation of these practices. Often we use European Funds, but sometime local authorities also support such projects.

"My organization - SYNAPSIS Foundation - has been developing services for autistic children and adults for 28 years. One of the most positive examples is the sheltered employment social enterprise, where we employ 24 adults with autism. Most of them have very high support needs (non-verbal, with behavioural problems, with epilepsy).

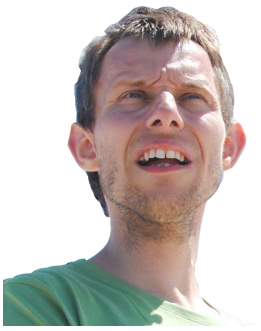
"Our strong belief is that everybody can work and that work tasks can give them goals in everyday life, through positive reinforcement and satisfaction. It has been confirmed after 10 years of activity. They are employed, they earn money, they sell all their products. They participate in sports activities, often much more than we expected at the beginning. They have developed skills not only in swimming or bike riding, but also rock climbing and skiing.

"They have many friendly trainers in the group of Polish alpinists. Participation in sport activities gives also them the best possibility to train social skills. They use alternative communication with trainers and it gives them the great satisfaction of being fully included in the society. They have the motivation to cooperate with alpinists, not only specialists in autism. They often can't speak but they can climb the rocks and mountains.

"There, they experience some of the happiest moments in their life. At the beginning nobody would have believed that they would achieve success in these sports. Now, all parents and trainers are very proud as well as autistic people. It brings emotional stability and harmony to their lives. It's about quality of life.

"It is necessary to start the deinstitutionalization process in Poland. People with autism need to be included in society and have a choice to receive support in lifelong education, supported living in small group homes and supported employment on the open labour market, or in sheltered employment. Also training in self-management skills is necessary in the preparation for as independent a life as possible.

"This investment will reduce the costs of many interventions in psychiatric hospitals, costs in social care and will bring real support for families, who often continue providing constant care during the whole life of the autistic person."



Maria Kaminski
Germany

Mother of a person on the autism spectrum (in the picture), on the logistical barriers to getting proper support.

"Society must be sensitised to the needs of autistic people"

"Which hurdles do we face? We face many bureaucratic hurdles. We have to apply again and again for the same services, and there are frequent changes of responsibilities and personnel in the offices. Furthermore, there is a lack of well-trained, autism-experienced staff.

"In the past 40 years, we have had to fight hard for our son, and even fight in court. This includes the lifelong opportunity to receive autism-specific therapy and individual assistance regardless of income and status.

"With regards to autism, it is often difficult to explain the need for help and to make it plausible. The symptoms of autism are often not immediately recognisable. Corresponding barriers must be reduced and society must be sensitised to the needs of autistic people."

UNCRPD Article 19

Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Autism-Europe thus notably recommends that the EU:

- Promotes access to quality support and services across the EU to render community living possible;
- Develops a quality binding system, which complies with article 19 of the UN CRPD, in order to prevent Member States from using freedom of movement of persons, goods and services to undermine the right of persons with autism to live in their community;
- Develops and adopts EU guidelines on evidence-based, rights-based interventions for autism, based on existing guidelines at national and international levels;
- Develops minimum quality standards for habilitation and rehabilitation services and programmes for autistic persons of any age in the EU;
- Adopts quality assessment systems for habilitation services which are centered on outcomes in terms of inclusion, participation and quality of life of the users.

6- Ensure access to quality healthcare on an equal basis with others

Harald Neerland
Norway

Father of a person on the autism spectrum, on barriers to healthcare on an equal basis to others.

"There is a lack of adapted dental care and health examinations"

"There is a lack of adapted dental care and health examinations. Our daughter has to have dental examinations under narcosis. In addition a thorough health check with drawing blood for testing and vaccination is difficult as she does not like needles.

"We currently have a system where a dental technician does a simplified (visual) inspection and determines the need for a more thorough check-up. If such a check-up is needed an application is filed with the nearest hospital for an examination under narcosis. Waiting period for such an examination is typically 6 months.

"We would like to see a shorter waiting period for examination under narcosis, and a coordinated effort with other health professionals to do the necessary checks, including blood sampling, while she is under narcosis."

Breaking barriers

University Hospital of Amiens, Healthcare Simulation Centre
France

Reducing the stress of healthcare visits for autistic people

The University Hospital of Amiens's Healthcare Simulation Centre is an initiative that is the first of its kind in France. The centre helps prepare autistic people to visits to medical specialists, visits that might otherwise only be made possible through the use of general anaesthetic.

To better support autistic patients, the health simulation centre of the University Hospital of Amiens decided to innovate with the organisation of training sessions before patients undergo a radiography. Autistic patients can go into a radiology room, go back to the scanner, touch what's around them, take their time and be reassured about the exam that will follow. Time is taken for the autistic person to adapt to the surroundings, and for the medical team to adapt to the autistic person's needs.

