Participants in attendance

AE members

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<tr>
<th>NAME</th>
<th>ORGANISATION</th>
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<tr>
<td>BRUNED José Luis</td>
<td>Fundació Autisme Mas Casadevall (Spain)</td>
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<td>CAPPAI Pierangelo</td>
<td>Diversamente ONLUS (Italy)</td>
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<tr>
<td>CASTRÉN Maija</td>
<td>Individual member, Autism Foundation, University of Helsinki (Finland)</td>
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<tr>
<td>CIRRINCIONE Pietro</td>
<td>Individual member, self-advocate (Italy)</td>
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<td>DE GAETANO Alistair</td>
<td>Individual member, self-advocate (Malta)</td>
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<td>FERENCZHALMY Zsófia</td>
<td>Hungarian Autistic Society (Hungary)</td>
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<td>FREULON Anne</td>
<td>Individual member, Autisme France</td>
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<td>GENET Laurence</td>
<td>Individual member, IME JEUNE APEDIA (France)</td>
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<td>HANOT Freddy</td>
<td>APEPA (Belgium)</td>
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<td>INGÖLFSSON Arí</td>
<td>The Icelandic Autistic Society (Iceland)</td>
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<td>KAMINSKI Maria</td>
<td>Autismus Deutschland (Germany)</td>
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<td>LAFRENIERE Germain</td>
<td>Individual member, TED sans Frontières (Canada)</td>
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<td>MANSOURIAN-ROBERT Jacqueline</td>
<td>Autisme France</td>
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<td>MICHAŁOWICZ Tomasz</td>
<td>JiM Foundation (Poland)</td>
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<td>MUSTAFA SOLYMAN Abuomar</td>
<td>QUDURATI Center (Saudi Arabia)</td>
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<td>OMAR Farrugia</td>
<td>Autism Parents Association (Malta)</td>
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<td>NEERLAND Harald</td>
<td>Autismeforeningen i Norge (Norway)</td>
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<td>PALACIOS Simona</td>
<td>Autismo Burgos (Spain)</td>
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<td>PARVIAINEN Tarja</td>
<td>The Finnish Association for Autism and Asperger's Syndrome</td>
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<td>PENKO Lidija</td>
<td>Croatian Union of Associations for Autism (Croatia)</td>
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<td>PETROVIC Suncica</td>
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<td>PETROVIC Vesna</td>
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<td>POST Monique</td>
<td>Nederlandse Vereniging voor Autisme (The Netherlands)</td>
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<td>POVEY Carol</td>
<td>The National Autistic Society (United Kingdom)</td>
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<td>RIVAUD Anne-Marie</td>
<td>L’Abri Montagnard (France)</td>
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<td>ROBERT Michel</td>
<td>Dialogue Autisme (France)</td>
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<td>ROCA Marta</td>
<td>Fundació Congost Autisme (Spain)</td>
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<td>SASNAUSKIENE Lina</td>
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<td>SCHMIT Claude</td>
<td>Individual member, Foundation Autisme Luxembourg</td>
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<td>SHPITSBERG Igor</td>
<td>Our Sunny World (Russia)</td>
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<td>SIROTKOVÁ Jana</td>
<td>National Institute of Autism (NAUTIS) (Czech Republic)</td>
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<td>SZILVASY Zsuzsanna</td>
<td>Individual member (Hungary)</td>
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<td>TABELT Annick</td>
<td>Fédération française Sésame Autisme (France)</td>
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<td>THAMESTRUP Heidi</td>
<td>Autism Denmark</td>
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<td>TZVETANOVA TZOLOVA Vladislava</td>
<td>Autism Today Association (Bulgaria)</td>
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<td>VERHAEGH Jan</td>
<td>Individual member, Self-advocate (The Netherlands)</td>
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<td>VIVANTI Donata</td>
<td>Individual member (Italy)</td>
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Annual General Assembly 2017 in Zagreb – minutes from the meeting

