

**Moving Forward for the Adoption of a European Strategy for Autism in Europe
Conference in the European Parliament - Tuesday September 29 2015**



On Tuesday 29 September Autism-Europe held a conference in the European Parliament, following up on the successful Written Declaration on autism. The conference brought together 12 speakers to discuss the need for a European strategy on autism. Among those speaking were Members of the European Parliament, officials from the European Commission, representatives from autism organisations, public authorities and researchers.

The conference was split into several sections, looking first at autism as a human rights and public health issue, focusing next on strategies for autism to address specific needs, and concluding with how treatments can influence the severity of how one's autism affects their life.

AGENDA

9.00 - Introductory panel

MEP Nicola Caputo, first signatory of the Written Declaration on autism

MEP Marek Plura, co-president of the Disability Intergroup and co-signatory of the Written Declaration on autism

MEP Miriam Dalli, co-signatory of the Written Declaration on autism

09.20 – Autism: a human rights and public health issue

09.20 - Anthony Montserrat, DG SANTE, Public health, policy officer

09.35 - Joaquin Fuentes, MD - European Society for Child and Adolescent Psychiatry (ESCAP) Autism Field Advisor: The need for research; evidence-based clinical practice, and transversal policies in supporting the quality of life of European citizens with autism spectrum disorders.

09.50 - Questions and answers session

10.00 - Maria-Luisa Cabral, DG EMPL, head of the Rights of persons with disabilities unit

10.15 - Donata Vivanti, vice-President of European Disability Forum - Promoting the respect of rights of people with autism under the UN Convention on the Rights of people with Disabilities

10.30 - Questions and answers session

10.45 – Strategies for autism to address specific needs

10.45 - Johanna Manikiza, ASD National Strategic Coordinator for Wales – Supporting an Autism Strategy through a national resource

11.00 - Evelyne Friedel, Vice-President of Autism-Europe – The need for a European strategy to better implement the rights of people with autism at the national level, European positions & National plans

11.15 - Questions and answers session

11.15 – Autism: "The severity of Autism depends on the Quality of Treatments offered"

11.15 - Dott.ssa Chiatto Imma (BCBA) & Dott.ssa Cavaliere Laura (BCBA), The right to an effective treatment: the effectiveness of the Applied Behavior Analysis in the treatment of Autism Spectrum Disorders

11.30 - Vincenzo Abate, President of an Autism Association and father of two autistic boys (twins 18 years).

Short video presentation.

11.35 - Questions and answers session

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Introductory Panel

Nicola Caputo MEP

[Nicola Caputo](#) opened the conference by introducing the success of the recent Written Declaration, calling on the European Commission and Member States to adopt a strategy on autism. A more coherent and evidence-based approach to the condition, he said, would be something he and the other 417 co-signatories of the Declaration would fight for throughout this legislature.

Mr Caputo began by thanking the 417 other Members of Parliament who gave their support to the recent Written Declaration on Autism. According to Mr Caputo, in Europe too little has been done on the subject of autism, which is why MEPs are now calling for a concrete action from the Commission and the Council.

Although there is no cure for autism, it has been shown that an early treatment can alleviate the level of dependence of those with Autism Spectrum Disorders (ASD). Mr Caputo then went on to point out that the Written Declaration calls on the European Union and its Member States to adopt a European strategy for autism that will support accurate detection and diagnosis across Europe, promote evidence-based treatment and support for all ages, foster research and prevalence studies and encourage the exchange of best practice.



Marek Plura MEP

[Marek Plura](#) has been heavily involved with the subject of autism throughout his political career. Even before this he worked on the issue in a pedagogical capacity. His wife also works directly with children on the autism spectrum. As MEP Plura pointed out, the strong support for this Written Declaration underlines the fact that it should not be a huge undertaking to convince policy makers of the need for a strategy on autism.



