Autism-Europe

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European Disability Card:

benefits and difficulties across EU

The portrayal of autism

. . . .

in series and movies

AE's

Autism and employment" report

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Contents

- 03 Edito
- 04 A European card to enhance mutual recognition of disability across Europe
- **05 Autism card** a step forward for the inclusion of autistic people
- 07 The portrayal of autism in series and movies
- 09 Interview with Carsten Lassen, CEO Specialisterne Denmark
- 11 Autism-Europe's report on Employment
- **12** AutismDay2022 campaign: a happy journey through life
- **13 Results of the IPA 2 project -** Improving school transitions (2019-2022)
- **15** Developing access to independent living in Basque Country
- 17 13th Autism-Europe Congress: don't forget to register!
- **18** Almost two decades before Asperger: On the autism research of Soviet child psychiatrist Grunya Sukhareva
- 20 The Denizli Autism Association supports Autistic Rights in Turkey
- 21 The Mars Foundation: Supporting autistic people and their families in Hungary
- 22 Members list

More news at: www.autismeurope.org



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Dear readers,

utism is often described as an invisible disability as many autistic people routinely face a lack of understanding in society about their support needs. Thus it is vital to alert and inform those interacting with them so that they can receive accommodation for their disability and co-occurring conditions. To this end, Autism cards have been in use for a number of years to facilitate communication in various contexts. In this edition, we share the experience of three recent examples of autism cards delivered at the local or national levels in different European countries.

Having an invisible disability is also a challenge when traveling abroad, hence Autism-Europe is following closely the preparation of the European disability card, whose objective is to facilitate mutual recognition of disability status across Europe. However, the EU disability card would not change national eligibility criteria or rules. The EU Member States would retain their discretion to decide who is eligible to receive the Card, using the national definition of disability. Thus we also need to ensure that autistic people's needs are addressed at the national level, whatever their age and the level of support they may require.

Overall, raising awareness is essential to promote a better understanding of autism in society. Series and films can help break prejudices and make society more aware of autism, and the diversity of autistic people. However, autistic people should be consulted so that the way autism is depicted in fiction does not perpetuate stereotypes. Understanding must be present at all levels of society, including at schools. The IPA-2 project featured in this edition aims at reducing the risks of social exclusion and school dropout by addressing teachers, autistic students, and their peers. Its objective is to promote a more inclusive, empathetic, and supportive perspective amongst education professionals and non-autistic peers.

Building positive peer relationships in schools is also one of the topics of AE´s International Congress taking place on 7-9 October 2022! For the first time, the event will be accessible online with high-quality access to its sessions, presentations, workshops, discussion panels, and more. You can also attend in person, in the historic city of Cracow, Poland. The Congress will bring together international experts to promote a positive vision for autistic people and their families to foster "A happy journey through life". We look forward to seeing you there!

Best regards,

Director, Aurélie Baranger



President, Harald T. Neerland



Image of the European Disability Card with "NL" from the Netherlands. The card is inside a EU flag



A European card to enhance mutual recognition of disability across Europe

The European Disability Card is a flagship initiative of the European Commission's Strategy for the Rights of Persons with Disabilities 2021-2030 to be launched by the end of 2023. Its objective is to facilitate mutual recognition of disability status across Europe. The European Commission announced that the card will be based on the experience of the dedicated pilot project conducted in 8 countries, and the European parking card for persons with disabilities. It could soon benefit autistic people across the European Union.

■he card does not change national eligibility criteria or rules. Member States retain their discretion to decide who is eligible to receive the Card, using the national definition of disability, and to determine the issuing procedure. In that respect, AE's Council of Administration (CA) member, Tarja Parviainen from the Finnish Association for Autism and Asperger's Syndrome, indicated that some autistic people experience difficulties having their support needs adequately recognised in Finland. Ms. Parviainen who took part in the national group monitoring the European Disability Card pilot project in Finland, highlighted that being denied the Finnish disability status would also exclude them from the EU scheme.

Finland was one of 8 EU member countries that ran the European Disability Cards pilot project between 2016 and 2018. The others included Belgium, Cyprus, Estonia, Italy, Malta, Romania, and Slovenia. The pilot project aimed at promoting the rights of persons with disabilities and voluntary mutual recognition of disability status. The pilot card

provided access to culture, leisure, sports, and transport. National service providers participated in the pilot project voluntarily. They committed themselves to offer the same services to cardholders from any of the eight participating EU Member States.

An EU Commission study conducted between 2019 and 2020 and published in

2021 found that the European Disability Card proved to be effective. In total, over 300 000 cards were issued.

The pilot cards led to an increase in the participation of people with disabilities in culture and leisure activities. However, there was no increase in access to sports, transport, tourism, and cross-border mobility. Yet, specific socio-economic actors benefitted from the pilot card scheme.

Indeed, the pilot card scheme has introduced a mutual recognition of disability status across the participating 8 EU Member States. The participating service providers recognised the

The implementation costs of the pilot card were low in all participating 8 EU Member States. The benefits outweighed the costs as service providers had positive economic returns. The accessibility of the services for people with disabilities has improved. Overall the pilot card has facilitated the recognition of disability by service providers.

> European Disability Card as an official document attesting to the disability status of persons with disabilities. This is particularly relevant for people with invisible disabilities as the 2021 EU Commission study suggests.

This particular attention to invisible disabilities, including autism, can also be found in the new EU Commission's Strategy for the Rights of Persons with Disabilities 2021 – 2030 released in March 2021. The Strategy affirms that "persons with invisible disabilities (such as chronic pain or intellectual disabilities), with rare diseases or with cancer, that often lead to impairments, do not always receive the tailored support needed nor do women and refugees with disabilities."

Having worked for several years with the European Commission and the European Disability Forum (EDF) to promote mutual recognition of diagnosis of autism between EU Member States, Autism-Europe warmly welcomes this flagship

initiative. The European Disability Card could become a useful tool to overcome the different definitions of disabilities across the EU which still leads to major difficulties for persons with disabilities traveling to another country as their disability cards or status is not recognised outside of their home country.