WEISGERBER André  
Fondation Autisme Luxembourg

Observers

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<td>Parent (Bosnia Herzegovina)</td>
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<td>BONDAR Yevgeniy</td>
<td>Autism Regions (Russia)</td>
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<td>BRUNETTI Alberto</td>
<td>Fondazione Domani (Italy)</td>
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<td>CLARCK Peggy-Ann</td>
<td>Raeger Autismecentrum (The Netherlands)</td>
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<td>ERGOROVA Anna</td>
<td>Autism Regions (Russia)</td>
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<td>FREY ŠKRINJAR Jasmina</td>
<td>Uni Zagreb, ESIPP Project (Croatia)</td>
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<td>LOPETAITE Sandra</td>
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<td>MAISANABA PEREZ Maria Angeles</td>
<td>Asociacion Autismo Sevilla (Spain)</td>
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<td>MRKANOVIC Alma</td>
<td>Professional (Bosnia- Herzegovina)</td>
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<td>RADZVILAITE Kristina</td>
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<td>YANKOVA ENEVA-LAMBOVSKY</td>
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<td>Mina</td>
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<td>ZAMORA HERRANZ Marcos</td>
<td>Asociacion Autismo Sevilla (Spain)</td>
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<td>GARATE Concepción</td>
<td>Autismo Burgos (Spain)</td>
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Staff

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<tr>
<td>BARANGER Aurélie</td>
<td>Director</td>
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<td>FERNANDEZ Cristina</td>
<td>Communication officer</td>
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<td>HAMMERSLEY Haydn</td>
<td>Assistant</td>
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<td>RAHIMPOOR Azita</td>
<td>Interpreter</td>
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<tr>
<td>URBAIN Françoise</td>
<td>Interpreter</td>
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Approval of agenda

The agenda was approved by all.

Autism-Europe current mission, structure and statutes

Zsuzsanna made a few comments on a number of current issues related to the current mission, structure and statutes.

She explained that there was a desire to change statutes to remove mention of “suffering” from autism and to take into consideration some evolutions.

She pointed out that the president of AE will be elected again in 2019.

AE has a future aim of broadening its geographical representation. We are currently missing Slovenia, for example.

Regarding finances, at one point AE decided to join more EU projects. She explained that the income from EU projects has been growing higher and higher, as of 2011.

We have also integrated fundraising into our mission. The majority of our funding come from the EU and member fees. This is just not safe. The staff at the secretariat are writing application for quadrennial funding but this is not guaranteed, so this is why we have to look for new sources of income. The safest is EU projects, but we also have to think about fundraising.

Activity report and work programme

Aurélie presented the 2016 Activity Report. In 2016 the main objectives were in line with the mission presented by Zsuzsanna, to support implementation of CRPD and to define EU policies in line with
this, to extend membership, to enhance self-advocate representation in the network, communication activities, projects and events, and capacity building.

AE’s EU policy work rests primarily on the implementation of the UNCRPD. AE contributed actively to the public consultation on the EU disability strategy 2010-2020. We drafted a Position Paper on the European Accessibility Act. We also created a Position Paper on the EU Pillar of Social Rights, and took part actively in structured dialogues in Brussels.

The EU Pillar was released in March 2016. It proposes to provide a framework to measure if countries’ social policies are in line with EU recommendations, and to offer guidance to improve them. We read this with other DPOs, and one concern is that disability is not adequately mentioned throughout the proposal, in line with the mainstreaming approach of the CRPD. It is mentioned in relation to and long-term care, but not fostering employment or education. It’s a very restricted approach, and not respecting the human rights model, but more the medical model. So we voiced our concerns.

Members were consulted on the position paper, and we are happy to announce the European Commission released a new text, which better mainstreams the CRPD, asks Member States to support dignity, an adapted work environment, non-discrimination, support in seeking and retaining work and community based care. It’s a positive step, but not the end of the road. Now the Council and the European Parliament have to agree on this text, and need to see how to implement it.

The European Commission released the proposal for the European Accessibility Act in December 2015, on common accessibility requirements for a number of goods and services. We drafted a Position Paper, and the Act is still in negotiation. It’s difficult as there is a lot of lobbying from companies who are worried this will trigger more costs for them. The main aim of the Position Paper is to recall the accessibility of communication, and raise awareness of the specific needs of autistic people.

Alistair, who has been working directly on the Act then spoke briefly off the record about the latest developments in the negotiation.

Aurélie explained that from the AE office we have been contacting MEPs from the Internal Market Committee, and applying pressure, so we will be in contact about how to add pressure from the members’ side later on.

Aurélie also explained that AE is continuing working on proposals for an autism strategy. In the ASDEU project we are designing a public health plan for autism that will be presented to the Commission.

AE ran a new campaign last year, “Respect, acceptance, Inclusion”. We engaged with EU decision makers. EU Commissioner Marianne Thyssen and some MEPs showed their support. We also had some famous supporters, footballers and the Prime Minister of Spain. We would like to particularly thank Spanish members who were very active. We had support from across Europe, but Spain particularly. We also had support from the First Lady of Malta. Material was translated into over 15 languages.