UNCRPD Article 25 - Health

In Article 25, States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties should also provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons.

Autism-Europe thus recommends:

- Fostering reasonable accommodation of health care premises (including somatic health, dental care, emergency and preventive services) and diagnostic instruments needed to ensure persons with autism access to health care of the same quality as other people;
- Promoting the training on autism needs and accessible communication in the curricula of health professionals and other relevant staff.

7- Respond to a variety of needs and make community life open to all

Marta Roca
Spain

Sister of a person on the autism spectrum, on overcoming the barriers to accessing community life.

"The person has to be in the centre of our work to better respond to the needs of people on the spectrum"

"There are difficulties in education, healthcare, work, housing, economic well-being and the capacity for choice and control over one's personal dignity.

"A good example to foster more participation are inclusive clubs for children and young people on the spectrum to improve independence from their families and promote participation in community life with activities such as sport and leisure.

"Society should develop autism-friendly spaces for those who need a very high level of support. Even if they can't live on their own, they can have an independent life from their family. A good example is where my sister lives at *Autisme la Garriga*, where people on the spectrum with severe intellectual disabilities and complex behaviour have their own home .

"It's a network of services that gives them a care home adjusted to their individual needs, a place to work and promote their participation in the community, participating in different activities.

"The person has to be at the centre of our work to better respond to the needs of people on the spectrum. Society has to understand that a significant part of the people on the spectrum also have an intellectual disability and require a very high level of support [...].

"We need a very varied range of services according to the great variability of the spectrum".

Breaking barriers

Aggeliki Menni
Greece

Co-partner of "A million senses", on breaking barriers to accessing quality leisure time.

"The most significant problems for parents during their holidays is the lack of free time away from their demanding day-to-day life"

"The most significant problems for parents with and autistic children during their holidays, is the lack of free time away from their demanding day-to-day life, and the limited solutions that are geographically restricted and that offer no flexibility to enjoy a relaxed family holidays in a desirable destination. Holidays are usually something very distant from the minds of families and autistic people [...]".

"A million senses offer holiday packages designed and adapted to the specificities of each family with a member on the autism spectrum.

"In collaboration with sensitised accommodation providers and non-judgmental staff, we support families from their arrival until their departure. Our qualified professionals are always within arm's reach in order to offer support and cover families' additional special requirements. During our supervised recreational activities with the autistic family members, parents can have free time to relax and 'recharge their batteries' while they can also choose from additional services (babysitting, excursions etc.) to extend their free time and enjoy more unique experiences […].

"We are constantly trying to help those families navigate through their unique challenges and hope that in the near future we will prove that Greece is a place of high autism awareness.

"Autism awareness in Greece is growing but more slowly than many other countries. Until 1998 people with autism in Greece were not included in the constitution, meaning there were no services that provided support, diagnosis, interventions and education.

"It is not surprising that even today we meet children abandoned by their families, in institutions that have no expertise in assisting and supporting them.

"Since 2000 a series of legislative measures have put autism on the map by creating a department for autism in the Sector of Mental Health of the Ministry of Health. For almost two decades there has been an effort to meet the needs of people with autism and their families, building on the foundations created by the department.

"There is still a lot to be done to educate society and service-providers who still view autism as a condition relating to social awkwardness. Autism professionals in the past few years have done a good job in increasing autism awareness in communities.

"The general population has a notion of what autism is and are quite accepting and understanding towards the challenges they face.

"However, they are still reluctant to have people with autism as friends, offer them jobs and include them in everyday life. There is still much work to be done towards acceptance and inclusion and, in my opinion, it involves giving the public the knowledge and skills to understand autism and the difficulties people on the spectrum may face […].

"Autism awareness in services means highly informed and trained staff, adapted facilities and, the most important of all, the sensitivity and willingness to be part of a hopefully growing autism-friendly community.

"Moreover, we have to change the approach of what holidays mean for families with member on the autism spectrum, and that they have the right to have restful and fun holidays for all the family members, and basically that they have the chance for family holidays. Changes can be a serious problem for a person with autism and that extends to how their family reacts.

"In addition, considering that everyone has the right to rest and leisure, we believe that it is necessary to take care of the state to subsidize holidays for families with autistic members."

"A million senses- unique holidays for unique people" is a start-up social enterprise established in Greece since 2016.

UNCRPD Article 27

Participation in cultural life, recreation, leisure and sport

Article 30 underlined that States Parties should recognise the right of persons with disabilities to take part on an equal basis with others in cultural life, and that they should take all appropriate measures to ensure that persons with disabilities have access to leisure, sporting and recreational activities on an equal basis with others.

