“I can LEARN. I can WORK” campaign celebrated across the EU and beyond

COVID-19 crisis:
The situation of autistic people in times of the pandemic

New EU Disability Strategy:
building a Union without barriers for the next decade

The ChildIN project:
training childminders across Europe for inclusion

The IVEA project:
enhances the inclusion of autistic people through employment

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More articles at: www.autismeurope.org

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Dear readers,

In March 2020, the World Health Organisation (WHO), a United Nations agency in charge of coordinating international public health, classified the global spread of the severe acute respiratory syndrome coronavirus type 2 (SARS-CoV-2) as a pandemic. This virus can lead to the Coronavirus disease 2019 (COVID-19), a contagious condition affecting the human body differently with few severe cases causing respiratory or multi organ failure. The pandemic triggered the development of several different COVID-19 vaccinations. By the end of 2020, priority groups in Europe began receiving vaccinations.

The first people to get vaccinated in many European countries were groups prioritized due to their fragile health. Unfortunately, people with disabilities were not considered a priority across Europe. As a result, several Disabled Persons’ Organizations (DPOs) continue advocating for the EU and WHO to strongly recommend priority access to vaccination for persons with disabilities. This group is in greater danger of contracting COVID-19. Some have limited mobility and cannot avoid coming into close contact with others who may be infected, such as direct support service providers and family members. Others may have trouble understanding information, communicating symptoms of illness or practicing preventive measures, e.g. hand washing and distancing due to intellectual and learning disabilities.

Autistic people are people with disabilities, too. Yet, people on the autism spectrum do not always have priority access to vaccination. We deplore that institutions where autistic people are living have become hotbeds for COVID-19. Furthermore, there has been a lack of resources for accessibility of vaccinations. We understand vaccination scepticism as there can always be immunological reactions and side effects to any vaccination as well as varying degrees of effectiveness. Autism-Europe (AE) is aware of divergent opinions about vaccinations in general. The effectiveness of the COVID-19 vaccine is very high and the chances of experiencing side effects from scientifically proven vaccinations is very low.

Throughout the pandemic, a significant number of people have been infected. There have been cases requiring both short-term and long term-care, as a result of the severity of the disease, and thousands of lives have been lost. This is why it is important that everyone be vaccinated as soon as possible. Autistic people also require vaccination. However, certain adaptations are required in order to make vaccination available to people on the autism spectrum. AE strongly demands prioritisation of autistic people and their families/carers/support persons, accessible information about vaccination (facilities) and transparency about the vaccination process in order to tackle scepticism and misinformation.

People with intellectual and learning disabilities have been identified as a priority group in countries like France, Germany and the UK. Therefore, AE calls the WHO and EU to stress to all member states the need to include autistic people and all people with disabilities in priority groups, putting special emphasis on ageing adults, and autistic people with co-occurring conditions and other disabilities.

President,
Harald T. Neerland
The “I can LEARN. I can WORK” campaign celebrated across the EU and beyond

Autism-Europe (AE) promoted access to education and employment for people on the autism spectrum on World Autism Awareness Day (April 2) with its two-year Europe wide campaign “I can LEARN. I can WORK”. Throughout 2020 and 2021, the campaign has received an immense amount of support from autistic people and their families, policy-makers, professionals, and the general public despite the pandemic and its current containment measures.

The objectives of the campaign are to promote access to quality inclusive education for autistic people and to foster positive initiatives related to the employment of autistic people. The second stage of the campaign in 2021, also addressed specific COVID-19 related topics including distance education, reasonable accommodation, mental health and pandemic related challenges.

Virtually raising awareness through campaign activities

On WAAD, AE called on the EU to better develop access to education and employment. AE outlined the theme of the campaign as well as AE’s key demands in terms of what autistic people need to be better set up for success in education and employment. This call caught the attention of the media and AE’s president Harald Neerland spoke live on prime time TV international channel FRANCE 24 about individualised support for autistic people.

In the context of the campaign, Autism-Europe partnered with broadcaster John Offord to release a special podcast on WAAD for his series, “The Different Minds”. In his podcast series, John Offord chats to people from all walks of life about the different ways our brain can work and interpret information. Offord interviews Adam Harris, self-advocate, member of Autism-Europe’s Council of Administration, and founder and CEO of AsIAm for the podcast. Harris speaks about the importance of self-advocacy and being part of the associative movement to advance the rights of autistic people.

The “I can LEARN. I can WORK” webinar

On 30th March 2021, AE hosted the webinar “I can LEARN. I can WORK” to exchange the latest EU policy developments and practices regarding access to inclusive education and employment for autistic people (in times of the pandemic). Autistic people and their families, autism organisations, professionals, employers, EU policy-makers and the general population took part in this collaborative event. The webinar also featured a series of testimonials of autistic people and their families across Europe on specific COVID-19 related topics, including distance education, reasonable accommodation, mental health and pandemic related challenges (see next page).

Listen to the podcast here:
https://www.autismeurope.org/blog/2021/04/02/podcast-a-conversation-with-adam-harris-member-of-the-aes-council-of-administration/

“Any intervention for a child or an adult with autism has to be individually designed, typically catering to that person’s strengths. A one size fits all approach does not work for this population.”

Harald Neerland, AE President.

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©FRANCE 24
Katrin Langensiepen  
Member of the EU Parliament from Germany

“We in the European Union have to make sure that persons with disabilities, persons who are different, and persons with autism, have the same access to a job in the labour market. This is a human right.”

Chiara Gemma  
Member of the EU Parliament from Italy

“It is crucial to strengthen the collection of data on the situation of autistic persons in order to adopt appropriate policies and initiatives. It is necessary to obtain reliable and comparable data for the adequate identification of gaps between persons with and without disabilities.”