Another success was the International Congress in Edinburgh. Aurélie thanked the NAS for all their work. There were 1700 participants from over 60 countries. Feedback was great. She also thanked the JiM foundation for sponsoring participation from some delegates by offering bursaries.

We have also cooperated with other DPOs, and Donata Vivanti was very active in the European Disability Forum (EDF) last year.
Donata explained that she has had a very busy year. There were lots of issues and programmes to work on. EDF’s action is to lobby for disability rights. Donata’s role is taking into account the specific needs of autistic people. EDF is engaged in international fields, not just in the EU. EDF also worked for disability to be included in the Sustainable Development Goals entering into force, which is not the case of the previous goals. They succeeded in that, with 19 mentions of disability in the development goals. EDF worked on the CRPD again, and there is a new report by EDF on its implementation, issued in December 2016. EDF also has an officer in Geneva every time there is a meeting to discuss the CRPD’s implementation.

EDF also worked on a strategy concerning the structural funds. EDF also had meetings with the European Economic and Social Committee (EESC), which in some ways is more advanced than other bodies. It has crucial members, including the president and vice president of EDF. We have real support from them. So we have to follow this up very well.

Pietro also participates in EDF’s expert group on ICT. Another AE member Erika, also a self-advocate from Italy, participates in EDF’s youth group of EDF.

Pietro explained his role in EDF’s ICT expert group, and from December his participation in the WWW consortium for accessibility guidelines. Internet has standards for accessibility, made by the WWW consortium (W3C). Now they are working on standards for disability about learning and cognitive disabilities, because until now internet accessibility only focused on sensory disabilities. He also participated in a meeting for the alternative report for the UNCRPD, and a meeting with the Italian state and Diane Kingston from the UN Committee. He was also a trainer in Poland for the implementation of the CRPD for the autistic spectrum, in two conferences.

Pietro participated in an event hosted by the president of the Italian Republic, and the president of the Chamber of Deputies on the 2 April.

He is very involved in sport inclusion. The Autistic Football Club now recognised by the Olympic Committee as a sport club.

During the Edinburgh Conference, Autism Europe gave acceptable language guidelines to speakers. It was translated into Italian to give to experts there to change language, because they often still use medical model language. Last year the self-advocate strategy was launched. We need to go forward with this, and update on statutes. Pietro reiterated that AE’s statutes are old. We need a more modern definition of autism, and modern approach in statutes. It’s also very important to have direct participation of people on the autism spectrum in autism organisations.

Aurélie suggested Pietro circulates an overview of all his activities in writing. She pointed out that Pietro also supported the office in designing AE’s new website.

Regarding communication activities, AE is in the process of completing the new website. Hopefully it will be officially released in coming months. We are hoping it will be more compatible for tablets, phones, more modern, easier navigability, be more accessible, and have an easy to read interface. We want it not only to be accessible for autistic people, but people with sensory disabilities too. We will have a forum for members, and a self-advocate forum too. So it will be a good tool for consultation. The home page will also have direct buttons to the easy-to-read versions of the site, and to social media accounts.

Then there will be a map for member visibility. This can also become a dynamic tool, not just for members, but for autism friendly venues, facilities etc. In the past year, we increased traffic to the
website. This was also because of the congress. We increased followers significantly on social media. We had more than 300 references in the press, and autistic organisations’ websites.

We created a new leaflet on the occasion of the Congress. Also in our LINK magazine we’re now trying to have interviews with self-advocates. Members are always welcome to contribute and send ideas, and for the newsletter too.

Aurélie presented AE’s participation in the ESIPP, DE-ENIGMA, TRASE, ASDEU and IPA+ projects.

Meetings were held in Sardinia and Paris, and study visits took place at both.

Omar said he liked the idea of the online forum. For him, one main reason to join was to be part of community. Being together in this, sharing knowledge, success, and downfalls, will make AE more unique and united. This is when AE will flourish, and we will save members effort when doing a project. Prevent repeating done projects.

**Approval of the minutes**

A vote was taken and the minutes from the last AGA meeting were approved by all.

**Approval of the Report of Activities 2016**

A vote was taken and the report of activities 2016 was approved by all.

**Work programme 2017**

Aurélie presented the work programme for 2017.

AE will continue working on the UNCRPD, the European Accessibility Act, the Disability Strategy, the EU Social Pillar.

AE’s next International Congress in Nice is also being prepared.

