

Uink

Autism-Europe

N°72/ December 2019

Join AE campaign

2020-2021

on employment and education

Autism-Europe's

XII Congress:

2, 200 autism experts gathered
to foster change and inclusion

EU Disability

Strategy:

the need for an
autism-friendly approach

The DE-ENIGMA

project:

autistic children exploring
emotions with robots

**LGTBI
and autism**



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Cover: Yuliya Dzyuba, a young blind and autistic pianist, delighted the 800 participants at the gala dinner of the AE's International Congress with some of her favourite pieces from her repertoire. Yuliya showed from the age of three years old extraordinary musical talent through her ability to recognize musical notes without prior auditory reference... What is called "having the absolute ear". This very year, she won the international "Young stars of Cannes" trophy. She regularly performs in concert in Cannes, Nice or Monaco, often accompanied by the musicians of the orchestra Arco Musica from Menton or the Monte-Carlo Philharmonic Orchestra. Picture by Thierry Carpio for Autism-Europe.

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Edito

After being the president of Autism-Europe for 8 years

A love letter to Autism-Europe and advocacy

Eight years ago I hesitated to apply for the position of president of Autism-Europe, because I felt that I was not prepared enough. And, in fact, I was not.

I met with one friend of mine, Simon, who was working in the field of advocacy and told him that:

- I was not prepared to give speeches in front of huge audiences;
- I was not prepared to make meaningful and interesting presentations;
- I was not prepared for the (sometimes heated) debates that came from the fact that we all want the same: good life for persons with autism and for their families, but we are in this discussion with very different cultural and social backgrounds;
- I was not prepared to see through the very complicated texture of the European bodies;
- I did not perfectly understand the importance of international legal tools or guidelines;
- and I had no idea how the work of international associations is financed;

His answer was quite short, “you will learn it all”. And, surprisingly, I did.

The biggest lesson I learned is that the significant issues of the world, such as the equality of disabled people, and the rights of persons with autism, which seem unsolvable for governments, can be navigated by NGOs. Those NGOs are formed by enthusiastic people who work hard and do an amazing job with little resources. The people working in the field of advocacy are strong, resilient, persistent, sometimes stubborn, but first and foremost open-minded.

I learned how to build a speech. Now, I know that it does not matter what message I want to convey, if I cannot find the way the audience understands it, they are not going to listen to me. And this is a skill I can definitely use in everyday situations.

I learned how to raise funds for our job. I learned that it is just like a household on a bigger scale; where you need to stand on more than one foot. I also learned fundraising techniques that will ease my job in the future, wherever I go.

I learned that international legal tools like the UN Convention of the Rights of People with Disabilities are vital as they mark the way where we are supposed to go and show the light.

I learned that sometimes the discussions are only heated because we all feel stuck. I also learned that international advocacy movements only work if we first find common ground, it means we have to be able to strike a balance, make compromises and meet each other halfway.

This role - despite having difficult moments - gave me so much and made me fall in love with advocacy. Although it is hard to leave, at the same time, it is time to leave. Changes are good and we have to embrace them because they always bring new thoughts and new dimensions.

I have to say thanks to everyone working with Autism-Europe at any level. Thank you for using your skills, knowledge and energy to make the world a better place for every person on the autism spectrum. I am thankful for the knowledge that you have shared with me and for the support and protection you gave me. I have no words to express how grateful I am for all of the life stories I heard and learned. You all have given me a lifetime inspiration.

Love you all,

Zsuzsanna Szilvasy

Autism-Europe gathers 2,200 autism experts from across the world in Nice to foster change and inclusion

Under the motto “A new Dynamic for Change and Inclusion”, Autism-Europe (AE)’s 12th International Congress brought together more than 2,200 people on the autism spectrum, parents, professionals, carers and other interested parties from 80 different countries all over the world from the 13 to 15 September 2019.

The triennial event, organised this year in Nice by *Autisme France* in partnership with AE, was dedicated to sharing advances in practical and scientific knowledge about autism to as wide an audience as possible.

AE congresses bring together people on the autism spectrum, researchers, practitioners, service providers, education professionals, and other interested parties to exchange and reflect on how to better the lives of autistic people. They offer the opportunity to share the most recent developments across the field of autism; reach out to autistic individuals as well as their families and carers; network with decision-makers in health, education, and social care who plan or deliver services for autistic people;

and discover the latest products and services in the sector.

Over 700 abstracts were submitted with the aim of exploring a broad range of perspectives, both theoretical and practical. During the selection process, value was placed on robust and well-evidenced knowledge, including academic research and professional, as well as personal and collective experience within key topic areas.

The congress addressed key topics, including: diagnosis and assessment, language and communication, access to education, employment, research and ethics, gender and sexuality, inclusion and community living, mental and physical health, interventions, strategic planning and coordination of services as well as rights and participation.

World-leading experts attended the event to lead plenary discussions and workshops. Speakers such as Simon Baron-Cohen (UK), Jean Decety (USA), Hilde Geurts (Netherlands), Sven Bölte (Sweden), Ami Klin (USA), or the French group of self-advocates Stefany Bonnot-Briey (France), Camille Ribeyrol (France), Jean-François Renaut (France), and Tristan Yvon (France), all took centre stage in the plenary room of the Conference Center to discuss key topics for the autism community. Beyond the plenary room, eight other spaces were provided to hold different kinds of sessions such as oral poster presentations, discussion groups, symposia, film screenings or cultural performances.

Topics addressed

- diagnosis and assessment;
- language and communication;
- access to education;
- employment;
- research and ethics;
- gender and sexuality;
- inclusion and community living;
- mental and physical health;
- interventions;
- strategic planning and coordination of services;
- new technologies;
- rights and participation, among others.

You can access videos of the plenary session’s presentations via Autism-Europe’s YouTube channel.

© Thierry Carpico



"We need to learn to listen to autistic people's voices. We need to translate research into actual practical changes to respond to the needs of people on the autism spectrum in the community. What an impact this knowledge can make to their lives".

Harald Neerland,
AE President elect.

© Thierry Carpico



"Understanding autism is necessary to provide autistic people with the support they need to be included and lead fulfilling lives in the community. This Congress has demonstrated the shift from looking at deficits to focus on how to achieve positive outcomes for all."

Danièle Langloys,
President of Autisme France.