Adam Harris  
self-advocate, member of Autism-Europe’s Council of Administration, and founder and CEO of AsIAm from Ireland

“We must use our learnings from the pandemic to come out of this crisis and create a fairer and more equitable Europe for autistic people. “further towards a Union of Equality.”

Ron Fortuna  
Specialist Teacher- Target Autism Consultancy from the UK

“There are some positives to come out of this situation. During these uncertain times we can shift our focus from a negative thought and turn it into a positive thought.”

Vincent Grimaldi  
SM&A and recruiting advisory firm for innovative companies, and member of Autism-Europe’s Council of Administration from France.

“Companies who recruit autistic people end up being better managed, more competitive and more profitable.”

Jean François Dufresne  
parent and Managing Director of Andros Food Group from France.

“The more integration among non-autistic people the better. Autistic people’s lives should be as close as possible to everybody else’s life.”

Sharon McCarthy  
parent and autism professional from Ireland

“Any strategy we use in order to support an autistic person in a physical classroom needs to be transferred in whatever ways possible into an online setting and when we do that we set the young person up for success to realise their potential and to become their true authentic, autistic selves.”

Michel Belliart  
autistic Ph. D. student in Medieval Studies from France

“During the lockdown it was really hard for me to continue working so I opted to focus on my thesis which involved translating (…) I translated a lot and this routine brought me some solace and also gave me a deep knowledge of my sources.”

Pierre Marcantonio  
autistic layout artist from France

“When I told my co-workers and my studio manager about my autism, I did not receive any negative remarks. They accepted me without requiring anything in return. It is this acceptance that has enabled me to work efficiently and comfortably in a team, whether in the office or remotely.”

Krystian  
autistic young boy from Poland

“COVID-19 is depressing and I wish life could return to the way it used to be when masks were not worn and there was life free of the virus. We need to stick together and support each other. I strongly believe that our community is strong enough to face all troubles.”
Thank you to everyone who has participated in the “I can LEARN. I can WORK.” campaign thus far!

Please note that there is still time to support the campaign. Those interested can post pictures of themselves on social media using the hashtag #AutismDay2021. They can either hold a tool that represents one of their skills (it can be linked either with their ability to learn, or their ability to work in a specific field) or hold the campaign visual.

The UN highlights the need for inclusion of autistic people in the workplace

On the 8th of April, the United Nations (UN) held its 2021 Observance of World Autism Awareness Day virtually due to the COVID-19 pandemic. The event addressed the disparities and discrimination autistic people face in terms of employment and stressed the importance of ensuring inclusive employment opportunities for autistic people around the world.

AE’s Council of Administration member Adam Harris participated in the first panel discussion of the observance exploring the “Disparities and Discrimination Exposed by the Pandemic” in the context of the workplace: “I am particularly excited to discuss the issue of autism employment in the context of the pandemic. COVID-19 has created unprecedented challenges for autistic people, problems which have long existed from social isolation to poverty, mental health to under investment have been seriously compounded. That said, we must be optimistic. All that we once took for granted about the workplace has been thrown into question from where we work, to what we wear and how we communicate. Many of these changes can be utilised to allow us to create workplaces which can affirm and celebrate autistic people and benefit from our skills and abilities”, said Harris.

Many policy-maker at European, national, regional and local level have shown their support for AE’s campaign, including Prime Minister of Spain Pedro Sánchez, chair of the Committee on Employment and Social Affairs (EMPL) of the EU Parliament Lucia Župančič (Slovenia), or members of the Disability Intergroup at the EU Parliament MEP Rosa Estarás (Spain) and MEP Radka Maxová (Czechia), among others. Other personalities who celebrated WAAD include President of the EU Parliament David Sassoli and UN President António Guterres. 

Find more information about the campaign here:
www.autismeurope.org/what-we-do/worldautism-awareness-day/current-campaign/
From the 7 to 8 November 2020, Autism-Europe (AE) held its Annual General Assembly (AGA) in conjunction with its Council of Administration (CoA) meeting online, due to the restrictions linked to COVID-19. More than 80 members representing individuals and associations from 26 different countries attended the event to discuss AE’s activities and membership.

At the AGA, members received a comprehensive update on the activities carried out by AE since the last assembly, and had the opportunity to share feedback. Highlights of the meetings included participants welcoming the following seven new member associations: Associació d’Afectats d’Autisme d’Andorra (AUTEA) from Andorra, The Local Charity Public Association “A Good Deed. Help to People with Autism” from the Republic of Belarus, Autism Support Famagusta from Cyprus, Fondation 3A from France, Chuvash Regional Public Organization for Helping Children with Autism Spectrum Disorders “Krilia” from Russia, Autism Foundation from Finland and Denizli Autism Association from Turkey.

Elections were held for the renewal by half of the members of CoA, that welcomed two new members: Barbara Znidarko representing the affiliated member Zveza NOV za avtizem from Slovenia, and Vincent Grimaldi de Puget, an individual member from France. Furthermore, updates about the projects and platforms in which AE is currently involved, discussions about AE’s next International Congress to be held in Crakow in 2022. An introduction to the Train-ASD project and its e-learning platform on alternative systems of communication followed by the project coordinator, Christine Syriopoulou.

Members were also invited to discuss the analysis of the impact of AE’s awareness-raising campaigns conducted in 2019 and 2020. They reflected on possible strategies and actions for adapting the current 2-year campaign, “I can LEARN. I can WORK”, to the current situation in 2021 and the on-going impact of COVID-19.

Members of the CoA and observers held a workshop in preparation for the review of the European Union by the Committee on the Rights of Persons with Disabilities and discussed the scope of AE’s future alternative report. In 2015, AE submitted an alternative report on UN CRPD implementation. The report examined the implementation of the UN CRPD from an autism perspective and highlighted the gaps that prevent the full enjoyment of their rights along with recommendations to overcome these gaps.

Participants were updated by the JiM Foundation about the organization of AE’s next International Congress to be held in Crakow in 2022. An introduction to the Train-ASD project and its e-learning platform on alternative systems of communication followed by the project coordinator, Christine Syriopoulou.