AE began the campaign “Break Barriers together for autism”. A debate took place in the European Economic and Social Committee on the 3rd April on employment, and was the opportunity to raise awareness of stakeholders from all Member States. We also launched a photography exhibition, with pictures from Luxembourg, Poland and the UK. André was one of the photographers. We will host more exhibitions in other venues and later in the European Parliament.

In 2017 AE will continue all the European projects in which it is currently involved.

AE is also preparing to welcome two new members: Autismo Sevilla (Spain), and the Fondazione Il Domani dell’autismo (Italy), and we have prospective members from Russia as observers who might apply next year.

Monique asked a question about cooperation with EDF on page 4, which reads “including those with high level of support”. In the Netherlands she sees that a diagnosis itself doesn’t necessarily make a difference. Maybe instead of using words Asperger or autism, we could move more towards using “hidden” and “visible need for support”. In the Netherlands euthanasia is legal when talking about unbearable psychological suffering. Now people with autism are applying for euthanasia. Many are
those diagnosed late. In Holland it’s a worrying trend as psychological suffering is based on there being no more treatments to offer people. The whole trend we see is worrying and must be happening elsewhere but hidden. People asking for this are the “hidden” people needing support but not getting it. So maybe we can include this in some way. I’m scared other countries will follow this.

Jan supported Monique’s intervention.

Germain added that in Quebec research showed 21% of autistic people had anxiety problems and half of them had considered suicide.

Freddy pointed out that euthanasia for psychological reasons is also legal in Belgium. They sometimes say there is no solution for these people, but is that true? Sometimes psychologists not sufficiently informed. He also pointed out that sometimes comorbidities can cause suffering.

Peggy-Ann from the Netherlands thanked Monique for bringing this up. We don’t want other countries to adopt this. What can we do? She invited other to think about this.

**Vote on Work Programme 2017**

The Work Programme 2017 was adopted.

**Accounts 2016**

Claude presented the accounts from 2016. We had a high income in 2016. The triannual grant brought in 182,337.97€

EU projects brought in a total of 90,958.32€

Membership fees: 55,361.48€

Fundraising accounted for 1,552.14€

Contribution to catering fees came to 7,971.42€

Financial Income (refund from state on Social cotisation) came to around 7,000€

Total income for the year was 346,008.11€

Regarding expenditure, payroll accounted for 202,414.85€

Travel and accommodation made up 50,325.60€

The total expenditure for 2016 was: 327,416.43€

This results in a 18,591.68€ surplus

AE’s total assets make up 431,327.32€

AE’s Equity comes to a total of 325,294.27€
Budget 2017

Claude presented the 2017 budget. The triannual project funding runs out this year. For 2018 we will make the application. We often get it, only once 6 years ago we were not selected in the first run. However, there is no guarantee. If we are not selected for this grant, our finances change quite a lot. We’re not quite as dependent as we were in the past. Now we’re in situation where we could continue our activities for a while.

A condition for the commission running costs grant (for the next four-year grant), is that we must put some of our own funds into this. We would have to put up 46,000€ of our own money to get this total budget. For the other European projects, we try to accept those not requiring co-financing.

New projects are also in the pipeline, but there is no guarantee if they have been accepted or not.

The total foreseen expenditure for 2017 is 328,550€.

Income for 2017 should also come to 328,550€. 1,000€ is foreseen for fundraising. Hopefully at some point we will become better at that. Member fees accounts for 45,000€. Thanks to congress in Edinburgh, we have 36,000€ extra income.

Normally the result of the budget is balanced, but then including the income which we estimated quite low, so we should have some extra income.

José Luis Bruned asked how much AE was receiving for the ASDEU project in total. Aurélie said it was 130,000€ in total for 3 years. Aurélie will send him the exact numbers.

Vote to approve financial report 2016

A vote was taken on the financial report 2016, and all participants approved it.

Vote on budget 2017

A vote was taken on the budget for 2017, and all participants approved it.

ASDEU project

Aurélie presented the latest information from the ASDEU project. The consortium that was presented at for the first time at the AGA in Barcelona. There is work packages on different topics. AE works on a work package on autism policies in the EU. This includes assessing existing policies for autism for all ages and communities, then creating a public health plan addressing autism.

We have conducted an extensive literature review on policies in EU. Mapping of what exists in various countries. We also conducted stakeholder consultations, a questionnaire, and also a round table at the last AGA. We then consulted UNCRPD focal points to update information on the policies.

The literature review focuses on healthcare, education and employment. Also look at disability policies in general.