So the European Disability Card has the potential to foster positive change. To be able to enforce it and to ensure a harmonised approach throughout the EU, Autism-Europe believes that the European Disability

Card should be implemented through binding EU legislation. The card should be adopted by all Member States and the scope should cover a maximum of

entitlements and benefits, including mutual recognition of social security benefits and access to transport.



Autism carda step forward for the inclusion of autistic people

The COVID-19 pandemic showed more than ever that autistic people and their families are particularly in need of tailored support measures. It is vital to alert and inform those interacting with autistic people so that they can receive accommodation for their disability and possible co-occurring conditions. Over the years, many examples of good practices have been introduced at the local or national level to tackle the diverse needs of people on the autism spectrum. One such practice is autism identity cards that facilitate communication and accommodations. Here are three very recent examples of autism cards delivered at the local or national levels across different European countries.

n 2019, the Autism Spectrum Information Advice & Meeting Point (Aslam), AE member organisation from Ireland, started consulting with their autism community and relevant partners to explore the viability of an Autism ID card scheme. They also wanted to enquire how such cards should be issued and managed. This consultation came after Aslam received many queries and requests from members of the public.

The result of the consultation by the Irish autism charity found among others that 76% of respondents felt that to receive such a card proof of diagnosis in the form of a doctor's note should be required. Over 50% of people felt that the most important requirement for the card to have an actual impact was to have public and commercial staff interacting with autistic people practicing inclusive behaviours and having a level of autism awareness training.

Aslam launched the AsIAm Autism I.D. Card that is delivered in such a way that autism community members can access it easily and affordably while ensuring safeguard from abuse. The card is a means of providing staff with an explanation of the cardholder's diagnosis and the nature of their challenges. It does not automatically provide discounts and or preferential treatment over other customers.

The objective is also for the card to be of use outside of Ireland - the autistic community of Northern Ireland is also eligible for the card. So for better recognition abroad the Aslam Autism ID Card also features the logo of Autism Europe. Currently, Aslam is asking for feedback. So, if you are an autism ID cardholder issued by Ireland's autism charity, let them know how you like it. You find all information on their website.



Find more here:

https://asiam.ie/advice-guidance/ community-inclusion/id-card/



The Autism card when visiting a hospital in Croatia

In July 2021, the autism association in the coastal town of Rijeka, a local member of the Croatian Union of Associations for Autism, launched the pilot hospital passport for people on the autism spectrum. It is the result of a cooperation between the autism association of Rijeka and the Clinical Hospital Centre (KBC) in Rijeka.

The passport is primarily intended for medical staff carrying out tests on autistic people. It contains data that facilitates access for the patients on the spectrum and allows them to pass through the hospital system faster. Based on interviews of parents or guardians, information is entered into the hospital passport on how to approach the autistic patient, how to perform a particular examination and how the patient on the spectrum will react to certain stimuli. The data also indicate how the autistic patients may display agitation or pain, or what can soothe them.

The launch of the hospital passport for autistic patients at KBC Rijeka made news across Croatia when national daily Novi List called it a "Step forward for patient care". The renowned newspaper learned at a joint press conference of the autism association of Rijeka and the KBC in the summer of 2021 that this type of passport was taken from similar card schemes used by the UK National Health System, and an expert team adapted it to the Rijeka hospital system. The hospital passport has a QR code on its first page that is very easy to read, and in addition to medical staff, it can be read by any official administration.

As there are plans to broaden the hospital passport to people with intellectual disabilities, the head of the early intervention program at Rijeka's autism association, Ivanka Pejić, said that the city is always listening to groups in need.

If you are (a relative of) an autistic patient at KBC, you can find all information to obtain the hospital passport on the website of the autism association of Rijeka.

Find out more here in Croatian:

https://autizam-ri.hr/2021/07/28/ putovnica-za-osobe-sa-poremecajemiz-spektra-autizma/



The autism card when in an emergency in Germany

In December 2021, in the town of Brandenburg (Germany), Carola Niekisch, an awarded entrepreneur and mother of an autistic son, involved in a local independent self-help autism group, together with an academic researcher and a medical computer science student from the local technical university, presented the digital health pass for autistic people.

The digital health pass comes in form of a mobile application (app). The app, which can be compared to the European COVID-19 app used to display proof of vaccination, generates an individual QR code. This QR code provides important information about the app-holder and their behaviour in emergencies. It also provides contact details of relatives to be informed, if necessary. The digital health pass holds two different versions of the QR code that can be used either online or offline. The respective QR code can be shown to keep the situation under control. It either refers to a dynamic website and displays the entered data or opens a text file on the smartphone if there is no Internet connection. Katja Orlowski, an academic researcher at Technical University Brandenburg, also suggests that autistic people can wear the QR code by having it engraved on necklaces, key chains, or even pins, as it will make it safe and long-lasting.

Autistic people should receive training to show this code when they are in distress. On the other hand, emergency staff, for example, should be informed about the fact that important information will be made immediately available to them by scanning the QR code if the person on the autism spectrum is becoming non-verbal during the emergency.

By photographing or scanning the QR code at hand with their cell phones, the people who have difficulties communicating with the autistic person in distress will have access to information regarding how their autistic counterpart should be treated, what medications they need, and the contact details of a parent or guardian who can intervene when informed.

To broaden the use of the digital health pass to people with chronic conditions or with dementia leaving their care homes and getting lost, the initiators are still looking for funding. You can find how to access the digital health pass on the website of the autism self-help group of Brandenburg.

Find out more here in German:

https://autismusgruppe-inbrandenburg.de/nothilfepass/





The portrayal of autism in series and movies:

a powerful way to influence society

"Nothing about us without us" is the motto of the disability movement and a powerful reminder that autistic people should be involved whenever autism is at stake. It also applies to cultural representation in TV and media, since it has real-life consequences and impacts the way society sees people, communities, situations, etc. Cinema, TV, and entertainment are part of human culture. They are a reflection of society and they can change narratives and perceptions.