© Thierry Carpico



"Self-determination and empowerment are legitimate and fundamental rights that belong to everyone. Our societies and political powers also have the duty to change attitudes but also to provide access for all to qualitative and quantitative means."

Stéf Bonnot-Briey,
self-advocate and AE member of the Council of Administration.

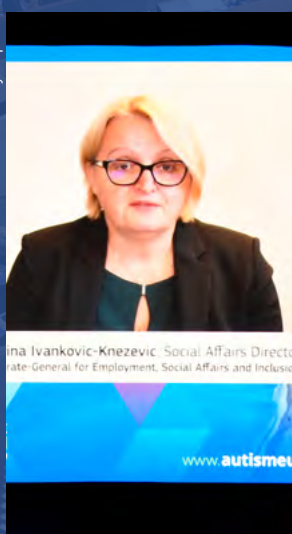
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"I am very happy and proud to open the AE's Congress in Nice! International scientific excellence is at the heart of our autism policy. Let's work together for "a new dynamic for change and inclusion!"

Sophie Cluzel, French Secretary of State for People with disabilities.

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"Your voice is heard here in Brussels, and it's been key on the implementation of the UN Convention on the Rights of People with Disabilities, the adoption of the European Accessibility Act, or the Web Accessibility Directive. Let us continue to work together on the inclusion of autistic people in Europe."

K. Ivankovic-Knezevic,
Director at the European Commission DG Employment, Social Affairs and Inclusion.

The Congress in figures

- **2,200** participants
- **80** countries represented
- **30** delegates attending with a JiM Grant
- **+ 700** abstracts reviewed
- **6** keynote speeches
- **12** symposia
- **10** oral communication sessions
- **483** posters
- **75** members of the Honorary Scientific Committee
- **35** exhibitors
- **14** official partners

An increasing global satisfaction from edition to edition



©Autism-Europe

According to data from more than 800 respondents collected by the external evaluation agency of the congress, Canaletto Research & Consultancy, the overall feedback on the event was very positive, as the Congress broadly met expectations of the different audiences which attended.

The vast majority of participants' estimate that the Congress met their expectations. The trend is consistent with the results achieved in the previous edition. Autistic persons were satisfied overall to have access to serious, reliable sources of information and fresh updates on where the current

research on autism can be found. However, there is more which remains to be done in order to improve participation and accessibility for future editions. Families have appreciated opportunities to learn about autism from trusted sources. Academics were particularly happy with all aspects of the Congress programme and opportunities provided during the event. Professionals showed satisfaction in terms of access to serious, reliable information and networking opportunities.

See you in Cracow in 2022!



Visual of the next AE's Congress in Cracow in 2022

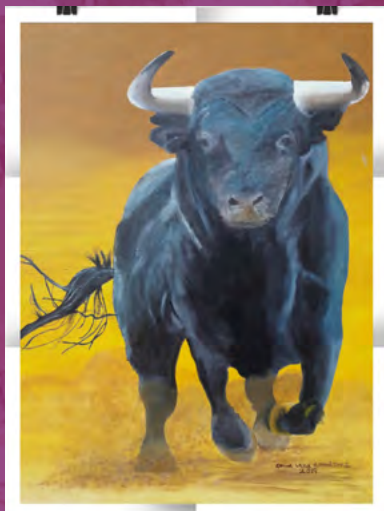
©JiM Foundation

The thirteenth edition of the triannual International Congress of AE will be organised by *Fundacja JiM*, a member organisation of AE, in Cracow in September 2022.

Marcin Krzyzanowski, Deputy President of the JiM Foundation, spoke at the closing ceremony of the twelfth edition and invited participants to attend the next Congress in Poland: "17 years ago, when my best friend Tomasz Michałowicz and me were founding the JiM Foundation, we never would have thought that we would be here, at this point

in time, announcing that we will be holding, together with AE, a Congress in Poland. I think that this experience will be something really remarkable for us, because at the JiM Foundation, we are still trying to make our workplace a better place, and we are doing everything in our power to support people on the autism spectrum and to help them in every way they need".

Art and Autism competition



Mexican young artist Omar Vera is the winner of the VIII edition of the “Art & Autism” international art exhibition, organised by Asociación Autismo Burgos and showcasing the work of people on the autism spectrum at the Congress.

Omar Vera is a 23-year-old apprentice of the painting teacher Marcela Ancona in the autism center ASTRA-Cancun, a non-profit organization promoting the well-being of autistic people in Cancun, Mexico.

Winning artwork of the design competition by Omar Vera

New publication:

People with Autism Spectrum Disorder. Identification, Understanding, Intervention- Third edition

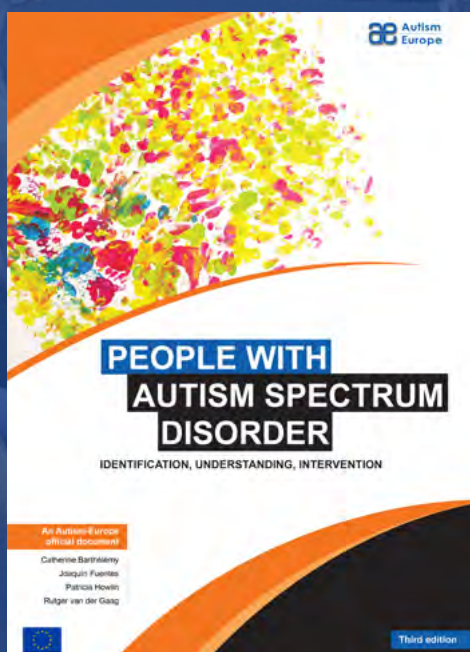
On the occasion of the AE's Congress, AE launched the third edition of its publication “People with Autism Spectrum Disorder. Identification, Understanding, Intervention”, giving an overview of state-of-the-art research in the field of autism and its implication for practice.

This publication aims at making evidence-based data from European and international research available to the wider public, so as to promote a better understanding of autism and in turn, have a positive impact on the lives of people on the autism spectrum. The document offers guidance on various key aspects from diagnosis to lifelong support in view of promoting an evidence-based and rights-based approach to autism in line with the social model of disability and the UN Convention on the Rights of People with Disabilities.

Since the first publication of this reference document in 2000, the understanding of autism has greatly evolved but disparities persist in Europe regarding access to evidence-based knowledge. In addition, many research areas are still to be explored to a greater extent to offer people on the autism spectrum the best possible care and support as well as equal access to opportunities.