We found that over last decade, several Member States and regions have adopted autism specific policies, sometimes strategies, sometimes single policies. We had 907 replies to survey from all EU countries. Main issues raised were: need to reduce red tape, speed up diagnosis, need for harmonised
guidelines in the EU, to improve adult diagnosis, to create one stop shop in countries for questions related to autism, uniform rules in the EU, facilitate freedom of movement, training of general practitioners, measures for employment and training, reasonable accommodation, vocational schools, support for autonomy, and access to care.

We realised that the literature review is no longer up to date, as policies evolve very quickly. We contacted UNCRPD focal points in 28 countries. 22 countries provided feedback.

To avoid bias, from ministries, AE will ask members to share feedback, and this will be the final stage. We will then have good picture of current situation. We will shortly circulate the report. Will ask you to read specific page on your country.

The next stage will be the drafting of a public health plan, submitted in 2018 to the European Commission. We need to reach consensus, consulting a range of stakeholders.

Pietro asked if the strategic plan suggested would be just a health strategy. Aurélie answered that we hope for scope on more than just health, so we’ll try to include as much as possible on education, employment and social policy.

Donata commented that she was a bit concerned about asking for information from focal points. Aurélie said that we don’t want to make focal points last stage. We want member feedback to be the last stage. Donata suggested we could also consult the High Level Group on Disability on this.

Lidija, asked how members should present this strategy when they go to stakeholders. How does it differ from the national strategies? Aurélie explained that the European Commission says this could serve as impetus for Member States to adopt their own autism strategy, and it’s a way of sharing good practice. It could support the adoption of autism strategies in countries that don’t have them, not override existing national strategies.

Zsuzsanna clarifies that in June the first version will be sent to members, and hopes they will be active in this.

Discussion on Education

Ari from Iceland led the discussion on education, mentioned at last AGA in Sardinia. Ari was asked to present the proposal here in Zagreb. It was proposed by board of his society in Iceland.

In short the overview is to have a survey, concerning possibilities to support autistic people in gaining access to higher education and avoid unemployment, and to use their capabilities to their full potential. To see how many autistic people start and finish higher education, how many drop out, and why.

The second part will be for the organisations involved to draw up an online education programme, to help obtain high school diplomas and enter university. We want them to be able to substitute courses they can’t do with others, with ones they can do in order to get diploma to go to university.

The third part will involve following up with other survey to see how this programme can help and how it can be sustained in future.
Steps: Survey or questionnaire (similar one on AE in 2007, but new study needed). Before this we need to know what info we need to build up this project.

If the survey supports a need for this, AE should apply for a project on this topic.

The survey should be distributed and answered by autistic persons, parents, carers, teachers, special education teachers and other persons who could be informed about this. It should be linked to the following subjects: Numbers of autistic students in school and higher education, how many graduate, the reasons for dropping out, the level reached before dropping out, how far students can get on their own with current levels of support, the number continuing on to university, the legal context for special needs and autism, measurements, main obstacles, differences between legal regulations and reality, places for special needs, and suggestions for changes.

Pietro asked about the implementation, and whether the online tool would replace lessons in university, or if there will be mixed solution. Student on autism spectrum face problem in university, not just social, but also functional in terms of planning, content, priorities. Going completely online, people miss opportunities for social interaction, and inclusion. We need universities to be inclusive, or we risk worsening autistic students’ executive functions.

Ari explained that online education is not a magic word, nor inclusion. Inclusion should mean SAME participation. Online education is not a substitute. The problem sometimes is that there are compulsory courses to enter university. The online course could just be a substitute for the lessons you have difficulty in. There could be an online education agreement with universities, where someone could be following a course with support from a teacher.

Omar explained that in Malta they had this problem with an autistic student not being able to enter university because of her grasp of the Maltese language. She did not need this subject for her studies. If student wants to do tertiary education, and this subject is not prerequisite for their studies, there should be leniency.

Tarja said there has been an autism university project lead by Leeds University in the UK. It found differences between countries was great. They got money from Erasmus Lifelong Learning. You can find on internet. Point is you need to find many ways to support finishing university studies.

Ari said that at we are trying to break barriers to accessibility from the top, supporting those who went as far as possible on their own, capable of enrolling in mainstream high school, but stopped by because of one of the core compulsory subjects. These individuals have potential. The goal of this project is to overcome this. And then there’s the possibility to have local universities that accept this, so students have at least access to one university nearby. If we are able to do such a programme and break this barrier, then we’ll have a model of how to do this, then we can go down the chain to high school, middle school etc.