Mr Plura reminded us again of the importance of conducting further research, embarking on prevalence studies for autism, and of sharing best practice regarding support and rehabilitation services for persons with ASD. Furthermore, an eventual European Strategy would be a document for inspiring good standards throughout EU Member States.

In 2013, when he was a Member of the Polish Parliament, a Charter for persons with autism was passed, regulating basic standards such as the right to live independently without fear of discrimination. This was inspired by the European Charter of rights for persons with autism drafted by Autism-Europe and adopted as a Written Declaration of the European Parliament in 1996.

Mr Plura concluded that the difficulty of creating a European strategy is that the costs incurred to accommodate for specific conditions are often deemed unnecessary. Meetings such as this, he pointed out, are important as they focus not only on the difficulty of living with disabilities, but also on the potential and the positive impact that can come from investing in persons with unique conditions.

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Miriam Dalli MEP

[Miriam Dalli](#) has been working and advocating on the issue of autism since the start of her mandate as an MEP. Back in her native country of Malta, she collaborates closely with Maltese NGOs working on autism.

Ms Dalli highlighted the difficulty of speaking about autism when in some people it allows them to live autonomously and to display incredible mental abilities, and in others it prevents them from even being able to speak with their peers or look them in the eye. Indeed, to a large extent the lack of adequate policies surrounding autism stems from a lack of understanding about the condition. One thing that we can agree on, however, is the help of having the condition diagnosed early, focusing on a need among many with autism for routine and repetition in their daily lives, as well as allowing certain room for choice in the therapies on offer according to individual needs, provided they are scientifically proven treatments.



Part one: Autism as a human rights and public health issue

Antoni Montserrat, DG SANTE, Public health, policy officer

Antoni Montserrat is a public health policy officer at the European Commission's DG SANTE. Mr Montserrat began by pointing out that we only currently have EU strategies (by which we understand a legal or policy document initiated by the European Commission and adopted by Member States) for a very limited number of health issues. This is the case for cancer, rare diseases, Alzheimer's and dementia, and mental health. For most conditions an EU strategy does not exist as in general certain Member States do not consider that there is enough space for extra-added value that could derive from working across borders. It is important, Mr Montserrat pointed out, to remember that any EU strategy needs the consensus of the Member States and the European Council, and so it is not enough for the impetus to come from the Commission alone. Thus Mr Montserrat encourages interested stakeholders to take action in their own Member States to strongly advocate for action to be taken at the European level.



It is very important, Mr Montserrat underlined, that the European Parliament is moving forwards with this, as the role for encouraging Member States to take on board a need for a European Strategy cannot come from the Commission, but instead from organisations such as those present at this event, as well as from the European Parliament.

Responsibilities for action on the subject of Autism Spectrum Disorder within the European Commission are shared between [DG RTD](#) (responsible for research), [DG JUST](#) and [DG EMPL](#) (responsible for the social integration aspects), and [DG SANTE](#) (responsible public health aspects). These three pillars combined is what constitutes the European Commission's current intervention in providing support to persons with autism. As far as research is concerned, Mr Montserrat explained that our understanding of autism can be advanced greatly by the research of [EU-AIMS](#), which starts its study of autism from the basis that there are no effective pharmacological treatments for the core symptoms of ASD, and that our understanding of the pathophysiology of the disease is poor. The project, which has the full title European Autism Interventions – a Multi-centre Study for Developing New Medications, has been supported by the Commission since 2013, and is aimed at developing potential treatments. EU AIMS is funded by the largest single grant for autism in the world.

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The public health aspect of autism had been neglected up for a lot of years, and only really became an important part of the Commissions approach as of 2005. In 2005 the Commission launched the project [European Autism Information System \(E AIS\)](#), which produced very important results, one of them being the proposal for validating a harmonised tool for early diagnosis of ASD across Europe. It also produced instruments for the prevalence and financial burden estimates for ASD. After this the Commission also used the European Pact for Mental Health and Wellbeing, adopted in 2008, the only text adopted during an EU presidency (in this case the Slovenian presidency) referring specifically to the case of autism. However its scope was limited to children and only covered very few aspects of their psychological wellbeing. After this the Commission financed and supported the [European Autism Action 2020 Conference](#), organised in Dublin in 2010. Unfortunately the resolution of this important conference did not have any succession in the following years.