The document is aimed not only at people on the autism spectrum and their families but also at professionals and public authorities responsible for implementing the necessary measures so that people on the autism spectrum can fully enjoy their rights and participate in society.

The publication has been co-authored by a team of leading European experts in the field of autism and includes an easy to read summary. It is freely available on AE's website.





Highlights of AE's last Council of Administration meeting in Brussels

On November 16th and 17th 2019, members of the Autism-Europe (AE)'s Council of Administration and observers from 15 countries, met in Brussels in order to reinforce their capacity to liaise with the CRPD committee and discuss AE advocacy and campaigning activities – in particular in relation to access to education and employment – as well as its various projects.

The first day of the meeting included the participation of Marine Uldry, Human Rights Officer for the European Disability Forum, who delivered a workshop on the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) review process and the various ways to provide input to the CRPD Committee. The objectives of this workshop were to reinforce the capacity of AE members to provide input to the Committee by developing a better understanding of the work of the Committee and its different activities; identifying how the Committee can advance the rights of persons on the autism spectrum; and being informed of the different ways to engage with the Committee.

At this meeting, representatives of European autism organisations met to discuss and vote on various issues related to AE's activities. This meeting was also an opportunity to initiate the presidential transition between Executive Committee member Harald Neerland (Norway), President-elect of AE, and current president Zsuzsanna Szilvasy (Hungary), who is ending her second mandate after 8 years in the position. It was an opportunity to thank Zsuzsanna and outgoing executive committee members – Evelyn Friedel, Maria Wroniszewska, Pietro Cirrincione, and Claude Schmit – for their work over the years.

Highlights of the meetings included the presentation of the implementation of the work programme 2019, the proposal of work programme 2020 and AE's awareness-raising and advocacy campaign for 2020-2021. Members also discussed the results

of AE's survey on barriers to education for autistic people (to which 2,200 people from across the EU and beyond responded) and AE ensuing recommendations. Other ongoing AE's activities have a strong emphasis on supporting access to education, employment and a better public health response (including mental health) for autism as well as fostering the participation of self-advocates.

The positive results as well as feedback from participants on AE's 12th International Congress held in Nice in September 2019 were presented by Anne Freulon, from *Autisme France*. AE's response to on-going public consultation by the European Commission on the European Social Fund (ESF) which supports social inclusion, combats poverty and fights discrimination was also discussed. To conclude the meeting, Suncica Petrovic from the AE's member the Serbian Autistic Society presented the experience of using robots to work with autistic children in the framework of the DE-ENIGMA project (in which AE is also involved); and Felicia Jibson presented the initiative PAGS®, a digital communication platform for skill development of neuro-diverse learners aged 5-25 with social communication difficulties, related to social, emotional, behavioural, and cognitive functioning.

After the Council of Administration meeting, an informal roundtable was held in AE's offices with autistic people from Liège, Flanders, and the Brussels Region to discuss their experiences in relation to accessing diagnosis, employment, or to education and services. These meetings are an opportunity to establish dialogue with autistic people across Europe.



Pierre spoke with Sophie Cluzel, French Secretary of State for People with disabilities, at the AE's Congress

Pierre Marcantonio, French autistic layout artist

"Expressing my 'inner child' allows me to spend many contented days at work"

During the 12th Autism-Europe (AE)'s International Congress held in Nice in September 2019, AE had the chance to talk with Pierre Marcantonio, a French young artist diagnosed with Asperger's Syndrome who is very passionate about the world of 3D animation, and defending the rights of people on the autism spectrum.

Autism-Europe: When did you receive your diagnosis for autism and what did it mean to you?

Pierre Marcantonio: I was diagnosed with Asperger's at the age of 23 in Lyon. Thanks to this diagnosis, I had a bit of a revelation in my life and started to see how there were a multitude of 'types' of intelligences in the world, not just a single type of intelligence which is normally applied to us, as humans.

AE: Tell us more about your profession.

PM: At the moment, my work focuses on creating and developing scenes in 3D using the technical software '3DsMax'. I put the scenes together with characters and objects which react with each other and their surroundings in a 3D space as well as assisting the director on camera angles and getting the best shots in relation to the 3D scene. From here, I translate what the director wants through the development of an animated sample like a kind of preview before it goes to the team of animators for their input, then onto the editing team who come up with the final animation which could feature as an animated illustration, an animated TV series, or even an actual animated film.

AE: What is the secret to success at work?

PM: I really love this type of work because it constantly stirs the 'child' in me. Expressing your 'inner child' is absolutely vital in this type of work. When I am in the creative process of doing my animated illustrations, say for when I do animated illustrations for children and a younger audience, and all my colleagues are also expressing their 'inner child' through their work. Then that is what creates the conditions for a certain work environment which is the ideal for me. All of these elements mean that I am channeling more of my energy into my work than I would otherwise, as I am also not over-exerting myself in this job. This allows me to spend many contented days at work without having time-off.

AE: What are the difficulties you face at work?

PM: It is true that, on one hand, I display certain difficulties coping in social settings. For example, I still have a bit of bother mastering 'irony' or off-beat humour to be honest, but these are neurodevelopmental skills and so they can be learnt, just as cooking skills can be learnt. On the other hand, I have

yet to understand better certain implicit expressions, even if I can make sense of other things that are implied. This type of behaviour is something that can also be learnt over time so I recognise that, for me, it is a gradual phenomenon, and that I have to be patient. It is not without difficulty of course, but it is something that I will learn and I am quite confident about that.

AE: What is full inclusion for you?

PM: For me, 'inclusion' is the fact of applying such a state of mind capable of accepting all types of people, and to those who may have all types of conditions as well as all types of circumstances, no matter what they may be. This state of mind that I am talking about is like a 'zen-like' peacefulness that an individual possesses. This inner peacefulness is what allows me to accept myself, whether in my work environment or in my daily life, or in my artistic expression. It is clear that each person demonstrates goodwill and their ability to accept others by showing that diversity is a phenomenon which already exists and can be accepted throughout the world.