Find more information about AE’s members here:
https://www.autismeurope.org/who-we-are/our-members/
New Disability Strategy: building a Union without barriers for the next decade

In March 2021, the European Commission released the European Strategy for the Rights of Persons with Disabilities (EDS) 2021-2030, which aims to deliver further significant improvements to all areas of the lives of persons with disabilities, including autistic people, within the EU and beyond. Over the coming decade, this Strategy will support both Member States and EU institutions in their endeavour to implement the UN Convention on the Rights of Persons with Disabilities (CRPD).

The Strategy takes account of the diversity of disability, resulting from the interaction between long-term physical, mental, intellectual or sensory impairments, which are often invisible, with barriers in the environment, as well as the increased prevalence of disabilities with age. It promotes an intersectional perspective, addressing specific barriers faced by persons with disabilities who are at the intersection of identities (gender, racial, ethnic, sexual, religious), or in a difficult socioeconomic or other vulnerable situation.

Accomplishing the initiatives envisaged in this strategy will contribute to reducing discrimination, inequalities and supporting persons with disabilities to fully enjoy their human rights, fundamental freedoms and EU rights on an equal basis with others, by 2030, to maximize their independence, participation and decent living conditions.

The objectives of this Strategy will need to be achieved through a strong commitment by the Member States, by promoting policies and actions that will bring about accessible environments, inclusive education systems as well as health care systems of high quality and effective pathways to fair employment for persons with disabilities.

Fulfilling EU’s obligations under the UN CRPD requires a strong commitment from Member States and EU institutions.

- The European Commission will reinforce the mainstreaming of disability matters in all EU policies and promote the rights of persons with disabilities globally.
- Persons with disabilities will be part of the dialogue and part of the process.

“Impoverished families have to pay €1000 per month for support so that I can go to class and have a normal life without my parents, like any young person of my age. This affects our daily life enormously and puts us in a precarious position.”

Joncour, young man on the autism spectrum living in France.

Autism-Europe has been actively involved in stages of the consultation for the EDS since the beginning of the review process and has contributed by voicing the needs of autistic people. The Strategy builds on the results of the previous European Disability Strategy 2010-2020, acknowledging that persons with disabilities still face considerable barriers and have a higher risk of poverty and social exclusion.

Objectives of the strategy

All persons with disabilities in Europe, regardless of their sex, racial or ethnic origin, religion or belief, age or sexual orientation should:

- enjoy their human rights
- have equal opportunities, equal access to participate in society and economy
- are able to decide where, how and with whom they live
- move freely in the EU regardless of their support needs
- no longer experience discrimination
The new Strategy, which builds on 8 priority areas, accompanied by a broad set of actions and 7 flagship initiatives.

The areas of priority are the following:

1) **Accessibility** as an enabler of rights, autonomy and equality, accompanied by the flagship initiative of the creation of a European resource centre AccessibleEU, to increase coherence in accessibility policies and facilitate sharing of knowledge;

2) **Enjoying EU Rights**, for which, as a flagship initiative, the Commission will propose the creation of a European Disability Card by the end of 2023 with a view to be recognised in all Member States. In this context, the Commission will establish, in 2023, a guide of good electoral practice addressing participation of citizens with disabilities in the electoral process;

3) **Decent quality of life and living independently** for which the flagship initiatives will be the issuance of guidance recommending to Member States improvement on independent living and inclusion in the community by 2023, the introduction of a framework for Social Services of Excellence for persons with disabilities, by 2024 and the presentation of a package to improve labour market outcomes of persons with disabilities in 2022;

4) **Equal access and non-discrimination** for which the Commission has envisaged a series of actions in the fields of justice, legal protection, freedom, safety and security as well as social protection, healthcare, education, leisure and housing;

5) **Promoting the rights of persons with disabilities globally** for which, in 2021, the Commission will update the Toolbox on the “Rights Based Approach”, encompassing all human rights for EU development cooperation;

6) **Efficiently delivering the Strategy** whose flagship initiative encompasses the establishment of a Disability Platform, replacing the existing High Level Group on Disability, to bring together national UNCRPD focal points, organisations of persons with disabilities and the Commission itself. In this framework the Commission will seek systematic inter-institutional cooperation and it will support Member States to use EU Funds in compliance with the UNCRPD;

7) **Leading by example** through, as a flagship initiative, the adoption of a renewed HR strategy to include actions promoting inclusion of persons with disabilities. The Commission will also adopt an Action Plan on web accessibility and will work to improve accessibility across its audiovisual communications and graphic design as well as for its newly occupied buildings;

8) **Awareness, governance and measuring progress** for which the Commission will strengthen the EU Framework under the UNCRPD and will ensure sound monitoring and reporting, by developing a monitoring framework, by 2021, and new disability indicators by 2023, with the aim of publishing an assessment report in 2024.
Autism-Europe: When did you know you had autism? What did it mean to you?

**Hector Diez:** Initially I was diagnosed with ADHD and I was used to dealing with psychologists. I started going to Autismo Burgos and I thought they were just going to help me to socialise. I was a bit confused because they explained to me that I have autism. The organisation helped me learn about autism and has been a reference centre since to seek help.

AE: What are the main barriers you face in your daily life? What kind of support do you need?

**HD:** The biggest barrier for me is time management. I mainly struggle with time management when it comes to my school exams. Every so often, even if I have studied and know the material very well, I don't have enough time to finish an exam.

I also struggle with socialisation. Sometimes people don't understand me, or I don't connect with them. I have received support from the psycho-pedagogue and at the Association, both of which helped me learn socialising and coping skills.

AE: Why do you study physics and why do you study at a distance education university? What are the advantages and disadvantages of distance education?

