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Cover: Patricia Saco, mother of a 7-year-old autistic and ADHD son and a suspicious ADHD daughter, won the Autism-Europe's LINK competition with this picture. The competition aimed at illustrating how autistic people and their families are coping with the COVID-19 pandemic.

"During the first lockdown in Spain, we were allowed to go outside for very short periods of time. As we were afraid of meeting people due to social anxiety and fear to COVID-19, we used to visit lost places, as this abandoned area next to a train station".

Picture by Patricia Saco for Autism-Europe

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Dear readers, dear friends,

About 23 years ago, my daughter was diagnosed with autism and since then, I have become involved in the autism community. Over the years I've "stolen" ideas and implemented suggestions from numerous parents and professionals. Some have worked and others have not. I believe my experience is typical for the majority of people looking for how to improve the lives of people on the autism spectrum: the information is available but will it work for me? Another element with all the available information is its reliability. Not every intervention is backed up by scientific knowledge or documentation on effectiveness. To me, one of the key objectives for Autism-Europe is to provide a critical voice in the pool of available information. The focus on evidence-based interventions will continue to be important.

I strongly believe in sharing information, experiences and good practices. Autism-Europe has a long history of doing so through various channels: including our triennial international congresses, publications and governing bodies meetings. It is also an important forum to bring the challenges of autistic people to light. One of my focuses as president is to find ways to improve the active involvement of our members and further develop benefits for them such as exchanges and learning opportunities.

Being involved in the autism community has helped me realize that there is an apparent, or perceived, gap between self-advocates and parents. This has always puzzled me because we all face similar challenges that we deal with in different ways. The autism family is much more heterogeneous than the neurotypical population. If we are to succeed, we must acknowledge the different experiences and manifestations these challenges bring. Bridging the perceived gap between self-advocates and parents is one of my priorities.

Autism-Europe's mission is to improve the quality of life of all autistic persons and their families in Europe. But what does that mean for individuals? There are numerous challenges facing autistic persons and their families, such as mental health, access to somatic health, growing old, access to education and work. But which issues should Autism Europe focus on? It is my hope that Autism-Europe will be a supplier of the premises for research. That is to be able to help shape the research agenda and focus on projects according to what our members find important. I hope we can further reinforce this dimension in the years to come.

Recently Autism-Europe held its first virtual Annual General Assembly and Council of Administration. The meeting was a success thanks to the hard work of our staff in Brussels. By holding the meeting online, we were able to visualize how we can use technology in an effective way. Our challenge however, will be how to make technology available to all. The use of technology is not only related to access, but also training on how to use it. I can see that this will become more important in the future, and I hope this can be reflected in our projects.

On 11 March 2020, the WHO declared COVID-19 a pandemic and since then we've seen disruption across Europe and the globe. Due to the pandemic, my first year as president of Autism-Europe has been completely different than what I initially envisaged when I took over. The shutdown of Europe has put a disproportional load on autistic people not only in terms of isolation but also in terms of limitations on contact with family members. It has become clear that we still have a long way to go for society to acknowledge the unique challenges autistic people face. I'm looking forward to working with all of the dedicated people involved in Autism-Europe to address these issues and others together.

President,

Harald T. Neerland



to show that no one should be excluded or discriminated against. "I can learn. People on the autism spectrum are not second-class citizens, but full members of society. I can work" campaign



Advocating for autism rights during the pandemic

Ahead of World Autism Awareness Day 2020 (April 2nd), Autism-Europe (AE) launched the two-year awarenessraising campaign "I can learn, I can work" to promote access to quality inclusive education and access to employment. Although the COVID-19 pandemic has impacted the implementation of the campaign, AE and its members have joined forces to echo and address the needs of the autistic people and their families. Their needs have become even more urgent during the pandemic, due to the lack of support and accommodation regarding access to home schooling, remote working and services in general.

Understanding the campaign's core objectives

The campaign is centred around informing and raising awareness about how to promote access to education and employment for people on the autism spectrum. AE is working together with its member organisations, policy-makers and other stakeholders to promote the objectives of this campaign from 2020 to 2021.

Several goals and objectives are linked to the theme of the campaign. There is a lack in awareness and understanding across the globe when it comes to autism. "I can learn. I can work." aims to bring attention to the specific needs of autistic people in relation to education and employment, in all their diversity, and how they can be addressed at various levels in society. As a part of raising awareness, the campaign aims to inform stakeholders about what they can do to foster inclusive education and positive employment for autistic people.

The campaign takes place at a critical time, as the EU is discussing the future EU Disability Strategy 2021- 2030 (EDS) in close cooperation with European organisations representing people with disabilities, including AE. The new strategy should be officially released in January 2021. In November 2020, AE issued a feedback paper on the roadmap presented by the European commission, and took part in a series of meetings with the cabinet of the EU commissioner for Equality, Helena Dalli. AE calls for an ambitious EDS beyond 2020 that takes into account the diversity of disability, support and accessibility needs. We emphasize the importance of fostering access to education and

employment to address the discrimination that many autistic people face.

AE has also voiced the needs of autistic people in the context of adopting the action plan dedicated to the implementation of the European Pillar of Social Rights. Access to education and employment are two key components of this European instrument that aims to foster equal opportunities across the European Union.

Additionally, AE urges decision-makers, relevant professionals, business leaders and the general public to consult and cooperate with people on the autism spectrum and their representative organisations to make education and employment more accessible, in order to ensure compliance with the UNCRPD.

The COVID-19 pandemic: a new challenge

The COVID-19 pandemic changed initial plans for the campaign, and AE focused on conducting activities virtually. From February to March, 2020 Autism-Europe ran an online competition entitled "I can work" to celebrate and share positive initiatives for the employment of people on the autism spectrum. The winning project entitled "Constellation Solidaire", aims to set-up an interoperable internet platform which will allow exchanges and cooperation between all the actors involved in the professional inclusion of autistic people. This platform will make full use of artificial intelligence techniques.

The campaign toolkit

AE released a campaign toolkit, a publication bringing together materials, strategies and recommendations for how individuals and stakeholders can contribute to build momentum around the campaign.