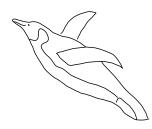
he autistic community has been for a long time present in different shows, TV series, and movies: from Rain-man (1988) considered both the most influential and one of the most damaging movies dedicated to autism, to the well-known Forrest Gump (1994), Tropic Thunder (2008) - made in an era when few in the film industry saw a problem with neurotypical people playing atypical characters - to the controversial movie Music (2021), the Netflix production Atypical (2017) or the acclaimed As we see it (2022).

Sometimes the best way to explain something is by examples, and we have already a few when it comes to autism in the film and TV industry. Here is a selection, if you would like to watch a movie about autism or if a friend of yours would like to learn more about the spectrum through fiction.

Let's start with an example you may be familiar with: **Atypical (Netflix, 2017)**. This already famous production deserves praise for the representation of autism. Its main downside may be that the main character, Sam, is interpreted by Keir Gilchrist, who is not autistic. However, The Miracle Project (an acting studio) and several of its talented students on the spectrum, helped move forward the inclusion of actually autistic cast members in the show. Sam's character does not display only the traditional aspects of autism but it also depicts him through comedy, warmth, and empathy. As laudable as it may be to come across a show that has done its homework about the condition, Atypical does perpetuate the stereotype of the white autistic boy and it does little to raise awareness of diversity. It is therefore refreshing to see an autistic girl portrayed in **Everything's Gonna Be Okay (2020**).

As highlighted by the autistic TV critic Matthew Rozsa writes for Salon: "Whereas Atypical often seemed to approach these problems (editor's note: of relationship and sexuality) from the vantage point of an outsider looking in, however, "Everything's Gonna Be Okay" dives into the mindset of the autistic character herself".









Nowadays most of the films dedicated to autism still tend to convey stereotypes rather than a realistic depiction of the experience of the majority of autistic people. Rain-man (1988) was the first movie to address autism, and it was a landmark. However, it contributed to reinforcing the cliché that autistic people are savants with incredible memory skills. Some clichés never die, but we can see a shift in recent years, even in Bollywood, which produced one of my favorite movies: My Name is Khan (2010). The main character is autistic but his narrative does not go only revolve around the condition. Shahrukh Kahn's character's Muslim faith is just as important as the fact he is autistic.

Is there any film that has failed to represent autism? Recently the movie of Sia, **Music (2021)** has attracted a lot of criticism. According to the autistic community, this movie is a perfect example of what is wrong with autism representation in films. The two main reasons are the casting of a neurotypical actress in the role of an autistic character – whose cloying performance infantilises the character -, and the scenes where the autistic character is being restrained to calm her down, which has been strongly condemned by the community. This has led to a petition to cancel the movie. Would this be the right decision? Is censorship the answer to the issue at stake?

This kind of controversial artistic productions can also teach valuable lessons and influence future productions. "Music" can remind filmmakers to pay attention to the voices of the communities they aspire to represent.

So, what is the advice for movie and show producers? How does the industry

move forward into a better future for autism representation? Actively involving autistic people should be a pre-requisite if the intention is to be accurate. Autistic people should be consulted and have the possibility to challenge aspects of the work. Great autistic actors would best play the sensitivities of autistic characters, as it is the case in **As we see it (2022)**.

It would be refreshing to see characters other than autistic savants who are valued mainly because they are gifted. Autistic characters should represent the diversity of autism, also from a gender, race and sexual orientation perspective to have a more realistic approach to autism. Most importantly, the TV and film industry must ensure that they are the main characters in their own stories in line with the motto "nothing about us without us".







Carsten Lassen

CEO Specialisterne Denmark

Autism-Europe spoke to Danish social enterprise Specialisterne CEO Carsten Lassen about their mission and function. Specialisterne is internationally recognised as the first and foremost example of how autistic adults can become effectively included in society and provide valuable, high-quality services to their employers. Their business model has been successful at employing autistic people with franchises across Europe in many countries who now have their own national 'Specialisterne'.

SPECIAL STERNE

AE: Do you have an idea of the unemployment rate of autistic people in Denmark?

CL: The Autism Society in Denmark says that the unemployment rate is between 80-90%, which is a similar trend across the rest of Europe. However, exact figures are difficult to find as you are not allowed to measure your workforce by their autistic diagnosis status.

AE: Whatdo you think are the biggest misconceptions in relation to autism and employment that hinder access to work for autistic people?

CL: Most companies think that it is a lot of extra work to onboard people with autism. When it comes to managing autistic people, they think they need a PhD in Psychology and that merely taking an autistic worker on, can become a full-time job in itself. There is also an anxiety to engage with autistic people because most people think that "they" (autistic workers) cannot 'handle it', and they are afraid to do something wrong.

One of the biggest misconceptions is in the monitoring the work of the autistic worker. Some employers think that when an autistic worker is having an 'off' day that they should be left alone. This couldn't be more wrong. At that point, the autistic worker needs close support. This lack of reaction from the manager is down to the fear of not being able to handle it correctly. Some autistic companies often think they can spot an autistic worker on the horizon. However, you cannot "see" autism in a person. This can lead to confusion about the worker and creates the question of "are they or are they not autistic?" in some amusing cases. These misunderstandings thicken as many people think that autistic people are all non-verbal or that they are just these "superbrains" who are incapable of communicating in an ordinary way. For example, they are either "Einstein" or "Rainman" and this is not right.

In addition, on the subject of repetitive work, not all autistic workers are automatically like this. That is simply not the case. You cannot put all autistic people in a box. This is just not how autism works.

In terms of qualifications, there is also a demand for workers qualified in STEM subjects (Science Technology Engineering Mathematics). De-mystifying autism is key to all this.

AE: To make the world of work accessible, it is essential to be adequately informed. What do you think is key for employers to be aware of in terms of providing reasonable accommodation for people on the autism spectrum?