**HD:** I chose to study physics because since I was a child I have been interested in the mysteries of the universe and science. Watching films and documentaries sparked my interest in the subject. As I got older, I suffered in the education system and didn't get good marks. This almost “killed” my desire to study physics because I was bad at it at school. But afterwards, I felt a calling or a vocation.

I decided to complete my studies through distance learning for several reasons: I didn't have the grades to study at other universities; it’s more comfortable for me to study from home where I have my routine, my habits, and my food; and with distance learning I can enroll in a few subjects at a time, even if it takes longer.

AE: What are the added challenges of the pandemic?

**HD:** Interacting and socialising with others has become more difficult. At the moment, my social skills sessions are online for safety, but I miss the face-to-face sessions because I can have more interactions. When your life is monotonous and repetitive every day, there are times when you don’t know what thoughts to hold on to and this causes overthinking which can be overwhelming and confusing.

AE: What would you like to work on in the future?

**HD:** I would like to dedicate my life to investigating the mysteries of the universe. Unfortunately, nowadays there is very little funding. I will aim to work on something else that is funded and at the same time investigate what I like.

“**My suffering in the education system almost killed my desire to investigate the mysteries of the universe**”

In January 2021, Autism-Europe (AE) talk with Hector Diez Gutiérrez, an autistic 19 year-old student of physics who is involved in training programmes with the Spanish AE member Autismo Burgos in the framework of the Erasmus+ project IPA2. This project aims at decreasing difficulties that students on the autism spectrum face, specifically during the transition from primary to secondary school, in order to tackle early school leaving and disadvantage.
AE: When you faced an academic transition either from primary school to secondary school, or from institution to university, what were your biggest challenges?

HD: I found the study method to be challenging. In high school it’s all about memorising, in university you have to understand what the professor is explaining to you, because you don’t need to learn things by heart. In primary school, the teachers and classmates are the ones who regulate you by making demands and keeping up the pressure to finish assignments all the time. At university I am the one who regulates myself. I have realised that I have ended up being the one who has imposed discipline on myself.

AE: As a student on the autism spectrum, have you ever faced problems such as anxiety, bullying or isolation?

HD: Yes, I have experienced bullying and found it difficult to see that hatred others had towards me. I have felt isolated because at times I had no friends or classmates and I was always alone. I have also experienced anxiety, I think like everyone else, about fears and insecurities.

AE: What have been your weapons to combat these problems?

HD: I make sure to let teachers know about the problems.

AE: What advice would you give to pupils on the autism spectrum who face these kinds of situations, and to other pupils and teachers?

HD: It is important to have an educator, or professional point of reference such as Autismo Burgos, or a social mediator who mediates between you and the school.

I think that, little by little, students and teachers are learning. The teachers are learning that classes should be motivating. They should prepare videos of the class lessons that can be watched on more occasions after the class and use drawings and diagrams in their lessons to help students understand better.

AE: Would you like to give a message or advice to other autistic people, either in general or in relation to their education and their time in the classroom?

HD: I would tell them that everything is going to be alright and that they should talk to educators, counsellors, or the professionals at an autism organisation. Stay motivated and keep going.

As collaborator of Autismo Burgos, Hector has been involved in the IPA2 Erasmus+ project, aiming at improving school transitions for autistic people in Portugal, Spain and Serbia.

“I think it’s very important to make sure that teachers have proper training on autism because I have suffered from the behaviour of certain teachers and colleagues, due to misinformation. I often felt that those who did not know a lot about autism, didn’t understand me. I found changes difficult especially when teachers and colleagues have to get to know you again.”, Hector said.

Scan this QR code to know more about the project, or visit:
www.ipa2project.eu
To investigate and understand the ways in which autistic people have been affected by COVID-19, Autism-Europe (AE) conducted an online survey from March to June 2020. The survey aimed at assessing the effects of the COVID-19 lockdown on the daily lives of autistic people and their families, including their access to support services, education, employment and healthcare, etc.

Autistic people have faced additional barriers and discrimination with regards to access to public information, necessary support, education and employment since the beginning of the epidemic. Even more worrying, discriminatory practices have meant that they have been more prone to be denied life-saving treatments, not least for people living in institutions.

It is thus essential that reasonable adjustments are provided to take into account the challenges that they face. To avoid confusion and anxiety, autistic people should be well-informed about the COVID-19 situation and information should be communicated in a clear manner through accessible formats. Autistic people and their families are significantly affected when they cannot access the essential food, products and medication they require. Therefore, specific measures should be in place designed to help autistic people easily receive the essentials they require during lockdowns. AE's survey has showed that autistic people and their families require special flexibility regarding the lockdown measures, in particular when it comes to the limitation on circulation and the safety measures, such as mask wearing.

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 socioeconomic factors. Given this, it is imperative that community-based support services are further developed and continuously provided in order to support autistic people. Indeed, it is more evident that ever than 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 pandemic has mainstreamed studying and working remotely. These practices may have some positive aspects for autistic people. However, it turned out that in most instances remote learning has only widened the gap between autistic learners and their counterparts due to a lack of adequate support. Parents of autistic children thus reported difficulty balancing work and home-life since the transition to at-home learning. Many autistic people and their relatives have faced job loss and extreme changes to their working patterns and communication. Providing decent income to autistic people and their families, will alleviate some of the stressors and challenges caused by the pandemic.

When it comes to the health and healthcare of autistic people, necessary support in relation to COVID-19 testing, accessing treatment and mental health care should be addressed in order to avoid discrimination and ensure fair access. Discriminatory practices, such as triage protocols, should be amended.

A coordinated effort is required to help address the many complex challenges that autistic people and their families continue to face as a result of COVID-19. By taking the time to more fully understand the situation of autistic people and their families, we can better help create innovative solutions to meet their needs.
Vaccine roll-out in Europe

Across the EU, flawed vaccine campaigns have not been prioritizing people with disabilities even though they are at higher risk. While health policy and services are a national issue, several Disabled persons’ organizations (DPOs) continue advocating for the EU and World Health Organization to strongly recommend priority access to vaccination for persons with disabilities (including informed consent, and accessible information).