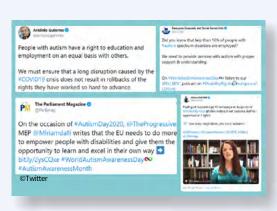




The campaign toolkit is also available in Easy-To-Read format

On April 2^{nd} , the AE campaign video was released and widely disseminated online. The video highlights the aims and asks of the campaign. AE kept the campaign momentum going by sharing key messages on how to promote the right to education and employment of autistic people on social media.

AE has also hosted an online conference on access to education in June 2020, generated buzz on social media for the campaign when posting about related policy topics or key days, and is currently preparing a report on employment and reasonable accommodation.





A campaign supported by EU policy-makers

Therefore, in spite of the COVID-19 crisis, supporters engaged virtually with the campaign. A wide array of individuals, families, associations, institutions, companies and public figures from across the EU and the globe participated in the campaign via social media. Many shared pictures of themselves completing the campaign gesture of holding a tool that represents one of their skills. The #AutismDay2020 hashtag was widely used and AE's social accounts were tagged in creative posts about the campaign.

EU policy-makers also endorsed the campaign on social media with photos, videos and posts about access to education and employment opportunities for people on the autism spectrum. Member of the European Parliament (MEP) Dolors Montserrat and MEP Maite Pagazaurtundua from Spain as well as MEP Lefteris Christoforou from Cyprus were among some of the political supporters who shared photos of themselves doing the campaign gesture. MEP Miriam Dalli from Malta and MEP Stelios Kympouropoulos from Greece also participated by posting videos online, sharing their views and calling for actions to foster access to employment and education for autistic people in the context of the campaign.

Countries who participated in the campaign this year:

Spain, Italy, Belgium, France, Poland, Greece, Croatia, Portugal, Malta, Cyprus, Turkey, North Macedonia, Russia and Canada.













Pictures of different campaign supporters across Europe.

Campaign aims for 2021

The second stage of the campaign will adapt to the current challenges linked to COVID-19 and highlight what autistic people and their families need at this time. Emphasis will be placed on topical themes including distance education, mental health and reasonable accommodation during the pandemic. AE will also continue to closely follow-up on key policy developments, notably in relation to the EDS and the Pillar of Social Rights.

New campaign materials, publications and (online) events based on the campaign's new aims will be prepared and AE will stay open and flexible to adapt to any unforeseen pandemic related situations that may arise.

Actions for the second stage of the campaign will focus on involving key-stakeholders in sharing their experiences and insights through interviews, podcasts and webinars.

Conversations will be centred around the theme of the campaign and highlight different topics in relation to access to education and employment.

AE would like to thank all who participated in the "I can learn. I can work." campaign in 2020. We look forward to another year of virtually raising awareness about access to quality inclusive education and employment opportunities for people on the autism spectrum.

More information about the campaign here: www.autismeurope.org/what-we-do/ worldautism-awareness-day/current-campaign/



COVID-19 emergency





Striving for an inclusive response that does not neglect the rights of autistic people

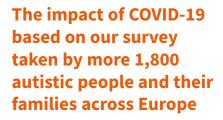
In March 2020, the World Health Organisation classified COVID-19 as a pandemic. The spread of the Coronavirus surpassed the expectations of health experts and lead to the implementation of extraordinary measures. The "new normal" is putting strain on many people's lives, especially the lives of people on the autism spectrum. COVID-19 has exacerbated existing inequalities experienced by autistic people and their families who face even more challenges compared to ordinary times. They have also seen an overall fall in their quality of life with disruptions plaguing their access to healthcare, education, and employment in times of COVID-19.

It is crucial that the rights of autistic people are not overlooked and that pre-existing issues are not intensified at this time of lockdown. To help autistic people and their families navigate through this difficult period and to shed light on issues arising from the crisis, Autism-Europe is publishing information,

resources, articles or social media posts on COVID-19.

AE has also published an extensive report about the impact of COVID-19, including policy recommendations, accessible via its website:

www.autismeurope.org.



To assess the needs of autistic people and their families, Autism-Europe (AE) conducted an online survey regarding the impact of COVID-19 in the early months of the pandemic (from March to June 2020). More than 1,800 autistic people and their families from 42 countries (including 34 European countries) took part in the survey in 10 different languages. The respondents answers as well as the feedback provided by our members across Europe, gave us insight into the difficulties experienced by autistic people. From these insights we have formulated policy recommendations and presented them in a report on the impact of COVID-19 published in December 2020.

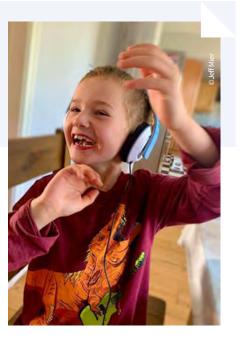
AE's survey found that accessibility was an issue in various areas. During the spread of COVID-19, the data shows that access to essential healthcare was clearly difficult for autistic people, and 26% of respondents indicated that they belonged to a high-risk group. In some countries helplines were an attempt to assist people at that time, but a majority of respondents were not aware of this assistance tool. More than half (53%) of the respondents

that got tested for COVID-19 were not offered reasonable adjustments for autism-specific needs during that testing. For respondents who were treated for COVID-19, around 44% experienced difficulties in contacting healthcare professionals or first aid responders. Triage to assess if patients should be prioritised for life-saving treatment was also a source of great concern for autistic people and their families. Many were unsure about if they would be excluded from treatments if hospitalisation were to occur as they would not be considered in the priority group due to discriminatory assessment practices.

The pandemic has brought with it a mental health crisis. From our survey, 19% of the respondents found their mental health greatly affected and 33% said that their mental health was at least fairly affected. The top reasons reported for mental health deterioration included disruption to their routines; social isolation and lack of social interaction; worrying for themselves, their family and friends; and lack of necessary support.

Autistic people have also experienced accessibility issues in relation to remote learning and employment. Almost half of the respondents were either not able to or did not know whether they are able to continue studying or working (remotely) or not.

COVID-19 caused severe failings in the provision of various services for autistic



In Ballina, Ireland, Caleb listens to music as part of his table therapies. Just this summer, he has adapted to having the headphones on.

people. Around 73% of the respondents found that the needs of autistic people and their families were not adequately addressed.