CL: No two persons are the same, diversity was created for a reason. If you want to consider everyone who acts the same then we would probably become extinct as a species. If you judge everyone in the same way, then as an employer, you have a problem. Whenever we go to a new company, we look at what the culture is in the company such as managerial style, how they work, what is their lunch routine, etc. The awareness that there are special needs for people with autism or other conditions should be taken into account in the onboarding process. Simple things like leaving early, or just understanding that you are not talking to a neurotypical person. All of this varies from person to person.

Interview



AE: One of your areas of expertise is precisely related to supporting reasonable accommodation in the workplace. How do you put it into practice? Can you give us some examples?

CL: We had an onboarding at Copenhagen Airport Security Department. They said neurotypical workers made too many mistakes. We had autistic people who took on the security role of processing passengers using body scanners. Despite the skepticism from trade unions who were worried about autistic people 'stealing' jobs, we soon found out that autistic workers excelled in this field. For this job, qualities of an extrovert such as being welcoming are not necessary and autistic workers needed concentration for many hours per day, looking at screens where x-rays scanned the luggage for bombs or prohibited items.

Based on competency needed for this job, our guys really did excel here. Now, the airport wants us to do all of this type of security recruitment and training autistic workers to do luggage screening. On average, the typical autistic worker is better on pattern recognition and has better focus on a task and this collaboration is a huge success story.

We also on boarded people who had to be proficient in migration software namely Microsoft Azure for the company Simcorp based in Copenhagen. Our people taught themselves Azure online starting in June. Then, they began their jobs at Simcorp in August. Two months after they began working, they were outperforming their neurotypical peers in that department and now, one of them is an instructor to train others in the software system.

AE: Could you share with us the success factors that you deem important to promote the inclusion of autistic people in the labour market?

CL: Firstly, you need courageous leaders. If it is not a 'top-down' decision for hiring neurodiverse workers, then most managers tend to go for the easy option and that means 'business as usual'. They go two ways and pay too much or outsource to Lithuania or India. Some companies can get their workload done at a very cheap rate elsewhere in the world. Some sort of incentive

structure that would reward managers that could live up to UN Sustainable Development Goal 8 (SDG8: Promote sustained, inclusive and sustainable economic growth, full and productive employment and work for all). Most managers say that this is a top priority but they do not know how to actually do it.

Employing autistic people is nowhere near being mainstreamed. There are not many CEOs who wake up in the morning and say "Crikey! We need to onboard autistic people!"

This is my task to make hiring autistic people a reality.

AE: In 2018, Specialisterne Austria conducted a study on the viability of hiring autistic workers and found that for every €1.00 spent, €6.28 was returned to the economy. Do you have a figure for Specialisterne Denmark?

CL: In Denmark, the welfare state functions so well and we are spending a lot on it, for every autistic person you move from welfare into paid employment, the Danish economy saves €35,000 per year. So obviously, there is an economic incentive for employing autistic person. It would cost around €5,000-10,000 to set up an assessment and programme for each person, this sum would be paid back within the first year of employment.

The impact on a country's welfare system is clear, as Specialisterne Ireland noted that a subsidy exists (Wage Subsidy Support Scheme) for companies that covers any loss in productivity that an autistic employee incurs (up to 20% of activity). Does such a scheme exist in Denmark?

CL: We have a "FLEX" system and what this means is that the Muncipality find out maybe that an autistic worker can only do 25 hours per week. So, how it works, the company pays the autistic worker for their 25 hours per week worked, and the State pays the rest which would be 12 hours more as the working week in Denmark is 37 hours per week for a full-time worker. Basically, the autistic worker cannot work the full working week. This system works all the way down to 16 hours per week for the worker.



Fostering access to employment for autistic people

Autism-Europe's "Autism and Employment" publication aims at fostering access to work for autistic people. Its objective is to make public authorities, employers, and other stakeholders aware of their diverse potential and how they need to be supported to reach it. The report outlines the legal framework regarding anti-discrimination in the field of employment. Autistic people have a right to reasonable accommodation to help them work effectively. Autism-Europe thus also calls on the EU to deliver clear guidelines on reasonable accommodation.

easonable accommodation is key to helping autistic people integrate into employment. According to the Article 2 of the UNCRPD: "reasonable accommodation" means necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms." The level of individualised adaptation to the workspace for the autistic employee can depend on their level of needs. An autistic person with complex needs is more than capable of doing their job with the right level of reasonable accommodation.

The report explains what reasonable accommodation means for autistic people through a series of testimonies and good practices, taking into account their diversity. It also highlights what kind of accommodation can be provided at various stages (recruitment, ongoing support), etc.

AE calls for a better implementation of the legislation tackling discrimination in employment at the EU-level

The European Union has the power to address discrimination based on sex, race or ethnic origin, religion or belief, disability, age, or sexual orientation. Thus, in 2000, the European Union adopted the Employment Equality Framework Directive 2000/78/EC4 which requires all Member States to adapt and develop national legislation to prohibit direct and indirect discrimination against people with disabilities (among others) in the area of employment and vocational training. The Directive applies, inter alia, to selection criteria and recruitment conditions, vocational guidance, vocational training, employment, and working conditions, including pay. Importantly, the Directive states that "reasonable accommodation" shall be provided, which means that employers are to take appropriate measures, where needed, to enable a person with a disability to have access to, participate in, or advance in employment, or to provide training unless such measures would impose a "disproportionate burden" on the employer. While all European countries now have such legislation in place, the impact of this directive remains limited in practice.

Autism-Europe considers that the scope of this directive does not provide adequate redress for the discrimination

in employment commonly faced by autistic people. In addition, under this directive, an employer may justify a decision not to hire an autistic person because the training and adaptations required for a person, especially for a person in need of a high level of support, would impose a disproportionate burden. Alongside other organisations of people with disabilities and Members of the European Parliament, Autism-Europe therefore calls on the "European Commission to prepare clear EU guidelines on reasonable accommodation. They should detail what forms it might take in line with an individual's needs so that Article 5 of the Directive can be transposed effectively into national law". AE also calls on the Commission to launch infringement procedures and to encourage Member States to ensure that a sanction system is in place in case of non-provision of reasonable accommodation, as it constitutes a form of discrimination.