As featured by the European Disability Forum, of which AE is a member, since the COVID-19 vaccine roll-out began, there has been much controversy and debate around its speed and prioritisation of ‘at risk’ groups. Unfortunately, there have been many instances across Europe where people with disabilities, including autistic people, have not been appropriately prioritized.

People with disabilities are in greater danger of contracting COVID-19. Some have limited mobility and cannot avoid coming into close contact with others who may be infected, such as direct support providers and family members. Others may have trouble understanding information, communicating symptoms of illness or practicing preventive measures, such as hand washing and social distancing due to intellectual disabilities and learning disabilities.

The situation of vaccination priority varies from country to country. Institutions and alternative living facilities have been hot beds for the spread of COVID-19 and yet, vaccination campaigns in these environments have been slow. Disability organization, CERMI in Spain reports that high support needs people and other people with disabilities outside of institutional environments are not being reached. They also warn that there is not enough accessible information on the pandemic and the vaccine, which leaves many without the possibility to make an informed decision.

People with Down Syndrome have been identified as a priority group in France and in Germany, along with other persons with intellectual disabilities and dementia living in institutions. In the UK, people with Down Syndrome and severe learning disabilities are included in priority groups, and other groups of people with learning disabilities have only recently been added after pushback from disability organisations.

In Italy, people with disabilities were not mentioned in the vaccination plan published in December 2020. However, the Extraordinary Commissioner for the Implementation of Health Measures to Contain the COVID-19 pandemic in Italy has declared that people with disabilities will be vaccinated in February. This came as a result of mass mobilisation of the disability community, who was rightfully outraged that they were left out of the first round.

European Citizens’ Initiative launched for a freely accessible COVID-19 vaccine for all

Opened until February 2022, the European Citizens’ initiative titled ‘The Right to Cure’ was launched by the coalition ‘no profit on pandemic’ in the hopes of making the COVID-19 vaccine and treatments freely accessible to all, including people with disabilities.

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

Invitation to Autism-Europe’s 2021 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 19 June 2021.

If sanitary measures related to COVID-19 allow it, the meetings will take place in Krakow, Poland. In this respect, we would like to inform you that the Executive Committee of Autism-Europe will meet on 3 May to decide whether the meetings will be held face-to-face, online or a combination of both possibilities.

Depending on the circumstances, side activities will be organised by our host association, the JiM Foundation, on Friday 18 June.

Agenda:

• Presentation of the Executive Committee report
• Presentation of the activity report: 2020
• Presentation of the financial report: 2020
• Presentation of the work programme: 2021

An Autism-Europe’s 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.
It is estimated that 1% of the population is on the autism spectrum (around 5 million people in Europe). If you include their families, autism touches the lives of over 30 million Europeans. The condition impacts all aspects of an individual’s experience, including how they learn. Autistic children share common needs with others and are entitled to appropriate childcare. However, they have specific and special needs regarding the characteristic difficulties in autism related to communication, social understanding, flexibility, and sensory processing. Meaningful access to appropriate childcare is crucial for autistic children.

In recent decades, there has been a growing interest in the availability and the quality of early education and care (ECEC) in the European Union: this is due to an increase in understanding about the role played by the early years of a child’s development as well as the need to support families’ work-life balance.

Currently available competence frameworks for childminders do not include specific learning for children with special needs as separate and fully developed modules. Currently, they are integrated in general modules of care. This has a direct impact both on their employability opportunities, and on the availability of skilled workers for families. However, some short lifelong learning modules are available for some of the most common disabilities. These are for the most part inadequate at addressing the needs of skilled caretakers of families dealing with children on the autism spectrum. In this context, the ChildIN project aims at providing specific blended training for childminders focusing on autism.

The evaluation of the competence framework was supported by a focus group made up of professional childminders, VET providers, healthcare professionals and individuals on the autism spectrum and their families. Key stakeholders are actively involved in designing the project at all stages to ensure relevance and appropriateness.

ChildIN directly contributes to the field priority of VET by providing upgraded pathways in lifelong learning for a profession whose impact is largely underestimated. The work is carried out across countries, according to European standards and in compliance with the learning outcomes approach, to contribute also to an overall aim of recognition of the profession, which is certified in some countries, but not yet in others.

The project coordinator, the IPERIA Institut from France, works closely with all the other partners, including: Le Consil départmental de la Nièvre from France, Academia Comenius and the Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo de Coimbra APPDA from Portugal, Techpal Sp. z o.o. from Poland and Autism-Europe from Belgium.

What professionals have said

“In the ChildIN Mobility Days, I have learnt more about the different kinds of intervention programmes and models as never before”

(Social worker and childminder, Portugal)

“I think that developing a training is necessary because autism is a very diversified spectrum, and we need to prepare caregivers for this diversity and to act in accordance with the individuality of each person.”

(VET provider, Portugal)

“It is important to have tools and methods that could ease the difficulties encountered by the child, the parents, and the childminder.”

(Childminder- France)
The need of childminding professionalisation

The ChildIN database

As an additional support, ChildIN has made available a free online database of resources on autism including reasoned description, assessed on the basis of their value in terms of learning quality, safety (this applies particularly to online games for autistic children), scientific soundness and community inclusion. These three dimensions have been assessed on the basis of a matrix designed jointly by the ChildIN partnership, that possesses high competences in all explored areas.

The database already has more than 200 resources in English, French, Polish and Portuguese, classified into the following main categories:

- Autism specificities
- Selected issues related to autism
- Education
- Care
- Others (like sexuality, self-awareness or family)

The database is also a tool to ensure sustainability and easy updating of the ChildIN training content after the project ends. Since methods and techniques, particularly game-based provisions, change over time, this tool will allow users to find updated resources at any time according to their needs. The database will be updated until the end of the project in April 2021.