Autistic people's usual support services have been heavily disrupted due to many contributing COVID-19 factors. Our survey illustrates the over-reliance on the support provided by family carers who also find themselves in vulnerable positions due to health, or socio-economic factors. Given this, it is imperative that communitybased support services are further developed and continuously provided in order to support autistic people. Indeed, it is more evident than ever that institutions are not an acceptable solution. During the pandemic they have often become hotbeds for infection and the isolation measures have led to many personal tragedies.



The faces of the pandemic

Impact of the COVID-19 confinement on autistic people:

Autistic person from Germany:

"In terms of my mental health, the fact is that I do not live alone and therefore have no more quiet retreats. The apartment is too small."

• Autistic person from Italy:

(During lockdown)..."The inability to go for walks or cycling also causes great stress."

A respondent from UK:

"In some ways it is helpful that people are social distancing and I don't have to worry about being kissed or touched by others. However, I have a non-autistic child to care for and I worry that I am not doing everything right because I might not understand all the appropriate information: health, school work, administration, mental health of a teenager etc."

An autistic person from the Netherlands highlighted the lack of specialised support:

"The visitors' arrangement in disability care is a disaster for me. [Support] seems to be mainly focused on people with disabilities who have higher support needs. Communication about what is and what is not allowed outside and inside the 'institution' (re: assisted living facility) is very poor and it is not at all clear what exactly is and is not allowed."

Socio-economicimpactofCOVID-19 containment: almost half (42%) of respondents reported that they are not able to continue studying or working.

Around 70% of respondents indicated that their usual support services had been interrupted

A respondent from Greece:

"[...] these people (autistic people) have been away from their program for a long time, which is important for them and their family to function in their daily lives."

Impact of COVID-19 on healthcare:

95% of autistic respondents did not get tested for COVID-19, and for those who were tested, around one fifth did not get any adequate and accessible information about the testing, and the procedure proved inaccessible for some due to sensory issues.

• An autistic person from France:

"We [autistic people] suffer from medical isolation."

• A relative of an autistic person from Malta recounted:

"I wanted to get my son tested but there was no way to get this done without sedating him. This was not provided by the doctors and it was such a traumatic experience ended up not doing the test after 1.5 hours of trying and quarantined instead for 2 weeks."

An autistic woman from Switzerland was hospitalized with acute abdominal cramps:

"I was in Emergency Room for six hours, the doctors deliberated my case, and in the end I was not tested. During the whole process, I was mute, paralysed. So I wonder if there is a way to communicate with medical professionals about everyone's situation without adding to the medical professions workload."

Over the last few years, LINK covers have featured autistic people and initiatives that improve autistic peoples quality of life. In order to choose the cover of this 73rd edition. AE

organised a photo competition to illustrate how autistic people and their families are coping with COVID-19. It was difficult to make a choice amongst all the excellent submissions. AE congratulates the winner Patricia Saco from Spain, and thanks all the participants for their support during these difficult times.





The European response

At the European level, there was a large effort to protect populations and to mitigate the effects of COVID-19. In Brussels, the extensive response of the European Commission varied from repatriating over 500,000 EU citizens, delivering aid and medical supplies such as personal protective equipment and ventilators, boosting medical research in innovate practices, and proposing a €750 billion economic stimulus plan for the EU due to the economic damage caused by COVID-19.

These were bundled in the Coronavirus Response Investment Initiative (CRI) and CRI+ as well as its extension Recovery Assistance for Cohesion and the Territories of Europe (REACT-EU). Moreover, temporary Support to mitigate Unemployment Risks in an Emergency (SURE) is available for Member States that need to mobilise significant financial means to fight the negative economic and social consequences of the coronavirus outbreak on their territory.

Gabor is an autistic social worker at the Red Cross, and he has a peer support group in Hungary. He is a trainer by profession and during the lockdown he met autistic people online several times a week.

Ursula von der Leyen, President of the European Commission

"We must look out for each other, we must pull each other through this.

Because if there is one thing that is more contagious than this virus, it is love and compassion.

And in the face of adversity, the people of Europe are showing how strong that can be."



When COVID-19 containment measures were relaxed in Spain, Claudia was terrified of leaving her house. All the sudden, all of her routines and relatives "disappeared". Thus, she was given a trained assistance dog, and her family saw immediately the positive effect it has on her, and on the rest of the family.





During the first lockdown, Leonardo made all these paper model of real trains from scratch. He is an English teenager living in Italy, and his passion is both English and Italian trains.

he European Parliament
has continued to function
during the COVID-19 outbreak
by passing laws, approving the EU budget,
and overseeing the European Commission. During
the lockdown in Brussels, the European Parliament's
canteens made up to 1,000 meals a day, which were
distributed to the city's most vulnerable, some of them
in 100 chauffeur-driven cars normally used by MEPs.
Moreover, the European Parliament's Helmut Kohl
building was used as a women's refuge for 100 women
in Brussels, as the domestic violence rate increased
during the lockdown.

In Strasbourg, in response to the COVID-19 outbreak, the Council of Europe created a COVID-19 toolkit for member states to respect democracy, rule of law and human rights in 13 languages. COVID-19 created an emergency situation which exacerbated various human rights issues, that are key for disabled people such as equality and non-discrimination, equal recognition before the law, and access to inclusive education.

The European Disability Forum's (EDF) 2020 General Assembly passed an extensive resolution, which calls on the European Union, its member states and countries in the European Region to ensure the full inclusion of persons with disabilities in their efforts to combat the COVID-19 pandemic. EDF has stated that "15% of the total population are persons with disabilities; and that the pandemic itself, and all of the measures taken to combat it are having a disproportionate effect on persons with disabilities and their families."

Catalina Devandas Aguilar, UN Special Rapporteur on the rights of persons with disabilities, spoke out on the situation of people with disabilities in institutions, psychiatric facilities and prisons. For them, there is a high risk of infection of COVID-19 coupled with the lack of external oversight, exacerbated due to emergency COVID-19 legislation.

"People living in institutions must not be written off"

Autistic people living in institutions also faced higher rates of COVID-19 contraction due to the close proximity of their living situation. The COVID-19 outbreak has been extremely difficult for the deinstitutionalisation movement as government measures sought to restrict contact between individuals to contain the virus.

For those people with disabilities living in institutions, they saw visits from family or friends curtailed, access to outdoor spaces restricted, and greater powers given to the institutions regarding isolating and general treatment. Unfortunately, 40-60% of confirmed COVID-19 deaths across European countries with community transmission are believed to have occurred in long-term care facilities, a proportion of which offer residential care for autistic people.