You can access the online version of the report on AE website.

#AutismDay2022



"A happy journey through life"

For 2022, AE and its members decided to use the motto of the 13th Autism-Europe's Congress – "A Happy Journey through life". The theme illustrates the fact that a holistic approach is needed across the lifespan to ensure that autistic people can live happy and fulfilling lives.

Throughout the #AutismDay2022 campaign, AE will share the needs of autistic people in relation to various policy priorities as well as personal testimonies from autistic people and their families on what a happy life means to them. At the EU-level, this campaign will strengthen the AE advocacy work to ensure that the Strategy for the rights of persons with disabilities 2021-2030 and the European Pillar of Social Rights Action Plan take into account the needs of autistic people.

Actions and visuals for the #AutismDay2022 campaign

AE has launched an **art competition**:

to give autistic people the chance to show through art what happiness means to them. We invite autistic people to send us artistic visual pieces (photography, collage, painting, etc), that reflects their passions, hobbies, or, generally, something that makes them happy. In order to share the voice and testimonies of autistic people and their families on what constitutes a good quality of life, AE launches **a survey** (available in English, French, Spanish and Greek) to share their experiences in different areas of life, including education, relationships, political participation, etc.

As every year, AE has created different visuals adapted to Instagram, Facebook and Twitter, as well as key policy messages and other material that can be found in the **campaign toolkit**. The campaign toolkit explains the rationale of the campaign and outlines in detail how and when people can support the campaign.

What is the World Autism Awareness Day?

On December 18, 2007, the United Nations General Assembly adopted resolution 62/139, which declares that every April 2 will mark World Autism Awareness Day (WAAD).

Do not forget to use the hashtag #AutismDay2022 in your social media messages!

Scan the QR code for more information about the campaign!





a Autism

Visual of the WAAD campaign 2022

#AutismDay2022



IPA2 project -Improving school transition

Launched in 2019, the IPA2 project – Improving school transition – is an Erasmus+ project that aims at decreasing difficulties that autistic learners face, specifically during the transition from primary to secondary school, to tackle risks of early school leaving and disadvantages. The project targets teachers as well as autistic students and their peers to reduce the risks of social exclusion, school failure, and school dropout. It aims at fostering a more inclusive, empathetic, and supportive perspective amongst education professionals and non-autistic peers.

utistic people face mainly difficulties with social communication and interaction, and repetitive behaviors. In education, autistic learners have specific needs at different educational stages. During the transition from primary to secondary school, the new school demands can produce more stress, depression, and anxiety symptoms in autistic students. It can affect their academic performance leading to school failure or even school dropout or absenteeism. Therefore, there is a need to introduce changes in the educational context by providing more training actions focused on teachers and classmates to improve the interaction with autistic students to provide adequate support, empathy, and understanding of their needs and requirements.

IPA2 designed a series of training and tools to support school transition

IPA2 focused on, on the one hand, training teachers to make professionals more competent and prepared to respond to their autistic students' demands. To this end, a training curriculum was designed through a co-created methodology considering end-users including autistic learners. On the other hand, by involving classmates of autistic students, the aim was to improve the quality of the social relationships that are established in school, since peers are crucial for the personal growth of the student on the autism spectrum and they are an important support in the classroom. Hence, IPA2 developed training modules for teachers to respond to the needs of autistic students, as well as guidelines for good practices for teachers but also videos for peers of autistic students. All these results are available through an e-learning platform to foster their transferability across Europe.

The IPA2 training course for teachers

The IPA2 training course for teachers from primary and secondary schools comprised several learning modules and was developed through a co-created methodology involving end-users to identify and validate the curricular and training requirements. The co-created curriculum was based on the expertise of teachers working with autistic people as well as autistic pupils and their families. Co-creation sessions were carried out in Portugal, Spain, and Serbia. Consultations were conducted with two groups for the validation and co-creation sessions. The first

focus group included teachers and family members. The second group was constituted of autistic people who shared their needs through personal interviews. In total, 15 autistic people and 58 professionals and family members took part in the co-created sessions of the modules.

In addition to the co-created sessions, a co-validation session was carried out in Portugal, Spain, and Serbia to finalise the learning modules. Due to the Covid-19 restrictions, an online survey was conducted to validate the results obtained in the co-creation sessions. In total, 183 respondents participated in the co-validation session in the three countries, including teachers from ordinary secondary and primary schools working either with or without autistic students, SEN teachers, and other teachers or professionals. The co-validation session confirmed that a training program focused on improving the transition of

students in the autism spectrum from primary to secondary school was considered crucial. In addition, training teachers from secondary and primary schools not currently working with autistic students was deemed necessary to ensure that they gain adequate knowledge and skills in case they welcomed autistic students in class.

All five modules developed after the co-creation and co-validation sessions were translated into the partners' national languages: French, Portuguese, Italian, Serbian, and Spanish. The teachers were asked to complete a pre-test and a post-test, before and after each module, aiming to evaluate the training experience. The results of this evaluation highlighted that education professionals found the training overall effective and useful. The training is

Content of the training course

The present course has five modules:

- Module 1: Basic and advanced knowledge about autism
- Module 2: autistic students' needs
- Module 3: Intervention Strategies in autism: Skills needed to be addressed in preventing school failure and absenteeism
- Module 4: Absenteeism
- Module 5: Coordination strategies

The IPA2 partnership comprised 6 entities from 5 European countries:

- Four NGOs working in the field of autism at the regional, national and European levels:
 - Autismo Burgos (Spain);
 - A Thousand Wishes Foundation (Serbia);
 - Federação Portuguesa de Autismo (Portugal),
 - Autism-Europe (Belgium).
- A technological company, Social IT (Italy)
- · A research institute as a scientific partner and coordinator: the Polibienestar Research Institute from the University of Valencia (Spain).