In 2013 the Parliament proposed to the Commission an initiative for ASD which was adopted by the Commission. A call for tender was launched and as such it was possible for the Commission to launch a programme called [Autistic Spectrum Disorders in the European Union \(ASDEU\)](#), which started in 2015. ASDEU focuses on conducting prevalence studies, improving mechanisms for the early detection of autism, standardisation of these methods throughout the EU, and recommendations about early diagnosis and intervention. It will also build on and transform the current state-of-the-art approaches we are already seeing across Europe. Finally, there will be an analysis of the current state of wellbeing for adults with ASD, considering diagnosis, medical problems, comorbidities, socioeconomic inequalities, housing and working conditions, psychosocial factors and health care utilisation. It will also look at ageing and the transition into later life for persons with ASD.

Joaquin Fuentes, MD – European Society for Child and Adolescent Psychiatry (ESCAP) Autism Field Advisor

Focusing on the notion of autism being a public health issue, Joaquin Fuentes began his presentation by talking about the current prevalence of autism in society. This, as he demonstrated, is far from clear. In Europe the prevalence rate of autism is commonly believed to be around one in every one hundred individuals. In the USA, in the thirteen states where the prevalence of autism is regularly monitored, the rate in 2010 was shown to be as high as one in every sixty-eight children, and more common in boys than in girls. In South Korea, a prevalence study of 55,000 children aged seven to twelve put the rate at almost one in every thirty-eight children.

This is where the new [Autism Spectrum Disorder in the EU \(ASDEU\)](#) programme comes in. Funded by the European Commission's DG SANTE, The programme will:

- Study the prevalence of autism in twelve countries
- Analyse the economic and social costs of autism
- Develop proposals for early detection programmes
- Train professionals
- Improve understanding of diagnosis, comorbidity and effective care and support for adults and senior citizens with autism
- Propose policies to promote harmonised support for people with ASD across member states



The 2.1€ million programme will coordinate the work of twenty-one teams across fourteen countries, being headed by Manuel Posada, Director of the National Health Institute of Rare Diseases Research in Spain. In its aim of getting a clearer and more evidence-based grasp of just how many children in Europe can be diagnosed with ASD, the programme aims to screen 120.000 children aged seven to nine in twelve European countries, both from specialised institutions and from

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regular schools. This vast study will also extend to eleven more countries, the sample of 16.000 very young children already screened for autism in Spain.

As well as understanding the number of people who have the condition, ASDEU seeks to determine autism's overall disease burden (DALY) and its economic cost to society in different countries and regions throughout Europe. Finally, it will identify areas of good practice with adults in Europe, and establish an "External Reference of Care" to propose a European Public Health Policy. The project will collaborate with EU-AIMS in achieving their research and new medication goals.

A particular emphasis was placed on the need for evidence-based clinical practice in order to develop effective detection, diagnosis, research and treatment. Moreover Dr Fuentes reminded us that the needs of persons with autism should be taken into account and mainstreamed into an array of services to citizens, including education, social services, housing, law and security, health, employment, culture and taxes.

In terms of treatment, he supported an approach that is not based on eminence or belief, but on scientific evidence. We have a full catalogue of international guidelines, informing what to do, what is accepted by different public agencies, and sure ways to treat children with ASD.

Dr Fuentes has been responsible for chairing a European Task Force on autism, established by the European Society of Child Psychiatry Societies, [ESCAP](#). The task force has people from all over Europe that will prepare European autism practice guidelines, position statements, training video-clips and dissemination symposia that will be presented for the first time in Geneva in 2017. This project will last three years, and Dr Fuentes is confident that these national societies from 32 countries will end up having an agreement on autism practice guidelines.