DE-ENIGMA: autistic children exploring emotions with robots



Recently completed in November 2019, DE-ENIGMA is one of the biggest projects investigating assistive technologies for autism, bringing together pan-European expertise to develop an intelligent humanoid robot. Autism-Europe was part of the team that developed state-of-the-art technical systems, based on Artificial Intelligence, to automatically detect and respond to the about behaviours of children on the autism spectrum during robot-based activities. One of the key objectives was also to test claims about whether predictable robot behaviour might positively impact children's interactions.

Autism affects children in many ways, but particularly their communication and interaction with others. Childhood challenges with these social building blocks can have significant negative impacts later in life. Robots are thought to be a potentially powerful tool for supporting learning in autistic children because they may be less socially demanding and more engaging than traditional teaching options. However, there are still many unknowns about autistic children and robots.

The DE-ENIGMA project explored the potential of a commercially available robot (Robokind's Zeno), combined with artificial intelligence, as a near-future tool for autism education. Focusing on emotion recognition skills, a key social domain, DE-ENIGMA has iteratively developed and tested prototype interactive games with Zeno. These games are targeted at

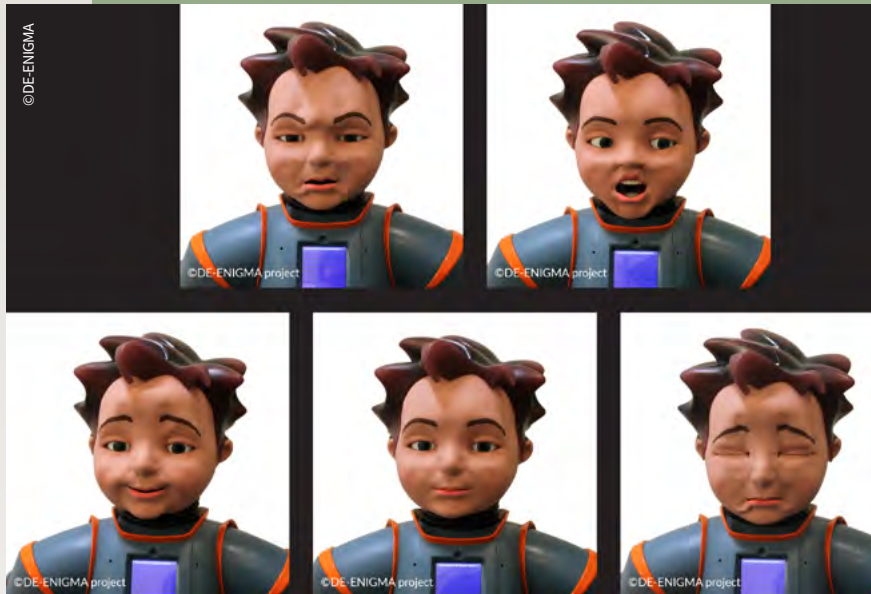
primary school-aged autistic children with additional intellectual disabilities, limited spoken communication, or both. They provide a platform for studying how autistic children interact with different elements of DE-ENIGMA technology and how different robot characteristics may impact them.

Iteratively designing activities and AI: Zeno gets smarter!

During the project, the DE-ENIGMA system has gone through successive design phases, evolving each time as we have learned from experiences with children and schools. Since beginning in 2016, the project has developed from using highly structured activities with clearly defined steps to a more game-like style of interaction that gives children more

chances to explore emotion content at their own pace and to choose how to interact with Zeno.

The first prototype followed a holistic approach to emotion teaching, recognition and (re)production in story-like contexts. Emotional facial expressions were introduced in structured steps as full faces in photographic, schematic drawing, and live demonstration versions (based on the "Teaching Children with Autism to Mind Read" programme by Howlin, Baron-Cohen, & Hadwin, 1999). The programme presented a large amount of information concurrently and relied heavily on verbal language for instructions and feedback. In evaluations with 128 children in Serbia and the UK (2016-2017), Zeno was very popular with our target group, but the prototype content proved very challenging for some children to understand.



A freely available dataset to contribute to autism research efforts

DE-ENIGMA also developed a dataset of autistic children's interactions with prototype 1, recorded by multiple audio, video, and depth recording devices. It includes 13 terabytes of multi-modal data, representing 152 hours of interaction from 121 children. Furthermore, 49 children's data have been labeled by experts for features such as:

- Facial mapping coordinates (smiles and frowns and other facial expressions can be recognised);
- Continuous values for children's levels of emotional valence and arousal;
- Presence of speech and vocal noises (e.g. who is speaking, vocal cues like laughter or crying);
- Different body postures and the angle and rotation of the child's head (the software can estimate);
- Whether the child is still paying attention to the robot or not interested anymore).

To date, it is the first publicly-available multi-modal database of autistic children's behaviors. The analysed annotated data functions are ready-labelled training data that can be used in behavioural and machine learning research. This dataset therefore allows the wider scientific community to research the behaviour of children on the autism spectrum to improve current recognition software which will lead to better automatic recognition of physical features in a neurodiverse population. This is a step towards improved technologies for neurodiverse children.

In the second prototype (2018), the DE-ENIGMA team sought to make DE-ENIGMA interactions more visual, flexible, and active for child users. The expansion of the system to add tablet computers provided an extra means for communicating with the robot and accessing activity content. Emotion content was substantially redesigned as short, game-like activities, based on key findings in the autism and developmental research literature about face processing and acquisition of emotional skills and concepts. The second prototype activities focused on two main topics: exploring facial features of the robot (i.e. eyebrows, eyes and mouth) and exploring emotional facial expressions, with Zeno demonstrating.

Within these activities, the robot would autonomously respond to actions that the child was taking. The DE-ENIGMA team continued to refine the content, tablet interfaces, and child robot interactions over five usability studies with children.

In the last phase of the project, the second prototype activities have been further refined into prototype 3A. Engaging and usable by autistic children with a wide range of abilities, the prototype provides a structured way for children to interact with Zeno and a supporting adult, facilitating controlled experimentation to test claims about whether and how predictable robots may positively impact children's interactions. Robots, as programmed devices, are thought to be comparatively easy for autistic children to understand and interact with, making fewer social and cognitive demands. This claim is widespread throughout human-robot interaction and autism literature, but to the best of the DE-ENIGMA team's knowledge, has not been explicitly evaluated.

A study at a special school in London (2019) aimed to test hypotheses about robot predictability affecting children's behaviour and to advance knowledge about designing successful human-robot interactions. Concurrently, DE-ENIGMA evaluated a new capability to automatically produce reports for autism educators about how their students interacted during sessions with Zeno, based on behaviours automatically detected by the system's perception modules. Educators rated reports for their perceived accuracy and their usefulness for educational practice. Results of both studies are in preparation.