Training evaluation results

The overall evaluation of the course was high in the three pilot countries, with a rating of 4.7 out of 5 on average. In particular, trainees appreciated the ease of use of the e-learning platform, to access the materials, modules, activities, and trainers.

Per country, the most satisfied trainees were the Serbian ones (4.81), then the Portuguese students (4.48), and finally, the Spanish students (4.24).

Methodology

Every module has both theoretical and practical content.

- Theoretical part: visualization of videos, • presentations, and a chapter's book.
- Practical part: self-assessment questions and some practical cases based on the theoretical content.

Guidelines for teachers and supporting videos

Furthermore, guidelines and supporting videos were developed by the consortium. The guidelines and tips for teachers have been elaborated in an easy format and layout and can be transferred to other contexts. The guidelines used the knowledge and inputs acquired through the project and based on the experience of teachers, especially, from ordinary schools that have/may have autistic pupils in their classrooms.

In addition, some videos designed by Autismo Burgos feature testimonies from autistic people to help highlight the difficulties they face at school and help non-autistic peers and education staff better understand their experiences. The videos are also meant to trigger a reflection on how to better support them.

All videos can be found on the "IPA2 - Improving School Transitions" channel on YouTube IPA2 - Improving School Transitions - YouTube.

Access the project result in several languages

The e-learning platform and the materials can be freely access in several languages here: https://www.ipa2project.eu/moodle/





Developing access to independent living in Basque Country

Apnabi Autismo Bizkaia – located in Basque Country (Spain) - provides lifelong support to over 1200 autistic people in different areas throughout their life cycle. One of their mission is to provide individualised support to foster independent living.

he association's overall objective is "to provide support and opportunities so that each autistic person and their families can develop their life quality project, based on ethical commitment and fostering collaborative responses, along with promoting their inclusion as fully fledged citizens in a fair and solidarity-based society".

APNABI supports the right to autistic people to live in the community, outside of institutions, with the right support. The project to support independent living was initiated in 2014 in line with their mission to provide the best possible response to the needs of autistic people from a person-centred perspective. The objective is that they can develop their own life project. The project is funded by the Basque Government and Bizkaia Provincial Council.

Supporting life skills to live in the community

Driven by development of inclusive practices and the involvement of the community, people with intellectual disability and their families are supported to live a normal life. To do so, education is key. Indeed, inclusion in the community requires a wide range of skills, which have frequently not been learnt during the classic school cycle. The skills include: cooking, shopping, paying the bills, cleaning, doing the laundry, but also using the community facilities, etc.

Adults with developmental and intellectual disability must also learn social adaptation skills and social strategies, including the basic requirements to live a normal community life. It includes: interacting with people, asking for help and support, communicating effectively, meeting new people and friends, etc.

Autistic people also need to acquire the skills that allow them to handle and identify resources and information online. It will allow them to be able to participate, access and handle the resources and information like any other citizen, and thus avoid the digital gap affecting the more functional part of the individual.

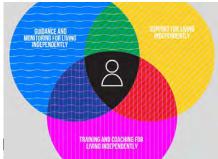
Specific services dedicated to develop independent living

In order to support access to independent living, APNABI has developed three interrelated programs, aimed at autistic people who do not encounter difficulties to carry out basic everyday tasks, but who needs support to foster their personal autonomy, enhance their quality of life, and support for full inclusion and participation in all areas of social, economic and political life.

The three programs are:

- Guidance and monitoring to live independently – professionals first have to know the person they support, his/her family and network through interviews and careful assessment. An independent Living Support Plan (ILSP) is developed with specific targets are defined based we focus on the person's life project.
- 2) Support for living independently is provided based on the independent Living Support Plan and needs of the autistic person.
- 3) Training and coaching for living independently before taking the leap of living independently in the community – it consists of four months' theoretical training in independent living skills, combined with practical experience on co-living in a flat for 3 weekends to put the skills acquired into practice.

Three closely related programmes



These programs have so far served 144 people who have received guidance and support. 7 people have taken the step to become independent from their families with support from the programme. The support is fully customised overtime.

This project is integrated across the APNABI adult life area, which currently has different resources: 10 day-care centres, 5 homes for autistic adults and 3 supported independent living housing units. Both the homes for adults and the day care centres are run with Bizkaia Provincial Council's Social Action Department and serve 214 autistic people and their families.

APNABI also developed skills to work in the open-labour marked through a supported employment programme, that currently train 65 people.

144 people guided and monitored

An Independent Living Support Plan (ILSP) is developed where the targets and future actions are defined together with the person and their surroundings 7 people have taken the step of living independently with customised support.

67 people have completed IL training: -4 months of training in independent living skills

-Practical experience on co-living in a flat for 3 weekends.



Guide: Me at home (YO in me casa)

As part of the Independent Living Training Programme APNABI has developed a Guide in easy-to-read that covers some important areas to foster independent living.

- Chapter 1. Personal hygiene and health
- Chapter 2. Taking care of my home
- Chapter 3. Clothes care
- Chapter 4. Healthy Eating
- **Chapter 5.** Safety in the Home using her experience with elderly people to promote research on the biological basis of neurodevelopmental disorders at any age. She is a member of A.P.R.I. and of Comitato per la Ricerca Scientifica of Fondazione Italiana per l'autismo (FIA) and moderator of the autism biology forum.

About APNABI

APNABI Autismo Bizkaia works to guarantee the fulfilment of all the rights of autistic people. Our mission is to help autistic people and their families to develop their life project, by providing support and generating opportunities, as well as promoting their inclusion in a fair and supportive society, as full citizens that they are. Our actions to fulfil this mission are carried out under the principles of quality, ethical commitment and the generation of collaborative responses.

Today, APNABI Autismo Bizkaia is a fully consolidated and recognised association. It is made up of 1,000 families and more than 220 professionals who, with the same spirit as then and with the collaboration of institutions and other agents, maintain a wide network of services and a programme of activities aimed at guaranteeing that autistic people receive a comprehensive, individualised and quality response throughout their whole life cycle.