Dr Fuentes finally shared his optimism at the decreasing rate of patients with ASD being offered psychotropic medication in Gipuzkoa, Spain (currently 27% as an average in 17 years) which has come in no small part as a result of social support services. The number of persons with ASD in this Province of the Spanish Basque Country living in psychiatric institutions is less than 0.1%, which means they are now living in the community, ensuring their quality of life.

There are 28 countries in the EU, and we know there are 6.8 million people with Alzheimer's and dementia. But we know that the level of autism is around the same as this, meaning we also have around 6.8 million people on the autism spectrum. Autism does not just affect the person with the condition, but also their families, so the number of those touched by autism is far higher. While we can be glad that there is a European strategy for dementia and Alzheimer's, these conditions start affecting people later on in life, whereas autism is with an individual from early childhood. So while the numbers are the same, the repercussion is not. Autism is therefore a public health issue, and Dr Fuentes called on all present to work together to create a better society for them.

Maria-Luisa Cabral, DG EMPL, head of the Rights of persons with disabilities unit

Ms Cabral presented the human rights perspective on a European Strategy for autism. Ms Cabral reminded us that it is being human that defines you, not your disability or any other characteristic they might have. Irrespective of your condition, you have the right to participate in society just like everyone else. This is one of the reasons that the Commission helps fund disability organisations in the EU. For example, Autism-Europe receives a running costs grant from the Commission, which makes up the largest part of its budget.

When the EU signed up to the [UN Convention on the Rights of Persons with Disabilities](#) in 2010, it committed to put in place conditions for all people to take part fully in the economy and the labour market. All Member States, apart from three, are also signed up to this Convention, so this is an

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objective they share with the EU. The EU recently underwent a very thorough examination by the UN Committee on the Rights of Persons with Disabilities (CRPD) which subsequently produced a set of recommendations on what the EU needs to do better to live up to its commitments¹. Irrespective of one's disability they should have the right to live independently, to be part of the community and to work, and this is where the EU's main area of work is. Unfortunately the situation is far from perfect. There are significant gaps between persons living with disabilities and those without. In employment we talk about 23 percentage points, in education 11 percentage points. Ms Cabral recognised that we must all do better to improve this situation in the EU.

The EU does have specific measures in place such as in employment, where is it prohibited to discriminate on the grounds of disability. In their job an employee also has the right to reasonable accommodation for their specific needs, according to EU law. With autism this might mean having clear and explicit rules in the work place to ensure there is a clear understanding on the part of the employee. This employment directive has been put in Member States' national legislation and the Commission is the in charge of monitoring how well this is being put in place by each country.

Other instruments such as the [European Social Fund](#) helps access to employment. There are 86€ billion dedicated to improving access to employment and benefiting from human capital. 20% of this budget has to be dedicated to the social inclusion of persons with disabilities.

Another essential thing is to be able to access basic goods and services. As most are aware, the European Commission is working on the European Accessibility Act. This directive should be adopted by the end of the year and will establish Europe-wide requirements that will make certain essential goods and services available to the widest group possible. As this directive would also break down national barriers to accessible products, the Commission would thus create a bigger market for them. This was the case in the US, which has very far-reaching accessibility legislation, and this is why for example we now have accessible iphones which use voice-recognition technology.

Ms Cabral concluded by talking about the [European Strategy on Disability \(2010-2020\)](#). The Commission is now mid-way through its implementation and is reviewing its progress. The Commission is running a public consultation and is inviting as many as possible to respond. As well as running a classic EU consultation with NGOs and stakeholders, the Commission will be reaching out to persons that usually do not reply to these types of public consultations, such as those with disabilities themselves. Such individuals can express first-hand if they have seen any improvements in their life since the strategy was put into place.