In order to demonstrate the integrated technical capacity of the robot, the final prototype features multimodal interpretation/reasoning to suggest robot actions that are appropriate for the child. This prototype demonstrates the way the robot and the exercise adapt to the children's responses and will also provide feedback on, for instance, micro-expressions, arousal, engagement, or performance of the children.

Keep calm and robot on

In the framework of the Autism-Europe's International Congress 2019, DE-ENIGMA partners Dr. Alyssa M. Alcorn (Centre for Research in Autism Education, UCL Institute of Education, UK), and Sunčica Petrović (*Autizam Srbija*/ Serbian Society of Autism) held the workshop "Keep calm and robot on: practical tips from DE-ENIGMA for working with robots and autistic children", addressed to anyone interested in the possibility of using robots with people on the autism spectrum, and would like to find out more. In this workshop, some practical "lessons learned" information from our studies with over 180 school-aged autistic children in the UK and Serbia were shared. Supported by video examples, qualitative information and practical tips that show what the child-robot interaction was really like were shown—including the mistakes and mishaps.

More information: <https://de-enigma.eu/>

A classroom of the inclusive kindergarten "Bajka" in Zagreb



©MDječji vrtić Bajka

Helena Vrhovec and Alemka Cindrić from "Bajka" shared their project to build a more inclusive society for autistic children in Croatia at the AE's Congress in Nice



©Autism-Europe

Helena Vrhovec Pošta and Alemka Cindrić, special educators for the mainstream kindergarten "Bajka" in Zagreb, and winners of the Autism-Europe's online competition "A New Dynamic for Autism"

"We need to work harder to build awareness and ensure access to specialised support in education"

In June 2019, the Croatian project *"Transition to integration program for children with autism"* won Autism-Europe's online competition competition "A New Dynamic for Autism". This award gave Autism-Europe (AE) the opportunity to meet two special educators involved in the project, Helena Vrhovec Pošta and Alemka Cindrić, at AE's International Congress in Nice and to learn more about their perspective on inclusive education in Croatia.

Autism-Europe: How did your project to support the transition from inclusive education for children on the autism spectrum come to light?

Helena Vrhovec and Alemka Cindrić: The project aims at reaching full and effective inclusion of children on the autism spectrum into the regular education system. In the beginning, we started with one group of five autistic children aged 3-7. Thanks to its effective strategies and a parent initiative launched by the City Office for Education of Zagreb, we have expanded the project that now has four more groups. In each group, a special educator and a preschool teacher work together on this half-day programme that includes some activities from a mainstream group. One of the advantages is that each child follows the programme for 1 or 2 years, which made it possible to include a larger number of children on the autism spectrum.

AE: What are the most important factors in your opinion to support successful inclusive education for autistic children?

H&A: The most important factor is to prepare all the participants involved in the process during the transition to a mainstream kindergarten. In general, we like to say that our formula for effective inclusion relies on the combination of evidence-based interventions, active parent participation, and of course, daily interaction of the children with their neurotypical peers.

AE: What does inclusion bring to the children (on the autism spectrum and neurotypical)?

H&A: The inclusion of autistic children in a mainstream classroom is definitely a win-win situation. Both groups of children learn to accept, support and cooperate with each other in everyday situations. Our main focus is to ensure that children on the spectrum from our program have daily opportunities to have directed and guided interactions with peers on playground, in peer's classroom, and during 'reversed integration' within our classroom.

Peer-mediated intervention gives us the best results and increasing social interaction between these two groups. With planned intervention, we teach peers specific skills for starting and maintaining interaction with autistic children, reducing

teacher's involvement and support, and their interactions become natural and positive. In addition to improving the social skills of children on the spectrum, we encourage positive reactions and peer sensitivity to diversity.

AE: Can you share with us a story of which you are particularly proud of in the context of your project?

H&A: We are so lucky to participate in the everyday achievements of our children so it's not easy to point out one story. For example, a couple of months after a peer-mediated intervention, the mother of one child told us that her son played with his sibling for the first time in his life and that interaction lasted for three hours. We are also very happy to hear from parents that our children successfully attend school, go to extracurricular activities, or have participated in an art exhibition. In spite of the great positive impact of our programme, we are aware that we need to work harder to build awareness and ensure access to specialised support in education.

Furthermore, we often have the opportunity to see swift changes in the preconceptions of people regarding children on the autism spectrum, after a period of getting to know them. Hopefully, our project and future research will stand as examples of good practices and maybe inspire other people to work on inclusion.

AE: How was your experience at the AE's Congress?

H&A: We were amazed by the number of people attending the Congress, coming from all around the world and sharing the same goal: to support people on the autism spectrum. It was a great opportunity to get to know different professionals, parents and autistic people; talk about their projects, discoveries; and share experiences. We were also so happy to present our research "Behavioural skills training in peer mediated intervention for autistic children", conducted in cooperation with colleagues from the Faculty of Education and Rehabilitation of the University of Zagreb (Jasmina Stošić and Matea Begić). All together, it was an inspiring and valuable experience for us, and we are honored to have supported and contributed to the Congress.



The ETTECEC project provides free online training on autism for preschool teachers in inclusive education across Europe

Providing teachers with accurate information and effective practical strategies is important to improve outcomes for children on the autism spectrum and their families. However, limited training opportunities are currently available across Europe in that respect. The ETTECEC project therefore provides online training to preschool teachers so that they can better meet the needs of autistic children in inclusive schools.

In the framework of the final conference of the ETTECEC project, hosted by Autism-Europe on December 4th 2019 in Brussels, the ETTECEC free online platform for teachers was launched and presented by partners from Slovenia, Spain, and Czech Republic. This two-year Erasmus+ project has developed and implemented an innovative pedagogical approach based on the inclusion paradigm of education, by developing a didactic online course focused on children aged 0-6 (pre-school).

The ETTECEC partnership brings together academics and professionals from several education centers and autism organizations across Europe. Those involved come from various backgrounds – both national and cultural – and have a wide set of skills. The project coordinator, *Asociación Mi Hijo y Yo* from Spain worked closely with all the other partners: *Svetovalnica za avtizem* and the Educational Research Institute (*Pedagoški inštitut*) from Slovenia, the *Fakultní mateřská škola Sluníčko pod střešou* při Pedf UK (*Mateřská škola*),

Schola Empirica from the Czech Republic, and Autism-Europe.