Recommendations for policy-makers

In the framework of the project, a policy brief on the basis of the experience of ChildIN in the field, has been released to provide useful insights for policy planning, contributing then to the improvement of the learning offer for childminders, and to the improvement of quality offer to care recipients.

In this document, ChildIN strongly recommends relevant public authorities and social partners of EU Member States, and the European Commission, in particular those bodies related to child rights, disability rights, and training and certification of home care professionals, to ensure the development of effective childminder training in order to respond to the support needs of autistic children across Europe, in line with the project’s findings.

Specialist training for childminders is an effective way to contribute to better outcomes for autistic children while improving their quality of life, and inclusion in society. Public authorities and other relevant stakeholders should therefore ensure that adequate resources and funding are dedicated to this issue as investing in education will have a significant impact on on the outcomes of autistic children.

1. Ensure appropriate training, continuing professional development and support for childminders
2. Support the acquisition of competences related to the care of children on the autism spectrum for an effective inclusion
3. Harmonise and recognise childminding across Europe toward a common curriculum

More information on the project’s website: https://childin.eu/
Scan this QR code to access the project website:

Graduation ceremony of childminders after having completed the ChildIN training in Nevers, France.

Transnational project meeting in Olsztyn, Poland.
IVEA enhances the inclusion of autistic people through employment

Since 2018, the Innovative Vocational Education for Autism (IVEA) project, of which Autism-Europe (AE) is partner, has trained 50 autistic people and 65 potential employers in Portugal, Hungary and Spain. Funded by the European Commission’s Erasmus+ Programme, the project aims at fostering social inclusion of people with autism through employment and to develop a European holistic guide and smartphone Application.

People on the autism spectrum usually struggle to gain and maintain employment for a range of reasons. The most obvious of these is their inherent difficulties with communication and social interaction, which affects their abilities to understand employers’ expectations and communicate effectively with managers and colleagues. The deficits in executive functioning and hyper-sensitivity to sensory stimuli, such as sound and light, that some people with autism experience can also make it difficult to get, an/or keep a job.

Autistic people have many positive qualities that make them desirable candidates for positions in the labour market. Additionally, they have skills which can be nurtured to help them better succeed at work and collaborate effectively with those that they work with.

The project partnership undertook studies and conducted a literature review to collect data on the employment of people with autism. This allowed the project partners to identify training needs and select the appropriate practices and tools which would be beneficial for autistic people and employers.

In order to evaluate the project’s competence framework, the IVEA project asked autistic people about their experiences accessing employment and what they thought was lacking in their training. Three focus groups took place in Spain, Portugal and Hungary with employers and persons on the autism spectrum and their families.

The focus groups identified soft skills and transversal competences such as social and daily life skills and independence. This helped partners better understand the difficulties, needs and the good practices on employment of autistic people and develop relevant training materials.

Prior to the COVID-19 pandemic, project partners in Spain, Portugal and Hungary conducted in person training sessions to test two developed training courses. One course for autistic people and the other course for representatives of potential employers (stakeholders, staff from NGO’s, administrative departments, shops). Participants of these training also participated in a final internship for autistic people in the entities referred to above.

Those involved come from various backgrounds – both national and cultural – and have a wide set of skills. The project coordinator, the Federação Portuguesa de Autismo (FPDA) works closely with all the other partners: Universidade Católica Portuguesa (Portugal), Autismo Burgos (Spain), Mars autistáktért Alapítvány (Hungary), IntermediaKT(Greece), and Autism-Europe.

What participants have said

Trainee on the autism spectrum: André Antunes (Portugal)
“i think the impact this project will have in my life will be a positive one and it will certainly help me even further when it comes to have work experience and a sense of responsibility.”

Employer: David Zamorano - Manager at Canela Tech, S.L. (Spain)
“The IVEA training is especially important for companies that employ people with autism so that not only the spectrum worker feels comfortable, but also the partners and/or clients who have to deal with them.”

Employer: Lili Juhász - Human Resources Manager at WE LOVE WHAT YOU BUILD (WLWYB) (Hungary)
“It’s important for us that all of our employees – autistic and neurotypicals – have their full confidence to do their work and to have the chance to show what they are capable of. It’s important to create an inclusive environment where everyone can be who they are and take part in our work. In this procedure the IVEA project helps a lot.

Trainee on the autism spectrum: María Oviedo (Spain)
“The IVEA project helps people with autism who seek employment to do so with better results, and is a fantastic tool for raising awareness among potential employers.”
Content for the European guide and application

The content for autistic people is sorted into four sections:

1. Common characteristics of people with autism with positive impact on the workplace
2. What autistic people need:
   a. The development of “soft skills”
   b. Communication
   c. Teamwork
   d. Social interaction
   e. Dealing with transitions
   f. Taking others’ perspective into account
   g. Reacting appropriately to criticism and praise
   h. Problem solving in the workplace
3. How to gain employment
   a. Curriculum Vitae (CV)
   b. Interview
4. How to maintain employment
   a. Networking: managing privacy in social media
   b. Workplace culture and dynamics
   c. Fully understanding tasks and the environment

The content for employers is sorted into three sections:

1. Resources for employers on autism awareness in the workplace
2. How and what employers, co-workers and persons with autism can learn from each other
   a. Resources and strategies regarding the different features of the workplace
3. What employers need to understand to support people with autism
   a. The benefits of employing people with autism
   b. Resources and strategies for employers and co-workers

The impact of the project

IVEA has taken part in national and international events and conferences to raise awareness about the importance of enhancing the participation of people on the autism spectrum in the labour market. Correspondingly, the projects main results and developed materials have been presented to over 2,300 professionals across Europe both offline and online.