In this respect, AE called on EU leaders to ensure its response to COVID-19 takes into consideration persons living in institutions in Europe as they face increased risks of abuse, neglect, health issues and mental distress. This call was made through the European Expert Group on the Transition from Institutional to Community-based Care (EEG), a broad coalition gathering stakeholders representing people with care or support needs and their families, as well as service providers, public authorities and intergovernmental organisations.

"The European Union is based on common values which include equality, respect for human dignity, and human rights. This should not be forgotten in times of crisis. The EU must urgently act, by mobilising and directing funding to ensure the safety and respect of the human rights of persons with care and support needs, of family carers and staff."



AE and the EEG call on the European Commission and Member States to mobilise their budget to guarantee the continuity of care and support and to take the following measures:



- 1. call on EU leaders to ensure its response to COVID-19 taking into consideration persons living in institutions in Europe, face increased risks of abuse, neglect, health issues and mental distress, adequate funding to social and care sector needed, as well as support to families and carers, can prevent an increase in institutionalization, can prevent a worsening of the conditions of those living in residential segregating settings;
- 2. welcome the Coronavirus Response Investment Initiative that will provide resources to face immediate consequence of this crisis. This budget will help strengthen healthcare systems, support SMEs and short-term employment schemes;
- **3.** regrets, though, that the social care sector, part of the frontline of this emergency, was not explicitly mentioned;
- **4.** call on the European Commission and Member States to mobilise this budget to guarantee the continuity of care and support;
- 5. welcome that the Solidarity Fund can now be used for major public health emergencies and that it will be mobilized to support the most affected countries:
- **6.** call on the use of part of this fund for the protection of the social and care sector;

- 7. welcome the proposal for a Council Regulation for temporary Support to mitigate Unemployment Risks in an Emergency (SURE) to help protect jobs and workers affected by the coronavirus pandemic. Part of SURE should go to the social and care sector to keep in employment the staff of the services that had to suspend their activities, and to allow increasing income support, flexibility and take of leaves for family carers;
- 8. welcome the actions from the European Central Bank and of the European Investment Bank to give loans to SME's hit by the COVID-19 crisis. These funds should also be made available to the social care sector to comply with the new needs emerging from this crisis;
- 9. remind the European Union and its Member States that they ratified the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child, legal instruments that need to be respected. The report *Coronavirus pandemic in the EU Fundamental Rights Implications*, released by the European Union Agency for Fundamental Rights, can be a good starting point for appropriate response to the impact of COVID19 on the most vulnerable people, including people in institutions. These are humanitarian steps to prevent immediate harm of the most vulnerable in society in addressing this health crisis.
- **10.** call on the EU to use this crisis to continue its process of transition from institutional to community-based services.



Peter Harvey, amateur DJ on the autism spectrum

"I think it's positive to do something for others and DJ-ing has had an impact"

During the first wave of the COVID-19 pandemic, Autism-Europe had a videoconference with Peter Harvey, an amateur DJ who brought music from his balcony to his neighbourhood in Brussels (Belgium) amid the lockdown.

Autism-Europe: Those deemed 'essential' workers were not locked down, but for everyone else, we could only go to the supermarket or the pharmacy, etc. Yet, you were doing your DJ set on your balcony every night, which the neighbours seemed to enjoy... why did you start doing this?

Peter Harvey: This idea came from Italy, when people would applaud and play music every night at 8pm to show their support for the medical staff at the front lines. The neighbours across the street had started to put on music at this time too.

You should know that I am a drummer first. It is only because of the confinement that I started to do "DJ-ing". I have a real interest in music, I am in a band with friends called "Les Smileys". I did the DJ-set non-stop every day from 7:45pm to 8:15pm during the 2 months of confinement, I really liked it even if it is quite tiring. I had feedback from my neighbours in the form of little notes slipped into my letterbox with thank you messages and other positive messages. There are also members of the public that come to listen in the street and dance because I always try to put lively music on.

AE: Are there positive aspects to confinement?

PH: Well, I think it is positive to do something for others and the DJ-ing has had an impact. Now, all of the neighbours are talking to each other when before, we never really spoke to one another.

AE: Any difficult aspects of lockdown for you?

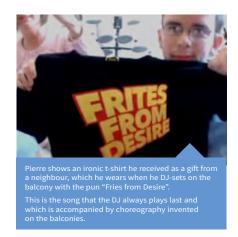
PH: First of all, I felt that I was on my own, but I wanted to show that I could be sociable and spread joy, and good humour to others. During lockdown, I realized how important it is to have friends. Normally, we do not think like that because we are too preoccupied with other things. However, it is essential to have friends, because some people do not have friends and even if they do, they are not necessarily their "real" friends. "Real" friends show their true colours in difficult times.

AE: Access to healthcare, housing, education and appropriate employment are real challenges for people with autism in general across European societies. Which of these areas requires the most attention in your opinion?

PH: Housing should receive more attention because everyone needs shelter, you cannot do much without a roof over your

head. In addition, special attention should be given to paid employment, especially for working close to home, whether you are autistic or not, it is vital for everyone in society.

I know that people with autism have heightened abilities in specific areas, which could be useful in finding a job. Personally, I like computers a lot, I am taking a course in computer maintenance and I would like to find a job in this field. However, I think that the world of work is more difficult to integrate into because there is a lot of interest in autistic children but not much interest in adults. There is not a lot of support for adults with autism.





"Success comes from putting the right person in the right place"

In the framework of its campaign "I can learn, I can work", Autism-Europe (AE) will launch a publication to promote access to employment and fight discrimination in the workplace. It will include an explanation of the EU legal framework regarding anti-discrimination in the field of employment, as well as examples from all across Europe of provision of reasonable accommodation for autism and good practices by featuring direct testimonies of people on the autism spectrum and employers.

n these pages, AE features some initiatives and practices from France where, according to the report "Evaluation of policy towards people with autism spectrum disorders" of the French Court of Audit Report (December 2017), only 0.5% of autistic people have a job in a mainstream environment.