The ETTECEC online training

ETTECEC has developed and implemented an innovative pedagogical approach based on the inclusion paradigm of education. It is addressed to preschool teachers who want to develop their skills to respond to the needs of children on the autism spectrum. The training can also be useful for teachers who work with children above the age of 6. The course includes different modules, all of them based on specific situations that could happen in the classroom:

- **Module 1** - What is autism?
- **Module 2** - What to observe?
- **Module 3** - Strategies to implement as a teacher

The ETTECEC project aims at improving the Early Childhood Education and Care (ECEC) systems of the partner regions, making them inclusive, and allowing children on the autism spectrum to be better prepared to enter the rest of the education system.

ETTECEC's fundamental philosophy could also make it equally relevant to other stages of education where it could be successfully applied (although considering the different needs and characteristics of the learners). The online course includes different modules based on specific situations that happen in the classroom.

To access the ETTECEC online training, visit the project Moodle platform by going to : <http://moodle.ettecec.eu/moodle/> and register for free. Once you have created an account, the course is freely available in English, French, Spanish, Slovenian and Czech.

Impact of the ETTECEC project

Since 2017, over 20 teachers from ten schools in Slovenia, Czech Republic, and Spain have been trained in relation to autism needs and in turn 270 children have directly benefited from inclusive education methods.

In the last months of 2019, hundreds of professionals, relatives, decision-makers, journalists, autism experts and other interested parties attended the four ETTECEC multiplier events held in Ljubljana, Las Palmas, Prague and Brussels, aiming at raising awareness about the importance of education in autism for preschool teachers and sharing the work and expertise of the project partners to a wider audience.

Before each of these events, project partners had meetings 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 about the importance of sustaining the legacy of the ETTECEC training after the project's completion.

ETTECEC international event in Brussels

In December 2019, Autism-Europe, as partner of the project, hosted the half-day conference "On Autism for preschool teachers" at the University KU Leuven in Brussels. It gave participants from different countries the opportunity to learn more about the situation of inclusive education in Europe and to discover the ETTECEC training, its methodology and impact. Participants from China, the USA, Belgium, France, Luxembourg and other European countries gathered to know more about the results of the work undertaken by professionals from Spain, Slovenia, Czech Republic Belgium.

More information about the project and access to the training:
<http://ettecec.eu>



What have professionals said... ...in Slovenia

Zala, assistant teacher: "I have not completed any course specifically for dealing with autism, but I am studying inclusive education. We need training on autism. We would also need professionals who are available for providing support when we need it. I need concrete examples from practice".

Anonymous preschool teacher: "This year I have new children and no one stands out and there are no behavioural issues so far. In case a need occurs, I will gladly use the ETTECEC online course because additional information, knowledge, experiences, and theory always help us improve our work."

...in Czech Republic

Věra Štěchová, school assistant: "I think that a training for preschool teachers is much needed because behaviour of autistic children is very specific and unusual in many situations. It can be sometimes very difficult to deal with them. That is why it is important to be well prepared. I think that everything that could help integrate these children into "normal" life is valuable: trainings, workshops, meeting with other parents, teachers, sharing experience and specialized books".

Petra Soukupová, economist and mother of an autistic child: "I am glad that the question of educating autistic children has been generally more discussed. I am very happy that our preschool has gotten involved in the project and has been helpful. As a parent, I don't know of any online training courses, however any education is helpful. It is also very important to get support in real life, though. Theory and practice often differ".

...in Spain

María del Sol Díaz Viera, preschool teacher: "I believe that the teaching staff must be informed and trained to attend autistic children in the classroom, we will use the information of ETTECEC to fulfil our request to be guided in the classroom and look for the necessary support for the student, both with functional diversity (autism) and neurotypical, so we can create inclusive classrooms".

Join AE's campaign 2020-2021 on employment and education!

In the framework of its Strategy 2018-2021, Autism-Europe (AE) will launch a two-year awareness-raising campaign to inform and raise awareness of how to promote access to education and employment for people on the autism spectrum. This campaign, which has as its slogan “I can learn. I can work”, will be implemented in several phases from early 2020.

Campaign visual in its blue form

I
can
LEARN
I
can
WORK



The campaign “I can learn. I can work” is articulated around two key themes that are central for the social inclusion of autistic people at various stages of their lives: access to education and employment.

One of the objectives is to promote access to quality inclusive education (including to university and vocational training) for autistic people and tackling the barriers they face across Europe. The other objective is to foster positive initiatives related to the employment of autistic people and to call for the implementation of the EU’s anti-discrimination legislation in the field of employment. Indeed, it is estimated that across the European Union less than 10% people on the autism spectrum are employed mostly in low-paid jobs or in sheltered settings.

As it does every year, AE will work together with its member organisations to effectively reach a wide range of stakeholders in society – including the general population, employers, policy-

makers (both at national and EU-level), etc. The campaign materials and activities will be disseminated early in 2020 via AE’s newsletter, and on AE’s website and social media channels.

The campaign takes place at a critical time as the EU is currently discussing the future EU Disability Strategy 2020-2030 (please see the article on this topic in this edition), for which AE is advocating. In November 2019, AE issued a position paper to inform the European Commission and other stakeholders about the priorities of autistic people and their families for the next period, including access to education and employment. The coming years will also see the implementation of the European Pillar of Social Rights that states that ‘everyone has the right to quality and inclusive education, training and lifelong learning in order to maintain and acquire skills that enable them to participate fully in society and manage successfully transitions in the labour market’. It is therefore a key opportunity to make our voice heard.

The AE survey on education included questions in relation to:

- Access to individualised planning and adequate support for autistic learners in the education system;
- Reasonable accommodation (ratio of disabled and non-disabled pupils in class, individual support in class, adequate support person, sensory accommodation, alternative language, etc.);
- The development of standardised autism-specific training;
- Availability of an Individual educational plan involving key stakeholders, including parents;
- Flexible curriculum;
- Supporting adequate training and working conditions for education professionals;
- Ensuring adequate working conditions to foster retention of qualified professionals;
- Facilitate better transitions;
- Ensuring access to lifelong learning.