More information on the project’s website: https://ivea-project.eu/
Join us in Cracow for a “Happy Journey through Life”

AE’s International Congresses are dedicated to sharing advances in the practical and scientific knowledge of autism to as wide an audience as possible, including autistic people, researchers, professionals and parents. Every three years, this event brings together a wide range of stakeholders in order to share knowledge about the latest research and best practices in the field of autism. The theme of the 2022 Congress is the future we want for each person on the autism spectrum: “Happy Journey through Life”.

Autism is a life-long journey. The need to focus on that aspect, stems from the fact that adults and the elderly are often overlooked, especially by policy-makers. The chosen theme also addresses the well-being of each autistic person. The Congress will focus on all aspects of life: diagnosis, early years, education, mental and physical health, life-long support, employment, new technologies, ageing and more. AE Congresses are the best-known forum for debating about current research topics, sharing advances in practical and scientific knowledge and exchanging experiences across Europe and beyond.

A balanced Scientific Committee

With the help of a balanced and diverse Scientific Committee, the 13th edition will be progressive, accessible, autism-friendly and networking-friendly. Its members include:

Professor Sven Bölte (Sweden), Professor of Child and Adolescent Psychiatry at the Karolinska Institute, Director of Center of Neurodevelopmental Disorders.

Dr Yevgeniy Bondar (Russia), scientist in the field of computational rarefied gas dynamics, father of an autistic boy, Member of the Council of Administration of Autism-Europe.

Professor Katarzyna Chawarska (United States of America), Professor of Child Psychiatry at Yale University, Director of NIH Autism Center of Excellence at the Yale Child Study Center

Dr James Cusack (United Kingdom), Chief Executive of Autistica, first openly autistic CEO of a research funder.

Professor Isabel Dziobek (Germany), Professor of Clinical Psychology of Social Interaction, Head of the University Outpatient Clinic for Social Interaction at Humboldt University.

Ewa Furgat (Poland) anti-discrimination and equality educator, member of the Anti-discrimination Education Association, member of the Amnesty International Association, self-advocate.

Marcos Zamora Herranz (Spain), psychologists, Autismo Sevilla’s CEO, president of AETAPI, executive Director of Masters Studies on Autism Spectrum Disorders at Universidad Pablo de Olavide.

Professor Ewa Pisula (Poland), Head of the Department of Rehabilitation Psychology at the University of Warsaw, Head of the Postgraduate Studies, Member of the Council for the Dissemination of Science at the Polish Academy of Sciences.

Dr Mateusz Platos (Poland) Faculty Member at the Faculty of Psychology at the University of Warsaw, Vice-President of the Association for Social Innovation ‘Mary and Max’.

Professor Emily Simonoff (United Kingdom) Professor of Child and Adolescent Psychiatry in the Department of Child and Adolescent Psychiatry, Head of the Department and Academic Lead for the CAMHS Clinical Academic Group in King’s Health Partners.

Venue and the historical City of Cracow

The event will be hosted at the ICE Cracow Congress Centre: the business and cultural flagship of Cracow. The centre is located within the walking distance of the Historical City of Cracow which is one of the 8th of the Most Excellent Cities in the World, according to Trip Advisor. It offers a unique atmosphere where tradition meets modernity in full harmony. Every visitor to Cracow should see Europe’s largest Medieval market, the Wawel Royal Castle and the Jewish Quarter, Kazimierz (where the Gala Dinner will be held).

For every LINK reader, we prepared a special discount.

When registering for the Congress, use the promo-code: “LINKJourney”, to buy tickets with a 5% discount! The code will work for 3 months after registration opens.

Working, housing and leisure opportunities to promote the autonomy of autistic adults in France

Since March 2017, the 3A Foundation (Foundation 3A - Autistes Adultes Autonomes - autonomous autistic adults in English) based in France, has been working towards supporting autistic people in their everyday lives. The 3A Foundation aims at partnering with adults on the autism spectrum for a more independent life by improving their access to work, housing and leisure.

The 3A Foundation was established by Marc Boulogne, a father of a young autistic person who wanted to create inclusive opportunities for autistic people like his son in terms of living, working and leisure activities. Many autistic people throughout France and Europe are unemployed and either remain in the care of their families or are sent to medical or social institutions that do not offer adapted support.

The association believes that adult autistic people can and must integrate into society and find, at the cost of some adaptations, their autonomy. The foundation assists autistic people in doing this by helping them access appropriate employment opportunities, independent housing and adapted recreational activities.

The 3A Foundation partners with companies to create jobs for autistic people, with landlords and housing managers to find autistic people housing and with sports clubs and cultural associations to develop adapted sports and activities which autistic people can participate in.

To enable a smooth transition between work, daily life at home and social activities, the association is working to set up an essential support system with competent and caring professionals working within a multi-service platform.

Additionally, 3A Foundation aims to encourage Departmental Councils and regional health agencies to develop SAVS (services to support social life) and SAMS AH (medical-social support services for adults with disabilities) specializing in autism. It aims at creating these services in the Loire-Atlantique region by forming a management association that can respond to a call for tender alongside the Order of Malta France.

The association is ready to respond to calls for projects that may be launched by the State and local authorities. A dynamic and motivated team made up of professionals carry out the projects and give the association body and heart along with young autistic people and their families and other supporters from diverse backgrounds. The association also benefits from the support of the Ordre de Malte France, a recognised authority which manages several institutions and services for autistic adults.

3A Foundation is first and foremost a facilitator, aiming to help autistic people express their needs and expectations. To better understand the areas where help for people with autism is needed, the association created the Autism-3A Social Innovation Group, which is made up of young autistic people. The group works together to organise meetings and videoconferences with correspondents in several European countries and provide insight to the association.

The 3A Foundation is an affiliated member of Autism-Europe.

More information: www.fondation3A.fr
Since 2006, the non-profit Andorran Autism Association (AUTEA) is supporting autistic people and their families by promoting the development of various forms of support throughout autistic people’s lives, and advancing their rights in order to build a more inclusive society.