Hiring people with autism is cost-effective

The initiative 'Vivre et Travailler Autrement' (VETA) was set up by Jean-François Dufresne, Managing Director of the multinational Andros Food Group. Dufresne is a successful entrepreneur, and father of his autistic son "Luc" who is almost entirely non-verbal and has complex needs. Dufresne was told by so-called professionals that Luc was 'unemployable'. Jean-François disagreed with this and responded appropriately. His initiative employs autistic people with complex needs to carry out work in one of their factories based in Auneau, Eure-et-Loir.

The factory currently employs 12 autistic people on part-time permanent contracts. Autistic employees work and develop their skills through close professional development. Strengths, typical of autistic people, such attention to detail, highly developed visual and auditory memory, and concentration on a particular task are utilised in their workspace. In this way, workers on the autism spectrum maximise their job satisfaction as well as that of their manager, Yannick Bontemps.

Yannick Bontemps shares about the scheme: "All in all, an autistic professional does not cost any more than a neurotypical one. They do the same work as non-disabled professionals. In some positions, they can be more productive. Hiring people with autism is cost-effective."

This initiative brings benefits to the autistic workers, their company and the wider community. Autistic workers progress and flourish in this setting as they have never done before. For the company, they benefit from highly efficient employees and enjoy the positive effect on all stakeholders in the company, for giving a chance to workers who are marginalized, in a society not built for them. Lastly, the entire community benefits. They save on the cost of caring for autistic people and regarding perceptions of disabled people, attitudes change.

Promoting personalised support

The *Pôle emploi* of Nouvelle-Aquitaine (the Regional Employment Office), currently offers a scheme focused on providing tailored support to autistic people looking for work. It aims to practically support autistic people in finding employment on a 12-month basis.

Each person on the autism spectrum is allocated two support workers for employment: one Employment Advisor and one Social work advisor. The former takes care of benefit entitlements, personal employment situation, suitability to the job market, how to find a job effectively, and supports communication between the employer and employee. The latter has a more personal role and assists the autistic person with day to day budgeting, getting around, housing, family issues, and healthcare.

More information: www.autismcanwork.org

Ultimately, the Pôle Emploi initiative has six objectives: (1) create a multidisciplinary network and bring expertise together; (2) develop an adapted and articulated service; (3) experiment with specific support methods; (4) bridge the gap between typical ways of working for autistic people and the neurotypical working environment, and work together to develop solutions for entering the world of work; (5) ensure feedback and reasonable accommodation are available during the conduct of the initiative; and lastly (6) evaluate the system by setting up quantitative and qualitative indicators.

Contact the Pôle Emploi in Nouvelle-Aquitaine for more details: autisme.33127@pole-emploi.fr

"Implementing reasonable accommodation is a short-term solution. In the long term, it is the managerial procedures and training that need to be rethought"

Vincent Grimaldi de Puget taught Autism Ecosystem as adjunct professor at the EM Lyon Business School. "Indeed, in the 21st century, good managers make the effort to adapt to the functioning of each individual. It is not simple but, fortunately, human beings are flexible enough to improve their managerial capacities through training and practice", said Grimaldi.

About providing reasonable accommodation for autistic people, Grimaldi points out that the challenge faced by businesses is in managing change, just as much as integrating foreign staff. "However, it must be understood that implementing reasonable accommodation for people on the autism spectrum is a short-term solution. In the long term, it is the managerial procedures and training that need to be rethought to better recruit and integrate the variety of individuals that the company needs. For the company, it is a question of making the most of the neural diversity brought by each individual."

Grimaldi highlights that there are several dimensions to consider when talking about key success factor for inclusion in the field of employment. "As with everyone, success comes from putting the right person in the right place. In general, my feeling is that an autistic person nowadays benefits from having his or her condition recognised. The main factors of success seem to me to be, firstly, recognition of the atypical functioning of the autistic person by those around him or her, and secondly, close support by a mentor who is aware of this atypical functioning.

"In the workplace, one of the dimensions is also the ambition to climb the ladder of hierarchy. And indeed, autistic profiles prove to be excellent leaders, especially when it comes to making strategic decisions in a complex and difficult environment. Their clarity of vision, integrity and sense of justice are attracting respect. If an autistic person is aiming for this type of career, I recommend remaining discreet about their condition so as not to cast doubt on their managerial capacities."

Follow Vincent Grimaldi de Puget on Twitter: @Vincent Grimaldi



"Hiring people with autism is cost-effective"

Users of this recruitment scheme share their experience:

Davide from Vienne: "My farming job is going well; I was recently renewed for 4 months at the organic farm (part of an employment network). I like the place and the organisation of the collective work (with daily tasks assigned by our technical supervisors, to be done alone or in small groups). The tasks are varied and allow me to work on understanding the entire growth cycle of the various crops, as well as on the preparation of baskets/orders and sales/delivery to customers. I find the organisation of these at the Jardins de Cocagne network to be interesting, and it is in this type of local solidarity and cooperative economy that I wish to continue working in the future".

Emilie from Charente-Maritime: "I am currently in the process of carrying out a skills assessment. These interviews are very enriching and I hope they will help me find my way. I'm thinking about a project combining animal mediation (short training) and my training as a specialist educator which would enable me to help people on the autism spectrum. I think that there is a lot of help to be provided because the system is not very supportive after the diagnosis. I would like to be attached to an organisation to have job security and to be accepted as I am without having my skills questioned".

ASD-EAST

Empowering teachers to foster inclusion of autistic children

ASD-EAST (Autism Spectrum Disorder-Empowering and Supporting Teachers) is the first trans-European partnership specifically focusing on improving the skills of specialist educators in Central/Eastern/Balkan settings. Running until August 2020 and coordinated by the University of Northampton, this innovative Erasmus+ project has united a partnership of schools, academics and governmental and non-governmental organisations to support effective inclusion of children on the autism spectrum.

utism Spectrum Disorders impact all aspects of the person's experience as a lifelong condition, including how they learn. Such autistic children and young people share common education needs with all others and are entitled to appropriate education. However, they have specific and special needs regarding the characteristic difficulties they face with communication, social understanding, inflexibility and sensory processing. Education is the key intervention for this group, and meaningful access to effective education is crucial.

Due to the diverse nature of the autism spectrum, no single educational intervention is appropriate for all. Teachers across Europe require a range of skills and strategies to address autistic learners' needs.