“I can learn”

Over the past years, education systems across the European Union have undergone systemic changes, to move towards inclusive models. However, many autistic learners still struggle in inclusive education, as they experience a lack of understanding of their individual needs and what adapted support means. Despite changes in the legislation of many countries, people report a lack of change in mindsets. They are faced with a lack of flexibility of the education curriculum and infrastructure to use their strengths. Bullying is also experienced by many. If they access mainstream schools, autistic children tend to face a higher rate of exclusion compared to their non-autistic peers. More must be done to make the education system accessible to autistic learners.

In late 2018, AE launched an EU-wide online survey in eight different languages to assess the barriers to education faced by autistic people. Following the analysis of the results of the 2,200 answers describing the state of play in Europe, AE formulated recommendations for policy-makers and key stakeholders.

The survey about access to education has allowed for greater debate in the AE network on this subject, and more crucially, it means that recommendations can be formulated with the collaboration of local and national autistic associations.

“I can work”

In early November 2019, the state of play of employment of people on the autism spectrum in Europe was discussed at the Committee on Employment and Social Affairs of the European Parliament. Around one-hour was dedicated to this issue, and AE was invited to do a presentation to share its expertise and make recommendations. Thirteen members of the Committee from 4 different political groups and 9 different countries expressed their willingness to promote actions at the EU-level to address the discrimination faced by autistic people in employment, but also in other areas of life, including awareness-raising actions around World Autism Awareness Day (April 2).

AE will therefore actively continue advocating for access to employment and is planning to launch a publication to promote access to employment and fight discrimination in the workplace. It will notably include an explanation of the legal framework regarding anti-discrimination in the field of employment, as well as examples of provision of reasonable accommodation for autism and good practices by featuring direct testimonies of people on the autism spectrum and employers.

How can I support the campaign?

1. Find a tool that represents one of your skills and then hold it. The tool can be linked either with your ability to learn, or your ability to work on a specific field;
2. Make a video/ GIF of yourself holding the tool (and maybe using it);
3. OR take a picture of yourself doing this;
4. Share it on social media using the **#AutismDay2020** hashtag.

Alternatively, you can just take a picture of yourself holding the visual of the campaign, that you can download on AE's website:

<https://www.autismeurope.org/what-we-do/world-autism-awareness-day/current-campaign/>



We need an autism-friendly disability strategy for the European Union

The current European Disability Strategy of the European Commission is coming to an end in 2020. What about the next one? The strategy was debated at the European Days of Persons with Disabilities at the end of November 2019 and concrete proposals for the upcoming period (2020-2030) are now expected from the European Commission.

The European Disability Strategy 2010-2020 is currently the main EU-policy document in relation to disability, it sets out objectives and actions for implementing disability policy at the EU level. The European Commission carried out a public consultation until mid-November to get to know citizens' and stakeholders' opinions on the activities carried out by the EU to improve the inclusion of persons with disabilities into society during the period 2010-2020. The information collected will be used by the Commission to assess what has been achieved. It also helps the Commission to draw lessons on how to improve disability policy in the future, with a view to making it more effective and focused.

In fact, the EU has a leading role to play in facilitating the implementation of the

United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The future European Disability Strategy should aim to support the full implementation of the convention at the EU level and in all the EU member states. It should also be consistent with the objectives of the UN Sustainable Development Goals (mentioning disability eleven times) and the European Pillar of Social Rights, which outlines EU principles in relation to social rights and employment and was proclaimed in 2017. By ratifying the UN CRPD, the EU commits to mainstream disability and the UN CRPD provisions into all relevant EU policies.

In the context of the review of the current European Disability Strategy 2010-2020, Autism-Europe (AE) issued a position paper to inform the Commission and

other stakeholders about the priorities of autistic people and their families, and make recommendations for the next strategy beyond 2020.

To ensure adequate mainstreaming of disability across all policy fields at the EU-level, AE advocates for the creation of disability focal points in all EU institutions and an efficient interinstitutional coordination as well as an adequately resourced monitoring mechanism.

Targeted actions to support autistic people and their families are necessary in education; employment; diagnosis and disability assessment; access to healthcare and habilitation; lifelong individualised support in the community; and support for families.

Discussing EU disability policy beyond 2020

At the European Days of Persons with Disabilities (EDPD), an annual Commission event marking the International Day of Persons with Disabilities (3 December), the outcomes of the European Disability Strategy and the future of EU disability policy beyond 2020 were discussed with over 300 participants. Among them was a diverse delegation of AE members which included self-advocates and family members from different European countries to advance the rights of autistic people. The organizers of the EDPD, after consultation with AE, paid close attention to the event's accessibility for autistic people given participants the possibility to wear interaction badges and to make use of a quiet room. Moreover, clear sign posting with pictograms was provided across the event venue.

On the first day of the EDPD event, during a presentation of the preliminary results of the EU-wide consultation on the European Disability Strategy, it was pointed out that for 55% of respondents accessibility of buildings and public services amongst the priorities for persons with disabilities for the next strategy. This is followed by the issues pertaining to ageing and disabilities (51% of respondents) and children with disabilities and their families (49% of respondents). Issues around independent living and inclusion in the community for people with disabilities were also high on the list of priorities (with 47% of respondents indicating it to be relevant for the next strategy) as well as access to work and employment for people with disabilities (43% of respondents).

The latter issues were raised in a video message to the EDPD event by Marianne Vind, a newly elected Danish Member of European Parliament at the Employment and Social Affairs committee, who was shocked to learn that the vast majority of autistic people are unemployed across the EU. She had found out about the high unemployment numbers when AE Director Aurelie Baranger presented in November 2019 the state of play of people with autism in Europe in front of the parliamentary committee using figures from the National Autistic Society which see only 16% of autistic people in employment (*cf. following article on AE's campaign*). For further guidance for the European Disability Strategy, the UN Disability Inclusion Strategy, the National Disability Strategy of Australia, as well as the Accessible Canada Act were presented at the EDPD event.