Donata Vivanti, vice-President of the European Disability Forum

Vice-President of the [European Disability Forum \(EDF\)](#) and member of the council of administration of Autism-Europe, Ms Vivanti spoke to us about promoting the rights of people with autism under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Ms Vivanti began by pointing out that although ASD is not specifically mentioned in the UNCRPD, article 4 of the General Obligations states that "combating discrimination of all persons with disabilities, including those who need a more intense support, is a question of human rights". Ms Vivanti also pointed out that the UNCRPD goes far beyond discrimination issues. Its overall purpose is inclusion, participation and respect for the dignity of persons with disabilities.

¹ Key UNCRPD recommendations listed in Annex

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On the 27th and 28th of August 2015 the European Union was examined by the UN Committee on the Rights of Persons with Disabilities (CRPD), which delivered recommendations on how the EU could strengthen its approach to upholding the rights of those with disabilities in Europe. The EU ratified the UN Convention on the Rights of Persons with Disabilities back in 2010, and was recently called to present its implementation of the Convention to date through the European Strategy on Disability (2010-2020).

Disabled people organisations fed into the recommendations given by the CRPD by participating in a delegation which met with the CRPD in Geneva. The delegation presented in Geneva consisted of the European Disability Forum, [Autism-Europe](#), [Inclusion Europe](#), [European Network of \(Ex\) Users and Survivors of Psychiatry](#), [Mental Health Europe](#), [European Network on Independent Living](#), [CBM / IDDC](#), [European Federation of Hard of Hearing People](#), [International Federation for Spina Bifida and Hydrocephalus](#) and the [European Union of the Deaf](#). Autism-Europe also presented recommendations in the form of its [Alternative Report on the EU's progress](#). Among some of the key suggestions taken on board were the need for more concrete measures to remove the barriers disabled people face when accessing education, healthcare and employment.



Ms Vivanti explained that support is needed for most persons with autism to be able to enjoy a decent quality of life. Lack of support can result in exclusion, dependency and in some cases institutionalisation. The EU has tried to deal with the barriers persons with disabilities face in accessing their basic rights through adopting EU legislations, policies, strategies, programmes and budgets (much of which was underway both before and after the UN CRPD, according to the EU report).

The EU's prerogative to decide on different policy areas depends on the level of competence in that domain that has been attributed to it by the EU treaties. There are three levels of competence: "exclusive competence" where the EU is effectively in charge of making decisions; "shared competence" where the EU institutions and the Member States work side by side; and finally "supporting competence" where it is primarily the Member States who control what happens.

The areas of exclusive competence where the EU can act to reduce the barriers for persons with disabilities are the following:

- Non-discrimination
- Legislation: TFEU Art. 10 and 19 (non-discrimination)
- Policies: European Disability Strategy 2011-2020
- Actions: EU Structural and Investment funds
- standardisation of goods and services including SSGI and habilitation services

The areas of shared competences where the EU must work alongside Member States to remove these barriers are the following:

- Public health policies and health protection
- Mobility and Consumer rights (*TFEU art. 169, Directive 2011*), including accessible information
- Inclusion (*ESIF*)
- Access to Justice (*EU Directive 2012/29 on Victim's protection*)
- Cross boarder mobility (*standardization of SSGI*)
- Employment (*EU Directive 78/2000*)
- Social protection & poverty reduction policies (*EU Strategy*)
- Culture, tourism and sport (*Programme Erasmus*)

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As the lists above show, in areas of protecting the rights of persons with disabilities the EU has considerable room to manoeuvre and make an impact. However, although there were several positive outcomes from the EU's approach to implementing the convention, the CRPD's recommendations show that there is still a lot of progress to be made².

Johanna Manikiza, ASD National Development Lead for Wales

Wales has become a leader in its approach to providing support to persons with autism. In 2008 Wales created its ASD strategic action plan. After an evaluation of the action plan was undertaken in 2014, and an interim delivery plan was launched this year, ahead of the launch of the Refreshed ASD action Plan in 2016. Ms Manikiza had therefore come to present some of the lessons they had learnt in their time implementing the Welsh strategy for autism.