From September 2018, ASD-EAST has developed specialist teacher trainings to support effective teaching which ensure the inclusion of autistic learners. The project aims to create a lasting impact on specialist teachers' skills in working with autistic learners and thus upon the lives, educational attainment, experiences and social inclusion of these children and their families

Understanding teachers needs across Europe

In order to develop an appropriate training curriculum, partners within the ASD-EAST project identified the types of skills and strategies which would be most beneficial for teachers. A study was conducted to examine the training received by specialist educators across Europe in relation to autism. The study gathered quantitative survey data and qualitative focus group data, from both mainstream and special education teachers.

The ASD-EAST Curriculum and Training materials consist of 6 modules, differentiated for training specialist teachers working at inclusive mainstream schools or special school settings, with children at primary school age.



The quantitative dataset included data from 294 teachers from Croatia, Poland and the Republic of North Macedonia. Analysis of the dataset identified low levels of previous training as well as a wide range of views regarding the characteristics and behaviours of autism. Responses to attitudinal questions revealed that there were differences in attitudes towards both the nature of autism as well as the needs and potential of children with autism between the three countries. Teachers also expressed low levels of confidence with the majority of participants expressing confidence in only 2 out of 22 domains of working.

The qualitative dataset was comprised of participants from six focus groups, one with teachers from mainstream schools and one with teachers from specialised settings in each country. The data highlighted key training needs including strategies for managing behaviours that challenge, adapting lessons and the school environment, and supporting the inclusion of autistic children. With these findings in mind, partners were better able to understand the areas in which teachers required more support.

Delivering trainings and realising their impact

To address the gaps in training, knowledge and confidence, a locally appropriate

model training programme and materials were developed and used to deliver trainings to specialist teachers in mainstream and special school settings. The twelve-hour trainings took place in schools throughout Croatia, Poland and the Republic of North Macedonia.

Three months after the trainings, follow-up questionnaires were sent out to uncover the impact the trainings had on the participants. Respondents were asked to identify any strategies that they had used from the ASD-EAST training, as well as which aspects of the training they had found most useful. The findings showed that about 85% had used strategies they learned during the trainings.

In the training sessions, participants were introduced to strategies across all six module topics, as well as strategies to support cooperation and collaborative working. Strategies from the ASD-EAST trainings had been put into use across all seven areas by more than 60% of respondents; with about 70% using ASD-EAST strategies for managing challenging behaviour, supporting communication and helping pupils to access learning and the curriculum. Overall, the trainings had a high satisfaction rate with 92.5% of respondents stating that their expectations were fulfilled.

Since 2018, the ASD-EAST project has delivered training sessions in Poland, Croatia and the Republic of North Macedonia to over 300 specialist educators. In 2020, over 1400 professionals attended the four different ASD-EAST virtual multiplier events aimed at raising awareness about the importance of empowering specialist educators to support autistic learners and sharing the work and expertise of the project partners to a wider audience.

Project partners held roundtable discussions with national, regional and local key stakeholders (such as representatives of the government, the municipality, NGOs, universities, institutions for education and/or disabilities etc.), to discuss the impact of the project and the importance of sustaining the legacy of the trainings and findings after the project's completion. The project has been largely covered by the media (including television, radio, internet, press, specialised media, etc.) both among the targeted countries and abroad. ASD-EAST has also been presented at international congresses and conferences in Europe and overseas.



Recommendations for policy makers

There are many benefits to investing in teachers who work closely with autistic children on a daily basis. It is evident that teachers who have a solid understanding of autism and have access to resources and professional development opportunities will have more success in supporting the needs of autistic learners in their classrooms.

Based on the data collected and overall experiences of teachers who took part in the developed trainings, ASD-EAST partners created recommendations for policy-makers to highlight the need to improve the social inclusion of people on the autism spectrum in classrooms through specialist teacher education.

ASD-EAST strongly recommends that European countries ensure the development of effective specialist teacher trainings to respond to the support needs of autistic learners. Ensuring equal access to education is of paramount importance and is also a legal obligation, under the UN Convention on the Rights of People with Disabilities (UNCRPD) - ratified by the European Union and all its member states.

Access all the resources from the project

The ASD-EAST project wrapped up in August 2020 and the developed programme and materials (including the ASD-EAST Autism Teacher Training Materials) are made freely available on the project website at: http://asd-east.org/resources/

In line with the UNCRPD, ASD-EAST developed three core recommendations including:

- Having appropriate Initial Training, Continuing Professional Development and support for teachers
- Ensuring that accurate understanding of autism and individualisation of learning and teaching are central to the training
- Creating a holistic approach and working effectively with families



Testimonies from teachers who took part in the trainings

"After being reminded about useful strategies that I'd forgotten, I feel more confident about working with children with ASD." (Special educator, Poland)

"From the strategies we were shown, I started using emotion recognition and dramatization, peer involvement, role playing." (Mainstream teacher, Republic of North Macedonia).

"I applied principles of self-regulation with one of the pupils in my school. I work with him individually and when he returned to the classroom he was better able to regulate his own behaviour." (Mainstream teacher, Croatia)

"The materials will support me to apply the strategies and adapt them to meet individual needs." (Special educator, Poland)

"I feel empowered to work on the socio-emotional skills of pupils and to work better with parents – although we could use more support on that too. I use practical skills for emotional regulation every day in my work." (Mainstream teacher, Croatia)



Train-ASD launches its online platform on communication and teaching approaches



Recent research in the European Union has highlighted the need for increased training of professionals who educate and train students on the autism spectrum. Among motivation and other challenges, one of the main barriers to learning is effective communication between educators and autistic students.

stablished in 2018, the Vocational Training on Communication and Teaching Approaches in Autism Spectrum Disorders (Train-ASD) project empowers specialist teachers and other professionals to support the effective inclusion of children on the autism spectrum in education. The Train-ASD project has developed a large-scale training programme on communication and teaching approaches to improve the vocational training of professionals in the field of autism. The platform has been designed to support teachers in the field of autism who are newly appointed or unemployed; experienced teachers; teachers who are supporting autistic children or other communication difficulties in mainstream schools; as well as other professionals, such as speech therapists, psychologists, ergotherapists or social workers.

Coordinated by the University of Macedonia in Thessaloniki, Greece, the Train-ASD project, has united a strategic partnership of schools, academics, governmental and non-governmental organisations and autism associations, including Autism-Europe, to provide training to teachers in Greece, Romania and Belgium.