To promote social awareness in order to bring citizens closer to the reality of autism and, in this way, to advance towards the fulfilment of the rights of people with autism under the principles of inclusion, tolerance and respect.

13th International Autism-Europe Congress: registration is still open!

A key date is getting closer: AE 's next International Congress will take place on 7-9 October 2022 in Cracow, Poland, and you are still on time to register! This will be the first full online Congress with high-quality access to its sessions, presentations, workshops, discussion panels, and more. You can join in person as well, in the historic city of Cracow. The Congress will bring expertise from around the world to promote a positive vision for autistic people and their families.

he chosen theme of the 2022 Congress hosted by the JiM Foundation is "Happy Journey through Life". It addresses the fact that autism is a life-long journey and brings focus to the well-being of each autistic individual. We plan for the Congress programme to be challenging, diverse, inclusive, and to create debate. This event will be a platform for researchers, practitioners, students, autistic people, and family members to come together.

The congress programme will include keynote presentations, pre-selected symposia topics, oral presentation, poster presentations (both selected via abstract submissions), panel discussions, workshops, "meet the expert" and networking sessions.

The sessions will strive to have a balance of presentations from researchers, practitioners (i.e. from health, education, or social

care), autistic people, family members, and carers, and those involved with policy or advocacy. At the end of sessions, there will be time allotted for discussion and Q&A.

The different sessions will cover a wide range of topics, including telehealth in autism services, diagnosis and support difficulties in the early years, school environment for autistic people, and gender identity and autism, among others.

We look forward to seeing you at the Congress!

Registrations are open, do not miss the chance to register at the best rates!



Invitation to Autism-Europe's 2022 Annual General Assembly

In accordance with the statutes for our organisation, we are pleased to invite you to attend Autism- Europe's Annual General Assembly on 14 May 2022.

The meetings will take place in Krakow, Poland and in hybrid format.

An Autism-Europe Council of Administration meeting and a study visit will also take place in conjunction with the General Assembly.The meetings will be hosted by the JiM Foundation.

All the working documents related to these meetings will be emailed to registered participants at a later date.

Agenda:

- Presentation of the Executive Committee report
- Presentation of the activity report: 2021
- Presentation of the financial report: 2021
- Presentation of the work programme: 2022

For more information, please contact Autism-Europe's Secretariat: secretariat@autismeurope.org





Almost two decades before Asperger: On the autism research of Soviet child psychiatrist Grunya Sukhareva

2021 marks the anniversary of the birth (November 11, 1891) and death (April 26, 1981) of Grunya Efimovna Sukhareva, an often overlooked but crucial researcher who almost 20 years before Austrian paediatrician Hans Asperger (1906-1980) and Austrian Jewish American psychiatrist Leo Kanner (1894-1981) diagnosed children with what today would be considered the autism spectrum.

orn to Jewish parents in Kyiv, like her sister Maria Efimovna (1897-1991) she started her medical career as an epidemiologist traveling to areas in Ukraine affected by outbreaks of encephalitis and other infectious diseases. During the early years of the Soviet Union after World War I and the Russian revolutions which caused a huge shortage of doctors, young Sukhareva joined Kyiv's psychiatric hospital. In 1921, she started working in Moscow organizing sanatoriums and psycho-neurological clinics for children and adolescents orphaned, displaced, or traumatized by the war, the revolutions, the ensuing civil wars, or the deadly "Spanish flu" - often re-narrated these days during the current COVID-19 pandemic. It was in Moscow when Sukhareva started studying several boys with what would be classified today as developmental disabilities. On this occasion, she borrowed from Swiss psychiatrist Eugen Bleuler (1857-1939) the decade-old term "autistic". Bleuer had used the term "pathological avoidant" when treating children with Schizophrenia. Sukhareva diagnosed the children she studied as "schizoid

psychopaths" (based on Bleuer's use of "schizoid" for "eccentric") and in 1959 changed the wording to "autistic (pathological avoidant) psychopaths". These diagnosed children received at the sanatorium social- and motor skills training through classes in gymnastics, drawing, and woodwork, playing team games, and going on group outings to zoos and other public places.

These revolutionary early interventions started almost two decades before Hans Asperger diagnosed children. Asperger used the same terminology as Sukhareva. That makes it even more remarkable that Sukhareva remained unnoticed for so long. There are speculations that Asperger, whose legacy to save autistic children in 1940s Vienna from the institutionalised killing of people with disabilities during the Nazi regime is today disputed (cf. LINK 71), either purposefully avoided or was not permitted to cite the scientific research of Grunya Efimovna Sukhareva. After all, she was from the Soviet Union which since its foundation was considered a pariah state and was at war with Nazi Germany at the time of Asperger's publications. Also, the famous child psychiatrist had roots in the Jewish people which were the main targets of the Nazis' abhorrent extermination policy since the mid-1930s.

Yet, it is likely that Asperger read Sukhareva's groundbreaking study as it had been published also in German in 1926. (In fact, Leo Kanner who escaped the Nazis and fled to the US is said to have quoted the renowned Soviet child psychiatrist as early as 1949 in a paper on autism in children.) At that time German was still more commonly used than English in the scientific community. Even Anglo-American scientists came to Germany to study with renowned scholars from Germanspeaking Central Europe. So it seemed logical at the time that Sukhareva's work was also published in German. But the Nazi terror and World War II changed the international scientific language to English. Therefore, the Anglo-American scientific world remained for decades completely oblivious of the astonishing work of Sukhareva.