AUTEA has 190 member associations and is the only association of its kind in the Principality of Andorra. AUTEA promotes the rights of autistic people in order to improve their quality of life and contribute to their full inclusion in society. They believe in the importance of raising awareness about autism and providing support and guidance to the families of autistic people.

In recent years, AUTEA has been developing innovative structures and services in collaboration with the Ministry of Social Affairs and the Andorran Health Services for the benefit of autistic people and their families.

The “Youth Group” project

The “Youth Group” project (Grup Jove in Catalan) was created in 2019 to address the lack of support and resources available to autistic adolescents and young adults to help them develop and maintain social relationships. Social isolation is one of the main concerns of the families of young autistic people. In its first phase, the project focused on developing young autistic people’s opportunities for social inclusion and social participation in leisure activities within their community.

The second phase in 2021 focuses on helping enrich autistic people’s social skills. This is based on good practices and intervention methodologies recommended by international guidelines (NICE Clinical guideline 2013) in particular the social scenarios of Carol Grey (Gray, 1996), Social Thinking (Crooke & Garcia Winner, 2016) and the UCLA PEERS program (Laugeson et al, 2015). In addition, “Youth Group” plans to offer a programme on cognitive stimulation of executive functioning and emotional self-regulation, with evidence-based interventions.

Home support for children aged between 6 and 9 years’ old

“Suport a Casa - 6 a 9 anys” is a specialised coaching programme focused on families and home environments. The objective of this programme is to address the support needs of autistic children and their families that arise from the age of six. After this age, families are not eligible to receive care provided by local early intervention services and children begin a new developmental stage that is accompanied by challenges.

This programme aims to contribute to the enrichment of parenting skills in a personalised manner that respects the abilities of each family member. It is designed to encourage positive interactions and develop effective communication between the child and his/her parents in their daily activities, in a holistic and naturalistic way. More specifically, the programme aims to positively impact the quality of life of the family members, their emotional well-being, as well as the parents’ sense of self-efficacy and control.

Youth and inclusion

Joves en inclusió (Youth in inclusion in English) is a highly specialised care structure for young autistic people between 16 and 30 years old with significant support needs. This service is managed by the foundation, Fundació Privada Tutelar del Principat d’Andorra with the collaboration of AUTEA, and is subsidised by the Andorran Government.

The programme offers fully individualised care in order to maintain the skills of the young people in care and an assist them in gaining more autonomy and independence. The service’s team offers intervention eight hours a day, five days a week, and keeps a ratio of one professional per young person. The programme uses a range of recommended techniques whose effectiveness is scientifically proven.

AUTEA is a Full member of Autism-Europe

More information: https://www.autea.org/ca/
Providing innovative support to autistic people and their families in Cyprus

Autism Support Famagusta Association is a non-profit organization, based in a regional area of Cyprus called Famagusta, that aims to provide quality programmes and care for children and young autistic people. The Association was created in 2013 by a group of parents who were passionate about promoting the rights of autistic people and providing support to families.

As the only association of its kind in Cyprus, Autism Support Famagusta Association runs a growing number of programmes and projects. Famagusta has a population of around 100,000 people and the association has gathered evidence showing that the amount of autistic people and support needed in the area is growing. It is Autism Support Famagusta’s mission to build a society that recognises, respects and promotes the inclusion of autistic people. The assistance they offer to families is designed to help them better understand autism and navigate daily challenges.

Summer School programme

Every summer, Autism Support Famagusta Association runs a summer school programme for children and young people on the autism spectrum. Running during the month of August, the programme provides a structured environment and daily educational activities implemented by staff who are trained in Autism approaches. The Summer school has grown significantly each year due to its success and demand.

The Smile Project

The Association has developed “The Smile Project” which aims to host, support and educate both parents and individuals on the autism spectrum. The first phase of the project involved the launch of a day center for young autistic adults over 21 years in Ayia Napa, Cyprus. The services offered at the day center are set up on the framework of UK Care Quality Commission standards and include policies and practices on employment, health and safety, or risk management. The center uses Person Centered Planning to aid young autistic people in lifestyle decision making and transition planning.

At the moment, there is very little Autism specific Day or Residential provision for adults or children in Cyprus. The second phase of the project involves the creation of residential programmes for family support and care for autistic people. The center will host structured programs all through the day with activities and self-help skills. The goal here is to provide adequate and safe care to help ensure a high quality of life for autistic people and their families. The wheels are in motion for this to be completed within the next 5 years.

In order to make this project a reality, the Association is hosting fundraisers focused on campaigning and awareness raising.

The state of support and autism awareness

Since 2016, Autism Support Famagusta Association has been hosting events with specialists such as Speech and Occupational therapists on an annual basis to deliver insight about autism in the classroom to teachers. The training is provided for free as they recognize a national need for more autism awareness and knowledge amongst teachers.

In Cyprus there is inclusion in mainstream, special school provision, and specific projects with Autism specific classrooms. Which route is taken, is determined by an assessment system run by the Ministry of Education’s Team. Early intervention is a crucial factor for families but unfortunately there aren’t many trusted and consistent options for ‘joined up’ provision for Diagnosis and Follow Up Support in Cyprus.

Families rely on the States Children Hospital for diagnosis and support. Due to delays, parents may search for a Child Psychiatrist, Neurologist or Behaviorist for a diagnosis on a private level. A number of parents also seek support and/or advice from professionals abroad, either via the internet or sometimes travel. This has huge cost implications and there is often no actual accreditation or governance for those giving advice.

The Association is continually learning and recognising the need to further expand their services to meet the demands as more and more families in Cyprus are in need of support. Furthermore, the Association works to provide information on autism to Government departments and ministries and encourage them to collaborate on autism strategy development.

Autism Support Famagusta is an affiliated member of Autism-Europe

Website: https://www.autism-supportfamagusta.com/home
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