The project partnership undertook studies on perceptions and ideas related to key autism training concepts in order to illustrate the current situation concerning the education of autistic students, training structures, educational material and curricula. This allowed the project partners to identify training

needs and select the appropriate practices and tools which would be beneficial for teachers.

To ensure the development of quality training programs, know-how expertise and best practices were shared among researchers, specialists and practitioners. The exchange touched upon teaching methods, alternative systems of communication and the management of behaviour specific to children on the autism spectrum.

Train-ASD e-learning platform and material

Based on the results of the studies and shared best practices, project partners created and trialled a comprehensive set of educational materials. Launched in September 2020, the e-learning platform hosts the developed course curricula and is freely available in English, French, Greek and Romanian.

The course curriculum includes state of the art learning practices and uses a modern approach to the systematic observation and assessment of children on the autism spectrum. Split into 12 different lessons, it contains e-learning materials and online technologies that bring remote practices closer together through face-to-face training.

The content of the platform is based around the following 12 topics:

- 1. Child Development
- 2. Communication and ASD: An Overview
- Systematic observation
 Assessment and triggering of communication
- 4. Oral Motor Sensory Stimulation for Children with Autism
- 5. Evidence-based Interventions
- 6. Introduction to Applied Behaviour Analysis (ABA)
- 7. PECS

- MAKATON
- 9. TEACCH
- 10. Tips in Classroom for Children with Autism
- 11. Social Stories
- 12. Assistive technology and Inclusion

What teachers have said about the training?

"The curriculum contains well-structured state-ofthe-art knowledge that is accessible to different kind of learners, including mainstream and special education teachers, therapists, parents, students, speech therapists, or school counselors."

"The Train-ASD platform is a modern e-learning tool with a dynamic and interactive structure. The information is very well organized and structured, which facilitates the learning process. Also, the evaluation at the end of each module is useful for memorizing the information."

"I did the training in two days. The curriculum was very comprehensive and relevant. I accessed the course using my computer, tablet and smartphone without any problem. At the end, I had access to the Train-ASD e-book and I received a certificate of completion."

The wide European impact

Train-ASD has taken part in national and international events and conferences to raise awareness about the importance of empowering teachers to support effective communication and teacher approaches. Correspondingly, the projects main results and developed materials have been presented to over 3800 professionals across Europe both offline and online.

In June 2020, it was announced that the Train-ASD project won the Gold Award at the Education Leaders Awards 2020 in the field of Digital Education. The Education Leaders Awards is a yearly competition for projects who carry out best practices in education in Greece. It aims to recognize leaders in the field of education and in 2020 over 200 nominations were submitted.

More information about the project: https://www.train-asd.eu/index.php/en/

Access the E-learning platform: https://elearning.train-asd.eu/?lang=en

Promoting inclusion of autistic teenagers through non-formal learning activities

Non-formal learning activities and leisure activities such as art, yoga, sailing or activities with animals (pet support, equine activities) can support the development of the social skills of autistic teenagers. The "Non-formal learning Activities for Autistic Teenagers in Europe" project (known as the NAATE project), has launched a booklet to provide helpful ideas for leisure and non-formal activities in order to achieve positive interactions and improve learning for autistic teenagers.

What teachers have said about the training?

While this publication is not intended to be a curriculum for non-formal activities, people working or interacting with autistic teenagers may find it helpful for information and resources for their schools, organizations, or summer camps. These activities have proven to be effective in several contexts. The inclusion of autistic teenagers in non-formal learning is even more important as this group are often excluded and their families often feel marginalised.

The NAATE project, running from February 2019 to November 2020, is funded by the European Commission's Erasmus+ Programme to support the training of youth workers and to develop the social

skills of autistic teenagers. It addresses the priorities of the EU strategy for Education and Training 2020 to be focused on until 2020. The priority "to enhance creativity and innovation, including entrepreneurship, at all levels of education and training" is central to the NAATE project and its impact on autistic people, their families, their local community, nationally, at the EU level, and beyond.

The NAATE partners come from three EU member states – providing autism specific services or educational support for learners with additional support needs – and have a wide range of skills. The project coordinator, Asociación *Mi Hijo y Yo* from Spain will work closely with the Center of Development and Support for Children and Teenagers – AASP (Autism Assessment Support Practice) from Cyprus, and Autism-Europe.





Merlijn's Journey for Education



Merlijn Goldsack is a young adult on the autism spectrum. He processes stimuli more deeply than other people and this made it difficult for him to attend school growing up in the Netherlands. Three years ago, Merlijn began a search for the different ways in which education systems adapt to enable people like himself to go to school. He documented the process and decided to share his search as well as his story with the world. In his film 'My Journey for Education' he travels abroad to Finland and the United States to investigate how education systems around the world address the needs of young people on the autism spectrum.

he film 'My Journey for Education' is about "what must be changed to ensure that children with autism can attend school in the Netherlands", Merlijn explains. "It all started with my friend Alex who now lives in New Jersey, USA. Alex mentioned something interesting which caught my attention. He told me that he felt like he didn't have autism when he went to school in the United States but felt like he had autism when he was living and going to school in the Netherlands. In order for me to understand what he meant exactly, I wanted to interview him and find out. I wanted to know what changes would have helped me also attend school".

When Merlijn was attending school growing up, he had difficulty dealing with the large amount of stimuli in the classroom. "Processing the constant stimuli made me very tired and took away from my learning. Also, it was unclear what was wanted and expected from me at school", he remembered.

In his film, Merlijn investigated the education systems in the United States and Finland: "I chose the United States because my friend Alex, who is also autistic, attends school there fulltime. Alex was also not able to go to school in the Netherlands so I wanted to see what the school systems in the United States do differently. I chose Finland because they changed their school education system a few years ago and I was interested in learning why and if the change was for the better", he explained.

In his journey, Merlijn witnessed the differences between education systems in the United States, Finland and the Netherlands. "I found schools in the United States very inclusive. Each student is given the support they need to be able to participate in the school system. In Finland, teachers are very calm and students don't need to physically attend school. They have the option to learn at home with help from a school. In the Netherlands there is no inclusive education and you have to go to school otherwise you don't receive education. This can leave students to feeling lonely and feeling like they don't belong. Students who are not able to attend school can struggle to join the society later on in life because they did not receive a diploma".