She was even in the Soviet Union mostly known as the mother of Soviet children and youth psychiatry rather than for her autism research. it might be because she conducted her 1935 doctoral thesis on schizophrenia in children and adolescents. That same year, she founded the child psychiatry department at the Central Physicians' Continuing Education Institute in Moscow. Sukhareva remained at the head of the department until 1965. From 1938 to 1969 she was the head of the Clinic of Childhood Psychoses of the Institute of Psychiatry under the Agriculture Ministry of the Russian Federative Socialist Republic (RSFSR, a constituent country of the Soviet Union) and worked in the clinic until 1979. Her career is especially unique since she survived the purges during Stalinism. It was a time when the field of psychiatry took horrible ideological turns and was

misused against political opposition. It was surprisingly progressive for the 1930s that Sukhareva defended the right of children with disabilities and mental health issues not to be taken away to the labor camps of the Soviet secret service NKVD, but to the sanatoriums and psycho-neurological clinics, she helped to set up.

Instead of being persecuted, Sukhareva became for many years a scientific supervisor of the Kashchenko Psychiatric Hospital in Moscow. She was a member of the Board of the All-Soviet, All-Russian, and Moscow Society of Neuropathologists and Psychiatrists, a chair of the Children's Section of the Moscow Society of Neuropathologists and Psychiatrists, and awarded an honored scientist of the RSFSR. Today the autistic communities, the autism professionals, and international researchers know Hans Asperger thanks to British psychiatrist Lorna Wing (1928-2014). Wing introduced Asperger's work which was until then only available in German to the English-speaking scientific community in the 1980s. Yet, rescuing Grunya Efimovna Sukhareva from oblivion was due to renowned British psychiatrist Sula Wolff (1924-2009). Born in Berlin to Jewish parents, Wolff spoke German when she was forced to leave Germany forever due to the Nazis rising to power. Wolff translated Sukhareva's autism work into English in 1996, 70 years after its initial publication in German and 15 years after her death.



The Denizli Autism Association supports Autistic Rights

Founded by parents of autistic children in 2014, the Denizli Autism Association (DAA) is a non-governmental organization that operates with volunteers who work for the rights of autistic people in Denizli locally and in Turkey. The association strives to ensure the integration of autistic individuals and their families in society, and it also plays an active role in advocating for national policies regarding autism.

DAA conducts activities of awareness-raising, advocacy, collaboration, and policymaking aiming to be an international counseling center. Having conducted child and family-based activities locally; DAA collaborates with various NGOs in policy-making for autism around Turkey.

All the activities of our association and its relations with collaborators are carried out in line with the principles of participation, benefit making, being solution-oriented, accountability, anti-discrimination, and sustainability. To help children and teenagers with autism integrate into social life, DAA conducts summer clubs and workshops, and implements reverse mainstreaming practices.

DAA's corporate capacity is improving

DAA continued to work on developing our organisational and corporate capacity in 2020. We participated in a total of 107 meetings and training in 2020 in order to improve our corporate capacity and advocacy skills. We prepared a DAA Directory of Governance and the DAA Constitution of Communication. We identified basic orientations for fundraising and communicated with social enterprises as a crowdfunding method. Our application for the lyilik Kazansın fundraising platform was accepted.

The support that we took within the Local CSOs Institutional Support Program, conducted by the STGM and funded by the European Union, was completed in August 2020, and we were selected as a grant beneficiary of the Haklara Destek Program. Our work within this program began in July 2020. The basic objectives of this project are to increase DAA's corporate capacity, develop connections with international networks and improve fundraising skills.

Our applications for the Etkiniz EU Programme and South Aegean Development Agency (GEKA) were accepted. We completed the project "Denizli Autism Association (DAA) Is Overcoming Prejudices". The members and volunteers of the DOD both got training for writing Erasmus+ Project and wrote three projects in practice under the supervision of their mentors. Local studies, support and education: DAA provides educational support and family counseling support to families living in Denizli and whose children are diagnosed with autism. They also organize seminars for families, teachers, and students.

National studies cooperation, solidarity, policy development: DAA is in cooperation with non-governmental organizations, local administrations and public institutions in Denizli, as well as roof organizations outside their thematic area. We carry out lobby activities. As Turkey's Council of Autism, we have prepared a report on individuals with Autism to submit to the Commission of Research for Autism and Down Syndrome at the Turkish National Assembly.

Monitoring human rights and disability rights

Among DAA's main objectives is to increase the capacity of monitoring and report human rights and disability rights. We work for establishing a monitoring system on a local level. The Etkiniz Programme provided us with long-term expert support. With the help of our expert, we designed a monitoring program for individuals with autism in Denizli. In January 2020, we started working on monitoring the discrimination, to which children with autism and their families are subjected in education. The results of our research will be published on our website soon.

Diverse Magazine

Focusing on the lives of autistic adults, the first issue of our magazine "Diverse" was published in Turkish and translated into English.

Denizli Autism Association

is an affiliated member of Autism-Europe **Website:** www.denizliotizm.org



The Mars Autism Foundation: supporting autistic people and their families in Hungary

The Mars Autism Foundation, a new AE member from Hungary was established in 2017, reaches the parents right at the time of the diagnosis, and builds an active, well-informed network of parents who can help and support each other. They provide online and offline training and counseling to parents and are developing an interactive online platform to provide information. Mars Foundation also participates in different international projects, like Erasmus+.

Mars Foundation has several hundreds of families, who are registered to their network.

Every month they organize online or offline training (in different cities all over Hungary) for 20-25 families, reaching out to 250-300 direct learners.

They also maintain a blog to distribute educational materials for parents. Some of them are downloaded by more than a thousand families.

The Mars Autism Foundation

is an associated member of Autism-Europe

Website: <u>www.marsalapitvany.hu</u>

Among their activities include:

- Training for parents whose child has been recently diagnosed with autism
- Develop an interactive online platform to exchange information amongst the affected ones
- Online counseling for family members of autistic children, involving experts
- Informative classes for elementary and high school students about autism, minorities, etc
- Courses for teachers working in mainstream kindergartens and schools with autistic pupils
- Awareness-raising campaigns for an accessible society for persons with autism
- Supporting autistic adults in the mainstream job market, and helping companies to employ persons with autism

Member Associations of Autism-Europe

ANDORRA

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Autism Spectrum Information Advice

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