Donata said the project could produce a tool, but not be a binding instrument as it is not an EU competency. The problem would be that you rely on universities, and then universities claim for their freedom of teaching, and individual teachers too. This creates lots of confusion. It could be interesting to have a tool rather than suggestions. In Education, there is also a strong trade union, they are in a strong position. If you want to promote something you have to discuss it with them too. Even in the UNCRPD they mention the obligation to provide support needed in education. This could be a way to rely on the convention to get the support needed. There are a lot of interesting areas to work on to have an effective outcome.
Igor pointed out this is very important in Russia now. Many autistic people have high intellects, but no opportunity to be a student. As Russia is so big, many people live far from universities and rely on online university.

**ESIPP**

Jasmina, a partner from the ESIPP project, presented it to participants. It is a three-year project supported by Erasmus+.

The objectives are to produce an evidence-based model on needs of parents, and deliver training in Croatia, Macedonia and Cyprus. Then partners will share the model curriculum with policy makers and those who want to use it.

There is a lot of evidence that autism can affect individuals with autism but also parents. The aim is to increase social inclusion. It helps parents understand their children, better understand and support them. It can reduce stress in family, and improve parenting skills and also the skills of children.

It is also a cheaper way of doing intervention that other types available. Children whose parents are trained can then have 365 days a year support.

The aim of ESIPP is to make parents more confident and to advocate for better services. There are already a range of parent training models available. Some are based on TEACCH, ABA and some more eclectic. There are problems in organisation, attendance of parents because of child care, waiting lists, and the fact that training sessions are generally based in US and UK.

So far they have conducted a literature review, asking parents in each country what they need. Then came up with 6 modules. These are, 1) Introduction to autism, 2) structure and visual support, 3) sensory sensitivities, 4) communication, 5) social development and interaction, and 5) understanding and managing challenging behaviour.

It’s approximately a 12 hour education programme. So far 2 groups of parents in 3 countries have taken part. It’s delivered during a weekend. There are external trainers. It consists of both lectures and then group activities.

We also have a structured evaluation process. We interview parents. Trainers write a diary when delivering training. There is a trainer focus group at the end. Then a document analysis delivered.

We have quality assurance partners, advisor group (people with autism and professionals), and an external project auditor.

We are active on the website and social media, thanks largely to Cristina. Materials will be translated in languages of the countries involved.

In feedback, some participants said it is a lot of information for 2 days, and that it is better to have 2 hours a week, with a new topic every week.

Pietro asked about the input of people on autism spectrum, and Jasmina pointed out that the advisory group has people on spectrum. Monique pointed out that autistic input remained small. She said that it was positive that the project leader talked about having duos working together - Parents together with autism perspective, and hopes that is being integrated.
Workshop on AE’s mission and priorities

Participants split into 6 groups to discuss what they thought should be AE’s future priorities. They then presented their feedback.

Group 1 feedback

The main aspect should be inclusion. AE should put up something like a charter which could serve as reference for what we understand as “inclusion”. Our main goal should be inclusion everywhere and for everyone. AE could create a framework on its website, information awareness. It is also important to have self-advocate programmes, to encourage adults to find a diagnosis, and help raise awareness around this.

Regarding new technologies and therapies etc, AE should be a reference of what is true and not true. It is difficult to check veracity of information going around, and this should be possible on AE websites.

It would be good to meet more than twice a year. The group said it would help to share ideas, spread good practice etc. It would be nice to have this kind of meeting where we have more workshops. Maybe we could do more of the voting on the internet, and spend more time discussing ideas and doing workshops when we meet up.

Group 2 feedback

- AE should be a fixed reference in Europe for ASC in new digital age and political changes
- training for parents
- sharing knowledge
- systematic investigation in fields and projects in several countries
- to balance participation of parents and people on the ASC (Autism Spectrum Conditions) in accordance to UN giving power only to organizations led by pwd (like Inclusion Europe and others already do since long time)
- statute update for seats reserved to people on the ASC (now only 2 seats reserved on 43 and we'll be 3 in the board by tomorrow)
- statute update for reducing annual fee for organisations led by people on the ASC (statute update for old words too about autism spectrum definition, standards and so on)
- we urge a shift by all AE members from being private service providers to go back to advocacy for human rights policies and public services, otherwise poor families without money in Europe cannot receive anything.
- European epidemiological study

Group 3 feedback

Group three split the mission into two categories: heart, and mind.