When the programme was launched the team had a good knowledge of the condition, but not of how to fill the gaps in services people with autism often faced. Initially the strategy focused mainly on children but as of 2010, following publication of the Adult task and Finish Group Report further actions for Adults with ASD were implemented.

The outcomes of the action plan to date can be seen in the increase in autism awareness in Wales. Wales has seen an increase in the number of children recorded in schools with three times as many children being registered with autism in Welsh schools now compared to eight years ago this implies an increase in diagnosis amongst children. The prevalence rates of 14 year-olds in Wales, based on the pupil level annual school census, is shown to be 1.4% which means roughly one in seventy-two children. Welsh Ministers have invested in the assessment and diagnosis of children and adults in relation to ASD and work to improve access, quality and quality of information provided is underway.

So where does this successful approach to working with autism stem from? First of all, Ms Manikiza stressed the need for proper infrastructure and supportive funding. Furthermore, she underlined the importance of sharing good practice which goes beyond mere story telling. It is important to have national resources to hand to help implement an action plan, as well as substantial baseline data and outcome measurements to quantify the success of different approaches. The Welsh model also focuses a lot on the running of projects, although Ms Manikiza reminded us to be mindful of issues such as the sustainability of pilot projects, as well as the sensitivity of prioritising certain areas and communities over others. Finally, coordination and liaison is essential as well as providing ways to fill service gaps for persons with ASD.

The ASD Development Team, currently working within the framework of the ASD Interim Delivery Plan, works specifically on the provision of expert advice; liaison and coordination; surveys; consultation activity; scoping of service provision; analysis of training needs and the development of training resources an integrated service model.

The strategy is hosted both by Public Health Wales and the Welsh Local Government Association. As well as providing expert advice to the Welsh government, Local government and health bodies, [the ASD info Wales website](#) offers a large number of resources for professionals and persons with autism as well as parents and carers, including an autism-friendly CV builder for adults with ASD hoping to find their way into employment. The website is also host to a huge array of other practical resources. The development team is also working on a large-scale new project which will provide training for

² Key UNCRPD recommendations listed in Annex

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teachers and support assistants in mainstream primary schools, to help them better accommodate for children on the autism spectrum.

The underlying drive of the Welsh strategy is to focus on the quality of resources, to show people the benefit of supporting individuals with autism, and to treat persons with ASD as equal to others in society.

Evelyne Friedel, Vice-President of Autism-Europe

Evelyne Friedel spoke more specifically about the role that both the European Union and the Council of Europe might play with regards to improving national plans for autism.

It started 20 years ago with a Written Declaration by the European Parliament, at the initiative of Autism-Europe. The purpose of this declaration was twofold. Firstly to show that persons with autism should have the same rights as all other citizens, and secondly that these rights needed to be addressed correctly at the national level. The interaction between the national and international level was thus crucial from the outset.



This Declaration was supported by the Commission as well, stating that appropriate legislation needed to be taken in each Member State. Today, we have this [new Written Declaration on autism](#) which is quite an improvement, asking for a European strategy on autism that looks at accurate detection and diagnosis, research, prevalence studies, best practices, support and habilitation services.

Only few European countries have developed specific autism legislation or national autism plans and strategies. This is the case for Bulgaria, France, Denmark, Hungary, and within the United Kingdom, England, Wales, Northern Ireland and Scotland. All these plans have a legal basis in so far they are provided in a legal act or have been adopted at the initiative of the Government. However, there is particular need for a Europe-wide strategy.