In his experience, the method or learning techniques that work best for him is working with a lot of visuals to understand words.

"To be able to keep my own control, I appreciated being able to go out of the class if the stimuli got too much to handle. I found it helpful when teachers listened and made changes if necessary."

Merlijn confesses that creating this film has impacted his life in a lot of ways. "I know myself better now. I accept the past and would not change a thing about it. I also know now that I definitely want to work in the film industry."

"I really want people to listen to children who say they are having difficulty in school. I want people to not be afraid to make a change for someone because we know that it is possible that things can be different. We can give more hope to the children who don't go to school and reassure them that there is also another way to have a good future."

"Personally, I don't think that there will be a change but I really hope that future generations will learn from the past mistakes through this film and give hope to the children that are scared for their future because they cannot attend school.

Since finishing filming, Merlijn has been building his own film studio called MerlinBleu Studio's where he helps small businesses, organisations and filmmakers create content.

Merlijn would like to thank his friend Linde Brinkhorst who went with him on his journey, and Paul Veld and Ben Willems, two amazing passionate film professionals from the production company OQTOO who adopted the film and helped Merlijn in every way they could. The film was made possible with the commitment, expertise and sponsorship of the Brunel Foundation who helped to finalize the project.

The documentary is now available with English subtitles on YouTube: https://youtu.be/MmAffUjdwOU

- **The Brunel Foundation** https://www.brunel.net/en/foundation/about-brunel-foundation
- OQTOO website https://oqtoo.nl/oqtoo-uk.html



Equipping autistic youth with knowledge and skills in Belarus



Since 2015, the public charity "A Good Deed. Help for People with Autism" (LCPA) based in Minks (Belarus) provides educational activities to autistic youth and practical assistance to their families. With over 150 members participating in their voluntary membership programme, LCPA aims to raise awareness on autism and run support services for families.

he organisation strives to equip autistic youth and their families with practical skills and to promote their participation in educational and social environments. LCPA offers a range of services, including:

- · family counselling;
- educational activities and programmes;
- · work sessions with ABA specialists;
- practical exercises via a creative workshop for autistic children;
- and seminars and training for parents and specialists.

Through its practical project, "Creative Workshop of a Good Deed», LCPA provides a platform for the socialization and development of autistic children and youth aged 3 to 21. Since its conception, around 100 children have participated in

the workshop. Students in the workshop acquire practical skills in working with various materials, making ceramics, mosaics, drawing and animating. Students also attend classes on communication and social adaptation to help promote independence and develop their communication, teamwork and self-care skills. Additionally, autistic youth in Belarus look forward to the organisation's annual summer camp in which they experience how to live in a city with outings to public places such as cafes, cinemas and museums.

LCPA supports families of autistic people by providing services and educational opportunities including seminars, trainings and speaker programs. Recently, they hosted a series of training seminars, together with two other organisations, which reached over 200 parents and specialists. They plan to host more events in the future once it is safe to do so. Approximately 300 teachers and 400 families have participated in LCPA's training and educational activities to date.

LCPA is dedicated to protecting the rights of people with disabilities and therefore they take part in numerous advocacy activities. They cooperate with the Office for the Rights of People with Disabilities, organize meetings with parents on advocacy, develop recommendations for interaction with education and health care systems, and defend the interests of families in educational institutions.

Alongside advocacy, LCPA is committed to raising awareness and providing education to the public on autism. To do so, they work with the state media and television to create documentaries and short promo videos about autism and implement joint projects with the Swiss Embassy and the US Embassy in Belarus.

LCPA is currently working on launching three new projects: the first is a project aimed at addressing accompanied living for autistic people; another is an expansion of the "Creative Workshop of a Good Deed» focusing on the development of social and consumer skills of autistic children; and the last is a project on supporting autistic people as they grow up called the "Life Inside Out" project.

Over
150 members
participating in
the LCPA voluntary
membership
programme

LCPA is an affiliated member of Autism-Europe.



Supporting meaningful living for autistic people in Finland

Autism Foundation Finland (*Autismisäätiö* in Finnish) is non-profit organisation created by a group of families whose vision is to help deliver independent and meaningful living for people on the autism spectrum. Established in 1998, Autism Foundation Finland provides a range of high-quality services to autistic people and their families throughout the country.

he foundation offers a comprehensive selection of services aimed at supporting autistic people in their day-to-day living. Autism Foundation Finland currently operates in 20 locations throughout Finland and their 350 professionals work closely with autistic people and their families to provide tailored assistance for daily activities, vocational activities and supported living. Their goal is to create a reassuring environment and to deliver successful outcomes for autistic people by enhancing their abilities and strengths through positive coaching and counselling.

The foundation adapts its services to the needs of each individual person and ensures that autistic people and their families are involved in each step of the process. The services Autism Foundation Finland provides are mostly procured by municipalities and the types of services offered include:

- · housing services
- daily activity services
- daily living/employment/study skills coaching
- · occupational therapy
- · sexual therapy and counselling
- · animal-assisted therapy
- · art and culture activities
- psychosocial wellbeing counselling for parents
- autism knowledge counselling for parents

A considerable amount of lobbying has been required in order for these services to exist. Autism Foundation Finland works with the autism community to ensure that the services accurately reflect the needs of individuals and with municipalities so that they clearly understand the benefits of the services. Autism Foundation Finland has been able to help thousands of people to live better lives by not only providing support services but also through awareness raising initiatives and projects.

Autism projects

Throughout the year, Autism Foundation Finland runs several projects dedicated to generating awareness and understanding of autism in society. At the moment, the foundation is involved in three projects including:

 Understanding autism: an on-going project where approximately 4,000 people including professionals, parents and autistic people were trained on what

- autism means, what research currently says, and the basics things everyone can do in their everyday life to make lives easier for those with support needs.
- ReVioN: a piloting project for developing a prison and distance based rehabilitation model for autistic prisoners and prisoners with ADHD.
- Developing Technology: a project which aims to bring together the challenges and opportunities related to autism and social services.

The foundation is always looking for new ways to support the growth of autism understanding and research. They believe in learning from others through collaboration in order to create new and meaningful solutions.

Autism Foundation Finland is an associated member of Autism-Europe.



Member Associations of Autism-Europe

FULL MEMBERS

(national associations of people with autism and parents)

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