- HEART Awareness raising; empower society and people with autism to have the same life quality as those who are typically developing.
- HEART Empowerment! For the individuals.
  - Freedom of movement with society
  - Freedom of movt within countries – European approach to make sure a person with autism has equal/same rights when it comes to healthcare/privileges and tuition.
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- **COGNITIVE** Link to UN Treaty regarding compliancy, to encourage countries to actually follow the principles. MOVE FROM ENCOURAGING TO THE FINE BALANCE BETWEEN COMPLYING/ENFORCING (making it as an integral part of a society change eg. Malta-civil service for new recruits/Catalonia)

**Future**

INTRANET; possibilities of exchange of knowledge/troubleshooting/working together

**Goals**

Encourage local authorities to give the good example using personal connections we each have in our own countries.

Passing on our own passion about autism to others’ outside of the EU and supporting them in their own unique development.

**Mission**

Autism-Europe’s statutory mission is to ensure the desired quality of life of all persons with autism based on the individuals and their families hopes and needs within Europe. Representing our autism society

**Vision**

Everyone has the right to develop, in their own way and at their own speed. It is societies responsibly to help create the environment which supports the person, irrelevant of ability. Understimulation and overstimulation are international problems in every country.

- Make companies socially responsible; get it away from money problems, focus on the ethical responsibility of people wanting to belong, have a quality of life and follow their dreams.

**Challenges**

- Problems of lack of participation of members in AE
- Regulations that are being interpreted in a different way
- UN Treaty: Autism Strategies that are not used because there are no legal/penalties for compliancy.
- Financial challenges of how much it costs in order to get a diagnosis

**Advantages of AE**

- HEART Passion/drive – inspire others by inspiring ourselves. Being honest about what doesn’t go right.
- MIND/COGNITIVE We have an accumulative wealth of experience and information which can be shared if we go from the perspective of the most vulnerable instead of the perspective of ego.
- MULTITUDE OF EXAMPLES OF GOOD PRACTICES TO INSPIRE OTHERS
- MULTITUDE OF EXAMPLES OF WHERE IT DOESN’T GO OK TO INSPIRE OTHERS
• Promoting the concept of an individual care budget which can be used to buy in self chosen professionals where there is a ‘click’ and support individual development.

Group 4 feedback

AE should have a bigger lobbying power in each country to force governments to provide services. Should be a basic role, especially in countries with less support from the government.

AE should be reference point, with a strong stance on vaccinations for example. In Croatia this is becoming a national health problem where people aren’t vaccinating. There is a point where we should state if vaccines cause autism, and if it is civic protocol or not. AE should be a place where parents from all countries will look to hear right and relevant information.

We have so much information from all over the world, but AE should filter that info. The most important information should be on the website.

But AE should have basic roadmaps or guidelines on what countries should provide from the beginning to the end of the life of an autistic person. Each country has specific chances, but we must give them a roadmap. So when we come to our government, we can say “Autism-Europe has explained to us what to do”.

The latest research on autism should be on AE’s website.

Group 5 feedback

• Sharing good practice and information from other countries.
• Lobbying for autistic people.
• Launching complaints against non-compliant governments (as AE did against the French government).
• Solidarity between associations
• All groups should be well represented within AE. Self-advocates and people with high support needs. We should combine and respect the interests of all. Some are afraid that one group could be more represented than others. Professionals also have their place in AE, but parents and self-advocates should have final decision-making power.
• Not to change the statutes as goals already within them.
• Limiting representation to Europe. Due to AE’s funding, our activities should remain mainly Europe, but can sometimes go beyond.
• Number of representatives per country discussed but opinions mixed.
• Avoid research communities communicating between themselves, and research on new practices not getting to the associations. Facilitate link between associations and researchers.

Group 6 feedback

Fostering social inclusion of persons with autism of any level of support needs in all areas of life: education, employment, independent living, etc, taking into account the nature of AE as an EU DPO depending on EU funds, and therefore needing to meet the EU funding programme requirements.
AE Priorities:

- Promote the development and adoption of specific strategy and policy actions for autism at the EU level, addressing the core aspects of autism across the spectrum, including the protection of the most disabled ones that are at higher risk to be refused or discharged by services (because of the high cost of their support needs);
- Develop and adopt ethical principles and approach to autism;
- Promote equal opportunities for persons with autism at the EU level, by developing and adopting EU minimum standards for both mainstream and specific services based, on the specific needs of autism, on ethical principles and on the rights-based approach to autism; since the standardisation of goods and services of general interest is an EU competence;
- Promote the free circulation of persons with autism and their families across the EU, through the shift to service systems for autism that are based on individual plans and individual budgets;
- Promote the recognition of family care-givers’ role for persons with autism, through:
  - The support and services to families of persons with autism to be included within the inclusion policies at the EU level
  - Empowerment actions for family members
  - Conciliation policies between working and family life, including flexibility and reasonable accommodation of working time to be specifically addressed in the forthcoming EU directive.
- Strengthen the networking and information exchange between AE members
- Empower AE members to advocate for the rights of persons with ASD at national level

DE Enigma

Suncica presented the DE Enigma project.