In France, for example, there have been three plans in the last ten years. These plans have been the result of a European impulse. This impulse came specifically from the Council of Europe. It is the result of the collective complaint launched by Autism-Europe resulting in a landmark decision rendered in 2003 by the [European Committee of Social Rights](#). The Council of Europe then pursued its monitoring of the plans adopted by France and adopted in 2009 a general recommendation rendered by the Council of Ministers. Subsequent to a second collective complaint, another decision was rendered in 2013. In addition, a report on the French situation was issued by the European Commissioner for Human Rights.

The case of France shows the need for a continuing international monitoring to ensure that national plans are efficient. It is worth mentioning that the Council of Europe's decisions state issues which should also be raised by the EU. Member States have to adopt the definition of autism retained by the WHO. Member States must also have sufficient statistics to ensure the needs of persons with autism. There should be appropriate care and support facilities for children in education. Member States must take measures under the following criteria: a reasonable time-frame reaching measurable progress. There is a need to focus on what is evidence-based, what is the certainty of effectiveness for persons with autism, rather than losing money for approaches that are not effective.

As a result of the 2003 decision, the national plans adopted by the French government focused on the diagnosis tools under a proper definition of autism, the training of health professionals, the opening new structures, the inclusion of children with autism in mainstream schools and the development of new methods of education.

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The decision rendered in 2013 by the Council of Europe added that even when people with autism are in specialised institutions, the working methods used must be predominantly educative in nature. Many responses given are not educative, especially outside of mainstream education.

The 2015 conclusion of the Commissioner was that the French authorities step up their efforts and need to invest more resources and appropriate support to avoid persons with autism ending into psychiatric institutions instead of work or mainstream education.

Notwithstanding 3 plans, the Council of Europe concluded in its recent reports, in the 2013 decision and in its 2015 Commissioner's report, that France is still not in line with the European Social Charter. People with autism are still not guaranteed access to education. In fact, very few children are in mainstream education.

In France there are around 500,000 people with autism. Around a quarter of these are children and teenagers, which only 17,000 were schooled in 2008, and only 76% of those who were schooled were in mainstream school education.

Regarding the strategy and role which should be retained by the EU, one may underline the following. When a Member State is implementing EU law, the Commission can assess if national law is compliant with the UN Convention on the Rights of Persons with Disabilities. There are many EU laws we can refer to defend rights for persons with disabilities. One example is the employment directive. As far as education is concerned, the Union could contribute to the development of quality education by encouraging cooperation between Member States and by supporting and coordinating their actions. Finally there is room for research projects and comparative studies which can be initiated at the European level, ensuring that there is a common background behind the development of innovative methods.

Imma Chiatto (BCBA) and Laura Cavaliere (BCBA)

Ms Chiatto, a pedagogue and behavioural analyst, and Ms Cavaliere, a psychologist and behaviour analyst, came to speak about the right to effective treatment for persons with autism, focusing specifically on Applied Behaviour Analysis (ABA) as a therapy for persons with ASD.

The pair explained how they believe ABA to be an efficient evidence-based method to treat autism. Applied behavior analysis, they consider, presents a viable means of intervention for adults and children with pervasive developmental disorders. Some literature studies also provide examples of success in teaching individuals considered previously unteachable.



ABA is an applied natural science devoted to developing and analysing procedures which produce effective and beneficial changes in behavior. It is one of the three fields of behavior analysis. The other two are radical behaviourism, or the philosophy of the science; and experimental analysis of behavior, or basic experimental research. ABA is thus defined as the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviours to a meaningful degree. Behaviour analysts focus on the observable relationship of behaviour towards the environment, including antecedents and consequences, without resorting to "hypothetical constructs".

In practice, they explained, ABA requires several different phases. Firstly there is the assessment of the child, understanding which skills he or she already possesses, and where they have deficits. Then

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comes the individualised programme development, training and implementation, and finally the progress monitoring and instructional changes.

It was pointed out that meta-analysis allows us to compare different types of treatment. Tests for children's receptive and expressive language, IQ, and adaptive behaviours showed some promising results for ABA. Earlier intervention was shown to bring about better outcomes, and when parents take part in training the child's learning is better as a consequence.