AE's key demands for the next European Union Disability Strategy:

- encouraging EU Member States to adopt adequately resourced cross-sectoral national strategies or action plans to respond to the needs of autistic people, in line with the UN CRPD and international recommendations;
- promoting coordination between EU Member States of relevant policies in the field of autism;
- harmonising practices, promoting community-based services and benchmarking necessary levels of quality across all EU countries;
- adopting principles of best practices and fostering exchange between EU Member States to respond to the needs of autistic people in various fields of life;
- promoting training of professionals in autism across all relevant sectors;
- supporting research to improve the quality of life and inclusion of autistic people;
- fighting stereotypes and raising awareness; supporting and involving autistic people, their families and their representative organisations through continuous structured dialogue.

AE vice-president P. Cirrincione participated at the panel "How to achieve sports for all" at the EDPD event.



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EMPL- Employment, Social Affairs and Inclusion

A panel during the second day was devoted to making sport accessible to all. Different examples of best practices regarding accessibility were showcased. One of the highlights was the presentation of AE's vice president and self-advocate Pietro Cirrincione on the Romulea Autistic Football Club, an inclusive football team welcoming players who are autistic and neuro-typical that aims at becoming the first inclusive team competing in the official Italian mainstream league.

He presented the challenges for players on the autism spectrum linked to communication and socialization issues

while playing football. Cirrincione criticized that special federations are not fully inclusive as teams with people with disabilities are not allowed to compete in mainstream tournaments. He wants players with autism to be fully included like anyone else.

Experiences of LGBTI and autism spectrum

ILGA-Europe and Autism-Europe cooperated for a submission to the Parliamentary Assembly of the Council of Europe on the specific needs and struggles of lesbian, gay, bisexual, transgender and intersex (LGBTI) people on the autism spectrum. The submission was prepared through a consultation that gathered inputs from ten organisations in Europe, including four autism organisations, five LGBTI organisations, and one LGBTI and autism organisation.

There is a growing body of research on the intersection between LGBTI and autism. This intersection bears unique challenges for LGBTI people on the autism spectrum, including social isolation, limitations in access to medical care, and ableism in LGBTI communities. Some studies indicate that there is an increased co-occurrence of the two experiences compared to the general population. For example, one study found that children with autism were four times as likely as the general population to experience gender dysphoria.¹

A community-based service provider for trans and gender diverse people in Finland indicates that a “considerable number of clients” are also neurodiverse (including ADD, ADHD, and on the autism spectrum).²

Another study, looking at sexual orientation among autistic adults in the Netherlands, found that 27% and 5% of women identify as bisexual or lesbian, respectively, 14% having no sexual attraction to any gender.³ This is compared to 8% of the general population of adult women in the Netherlands identifying as lesbian or bisexual, combined.

1. Elizabeth Hisle-Gorman, Corinne A. Landis, Apryl Susi, Natasha A. Schvey, Gregory H. Gorman, Cade M. Nylund, and David A. Klein. LGBT Health. Apr 2019. Available from <http://doi.org/10.1089/lgbt.2018.0252>

2. Input from Seta.

3. Nederlands Autisme Register 2017, Free University Amsterdam. Available from: https://www.nederlandsautismeregister.nl/assets/Documenten/NAR_rapport%202017_compleet_LR.pdf

More about ILGA-Europe

ILGA-Europe, the European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association, have more than 600 member organisations across 54 countries in Europe and Central Asia.

As part of recent efforts to increase intersectionality in the work on LGBTI issues in the region, ILGA-Europe hosted a meeting for D/deaf and disabled LGBTI activists in November 2019, which led to the dissemination of the hashtag #DisRainbow and of lessons learned, including promoting D/deaf and disabled LGBTI leadership, building alliances, leaning in to language discussions and debates, working to ensure accessibility of events, making information fully accessible, being aware of timing and context for efforts, and making sure that activities are always for everyone. ILGA-Europe has also launched a new disability-focused sub-granting initiative, which is currently in the kick-off phase with 5 grants awarded.

For more information or to get involved with this work, contact Cianán Russell: cianan@ilga-europe.org

Autistic trans and gender diverse people

- The process of coming to terms with one's gender identity may also be longer for trans and gender diverse people with autism, particularly when they receive an autism diagnosis during childhood;
- Trans and gender diverse people face significant barriers in access to transition-related healthcare; these barriers are markedly increased for trans and gender diverse people with autism;
- There is no one-size-fits-all approach to transition-related care, regardless of whether the trans or gender diverse person is neurodiverse, and as such, a holistic patient-centered care approach must be equally applied to autistic trans and gender diverse people.
- Trans and gender diverse people also regularly access legal gender recognition processes. All of these stages are reportedly more difficult for people with autism. In legal gender recognition, as in other areas of life, it is key therefore to ensure that autistic people can enjoy their legal capacity.

Lesbian, gay, and bisexual autistic people

- In terms of dating, LGB people on the spectrum describe feeling that they should hide their autism at the start of new relationships, partly because of fears of ableism and partly because they find it difficult to explain what autism is to potential partners. Some autistic LGB people prefer to date other autistic people.

Autism and LGBTI communities

- It is important to develop awareness and build bridges between LGBTI and autistic communities, in particular amongst young people. The participation of autistic people and other disabled people should be fostered in LGBTI organisations (and vice versa).
- It is key to develop the capacity of organisations to combat intersectional forms of discrimination in all areas of life as well as their capacity to accommodate the accessibility needs of LGBTI people with disabilities.

Developing access to support spaces and accessible sex education adequately reflecting diversity

- There is a need for systematic training in this area as well as more generally, to improve access to sex education.
- The lack of adequate access to sex education contributes to the fact that autistic people are more vulnerable to abuse and are three times as likely to experience sexual exploitation as their peers. Due to difficulties in understanding social rules and boundaries, autistic people are more likely to be taken advantage of and abused or may also unintentionally engage in offensive behaviours, such as stalking.
- It is therefore essential to develop sex education tailored to the needs of autistic people to build their confidence and to protect them from harm and from unintentionally harming others. It is also essential that such trainings address the different sexual orientations and gender identities and that autistic people are involved in co-producing them.

Invitation to Autism-Europe's 2020 Annual General Assembly

Online

In accordance with the statutes for our organisation, we are pleased to invite you to attend Autism-Europe's Annual General Assembly, which will take place in Krakow, Poland, from the 6th - 8th November, 2020.

Agenda:

- Presentation of the executive committee report
- Presentation of the activity report: 2019
- Presentation of the financial report: 2019
- Presentation of the work programme: 2020

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

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

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

Member Associations of Autism-Europe

FULL MEMBERS

(national associations of people with autism and parents)

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