The project starts with the hypothesis that autism makes it harder to understand verbal and non-verbal clues. This can have huge impact on social life and community life. This led to attempts to teach this using humanoid robots. Humanoid robots are seen as being more predictable, less threatening, and more comfortable to communicate with, whereas humans have their subtleties.

The partners in the project would like to build a robot that will be reactive. They hope the robot will help understand children, their choice of words, their gestures, and how these are combined to convey certain meaning. It is then about changing behaviour based on a child’s emotional state.

A video was then shown presenting the project robot, Zeno.

DE Enigma uses an off-the-shelf robot from America. They want to see 128 children use the robot, and observe.

66 of these children have already been observed in Serbia. The last recording sessions happened in London. They observe 5-10 year olds. They are attached to a programme on teaching emotion perception. We will then annotate each recording.

Now technical partners will come up with a machine learning responses, and showing how to see children’s behaviour and how to react. We will have 3 prototypes of the robot. After analysis, we will arrange new games dealing with more than just emotions, but also relying on social skills and putting
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kids in situations, identifying emotions in selves not just others, etc. We will then try to integrate this into a final prototype to support children in everyday situations.

After seeing 66 children in Belgrade, Suncica said she could confidently say they enjoyed it. The programme is useful for them. For some it helped them cope with their own emotions. Many letters and drawing were sent to Zeno the robot.

A lot of attention is being paid to adapt it from verbal to non-verbal kids.

The consortium is made up of 8 universities, then companies, and then finally user group organisations (Autism-Europe, the Serbian Society of Autism and the Centre for Autism within the University College London). The University of Twente are doing the human-robot interaction, then there are technical partners such as Imperial College London, the University of Passau doing audio features, IMAR (Institute of mathematics) working on postures and the analysis of gestures, and then a robotics company in Portugal have to assemble all elements into one small final robot.

Pietro asked if there was also a female robot available, and how much the robot costs.

Suncica replied that the company used to make both male and female robots, but they stopped the female version for reasons unknown to us. It costs 5,500 US dollars.

Omar said that if children enjoy using technology, let’s embrace it. We should also consider the expense of the robot to see how sustainable it is. Unless the robot is kept to a certain price, it has a limit.

Suncica underlined that the project partners are also taking a serious approach to service implementation and how to make it sustainable. We know the cost is a lot, so we are working seriously on this.

Prospective members

Autismo Sevilla

Autismo Sevilla applied to be affiliated member of AE. They presented their activities to AE members.

Pietro asked if on Autismo Sevilla’s board there are only parents or people on the spectrum too. He also asked if they could explain if they are mainly service providers, or lobbying.

Marcos from Autismo Sevilla underlined that they are both service providers and advocacy providers. He explained that it is a family organisation, and the professionals there work for the parent organisations. The leadership is from families in the executive committee. As of yet there is no persons with autism on the executive committee, but they are involved in the ethical committee.

A vote was taken and Autismo Sevilla was accepted unanimously by participants.

Il domani dell’autismo Fondazione

Il domani dell’autismo Fondazione was running for affiliated membership. They presented their activities to AE members.
A vote was taken and participants unanimously voted in favour of welcoming II domain dell’autismo Fondazione

Autism Regions

Autism Regions is a newly-formed Russian organisation, not applying for membership this year, but simply introducing their association.

Russian have long history of prominent organisations. The problem is that they are divided. Members of the association are all from different parts of Russia. There is a huge area, and very spread out, poor public services, and no adults with a diagnosis.

Other thing is development of educational projects, advising and developing autism-friendly settings, such as autism-friendly movie screenings.

Their mission is to defend the rights and dignity of people with autism and their families. They want to develop services based on evidence and build a more tolerant Russian society.

Zsuzsanna concluded the meeting by welcoming the Autism Regions association to apply for membership next year. She thanked all participants in the day’s meeting.