Autism-Europe recommends that the EU:

- Promotes training on autism in the curriculum of sport trainers and coaches, as well as other professionals active in the cultural life and recreation sector;
- Includes the participation of autistic persons in mainstream sport and cultural activities as a priority in relevant EU-funded programmes, in particular Erasmus+.

8- Ensure public spaces and transport are accessible

Mary Passeri

UK

Mary Passeri and her son Adriano who is on the autism spectrum, United Kingdom, about barriers to accessing public transport and spaces.

"They let us go through the controls quietly. We weren't in a rush or squeezed with any people. He managed really well"

"My son is autistic. I want to bring to mind and compare two recent journeys by plane. Indeed, for many autistic people, the accessibility of transportation can be an issue as their invisible disability is not always taken into consideration. As a result travelling through the airport can be a particularly difficult experience.

"Exciting as it is, air travel is also often stressful for people on the autism spectrum, and can become traumatic. Difficulties may begin long before takeoff. Airports are noisy, have bright, flashing displays that are distressing for people who have difficulty with sensory processing. Impatient travelers jostle anyone in their paths. There is also the stress of going through airport control, where waiting in a queue in a crowded and loud environment, following complicated orders and physical contact are almost unavoidable.

"The last time we flew from Heathrow it was murder, my son was terrified. Security grabbed hold of him and we had to leave and go back home.

However, Manchester airport, for example, is ready for autistic people. They let us go through the controls quietly. We weren't in a rush or squeezed with any people. He managed really well."

Breaking barriers

MAG Manchester Airport

Manchester Airport

UK

Autism-friendly air travel at Manchester Airport

Manchester airport is one of the airports in the UK that has adopted an accessibility policy for autistic people that involves being fast-tracked through security, having access to information designed for autistic children to prepare them to this new experience and change in their routine.

The good news is that Heathrow airport has now got on board and announced the launch of new accessibility programme for hidden disability in December 2017! Well done! We hope more airports will follow!

UNCRPD
Article 9 - Accessibility

Article 9 seeks to enable persons with disabilities to live independently and participate fully in all aspects of life. It underlines that States Parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

Autism-Europe recommends that the EU:

- Adopts a strong European Accessibility Act that respond to the accessibility needs of autistic people - for example by promoting standardised direction signs and signals in transport systems, public services and buildings and making sure that the use of alternative and augmentative communications systems are clearly included in the accessibility requirements of the Act;
- Provides that information is made available in easy-to-understand formats, including with content available in text, pictures and pictograms.

9– Ensure access to the right to vote

Miguel Á. de Casas

Spain

Father of an autistic person and President of *Autismo España* on the barriers to legal capacity and particularly the right to vote.

"It is necessary to modify the laws on legal capacity in Spain so that all persons with disabilities can exercise their right to vote and access to justice"

"Autistic people may have a legal incapacity that makes them unable to vote. Sometimes, parents promote the modification of the legal capacity of their sons and daughters, because they consider it the best way to guarantee the economic and personal protection of their children (many times because family members are not aware of what alternative options exist). However, this choice limits their possibilities to exercise the capacity to carry out legal acts, such as deciding on personal aspects related to family planning or medical treatment or using the right to vote.

"Some people with disabilities need to consult a judge to request the modification of the sentence that gives them legal incapacity. Even though it's not very common, there have been situations in which the judge has changed the sentence, and therefore these people can then exercise their right to vote. Once their legal capacity is restored, they can participate in the electoral processes, as well as make decisions about their own lives.

"Firstly, it is crucial to promote awareness throughout society about what the implications are of having legal incapacitation for an autistic person.

"It is also necessary to modify the laws on legal capacity in Spain so that all persons with disabilities can exercise their right to vote and access to justice. The law must be amended to comply with the Convention on the Rights of Persons with Disabilities.

"People with autism may find barriers that make it difficult for them to manage social situations, but that does not mean that they are not able to make decisions about their own lives and to choose what politicians they want to rule their country and their cities. The right to vote allows them to select politicians that promote policies that guarantee the rights of autistic people."

UNCRPD Article 9

Participation in political and public life

This article provides that State Parties should ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected.

Autism-Europe recommends that the EU Member States:

- Ensure all autistic persons the right to vote and the right to run as a candidate for elections;
- Make polling stations accessible to autistic people and that voting procedures (including for remote voting) are accessible and easy to understand;
- Ensure that election campaign facilities and materials, political debates, political party programmes and websites are accessible to, and inclusive of, persons with disabilities.

Autism Europe aisbl

Autism-Europe a.i.s.b.l
+32 (0)2 675 75 05
secretariat@autismeurope.org
www.autismeurope.org