Vincenzo Abate

Mr Vincenzo Abate presented his organisation [*La Forza Del Silenzio \(The Strength of Silence\)*](#), an organisation working with young people with ASD in the Campania region, Italy. Mr Abate has two sons with autism. *La Forza del Silenzio* was created by Mr Abate due to a need for services for young people with autism in his community. The organisation applies all the methods that were described by the previous speakers, most notably that of ABA.

The organisation recuperated a building which had been confiscated from a criminal gang in the city of Bologna. The building was then refurbished by *La Forza del Silenzio* to provide a safe place for offering training and information classes on therapy techniques, as well as workshops for young people with ASD where they could be supervised by trained professionals. It also serves as a venue for hosting events and important visits.

The centre also organises activities outside of the centre to help the children take part in community activities, and arranges meetings with other organisations specialised in working on other conditions.



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ANNEX

Main concluding observations by the UNCRPD

On Article 5 “Equality and non-discrimination” the CRPD recommended:

- Comprehensive equal treatment legislation
- a duty to provide reasonable accommodation in the areas of social protection, health care, (re)habilitation, education and provision of goods and services.

On Article 7 “Children with disabilities” the CRPD recommended:

- developing support services in local communities for boys and girls with disabilities and their families, including through the use of ESI Funds

On Article 8 “Awareness Raising” the CRPD recommended:

- combatting prejudice against persons with disabilities, and especially persons with psychosocial disabilities and intellectual disabilities.

On Article 12 “Equal recognition before the law” the CRPD recommended:

- ensuring that all persons with disabilities deprived of their legal capacity can exercise all rights enshrined in EU Treaties and EU legislation, such as on access to justice, to goods and services, to employment, and to health care, as well as to consumer and voting rights

On Articles 14 “Liberty & security”, 15 “Freedom from torture”, 16 “Exploitation and abuse”, and 17 “Integrity of the persons” the CRPD recommended:

- taking action to prohibit involuntary detention and treatment, including the disability perspective in EU policy on violence, abuse and exploitation

On Article 18 “Liberty of movement and nationality” the CRPD recommended:

- ensuring that all persons with disabilities and their families can enjoy their right to freedom of movement on an equal basis with others across its Member States

On Article 19 “Living independently and being included in the community” the CRPD recommended:

- developing an approach to guide and foster deinstitutionalisation
- strengthening the monitoring of the use of ESI Funds to ensure they are being used for the development of support services for persons with disabilities in local communities
- suspending, withdrawing and recovering payments if the obligation to respect fundamental rights is breached

On Article 21 “Freedom of expression and opinion, and access to information” the CRPD recommended:

- facilitating access in accessible languages, formats and technologies appropriate to different kinds of disabilities, including easy-to-read formats, for all persons with all types of disabilities

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Conference in the European Parliament - Tuesday September 29 2015**

On Article 23: Respect for home and family the CRPD recommended:

- promoting support to families with persons with disabilities.

On Article 24 “Education” the CRPD recommended:

- taking measures to facilitate access to, and enjoyment of, inclusive quality education for all students with disabilities
- including disability-specific indicators in the Europe 2020 Strategy when pursuing the target on education

On Article 25 “Health” the CRPD recommended:

- taking measures to ensure access to quality health care for all persons with all types of disabilities
- evaluating the impact of Cross-Border Healthcare Directive with regard to gaps in access for persons with disabilities, including accessible information, reasonable accommodation and training of professionals.

On Article 27 “work and employment” the CRPD recommended:

- taking effective actions to measure the employment of persons with disabilities;
- increasing their employment rate in open labour market, especially for persons with intellectual and/or psychosocial disabilities,

On Article 28 “Adequate standard of living and social protection” the CRPD recommended:

- preventing further adverse and retrogressive effect of austerity measures on the adequate standard of living of persons with disabilities.

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