



November 2018

## Welcome to the ASDEU newsletter: our final issue

This newsletter is being sent to you so you can access the key findings of the Autism Spectrum Disorders in the European Union (ASDEU) programme.

This unique three-year programme has now concluded. It has been the most comprehensive clinical and policy autism research ever done in Europe, generating important findings about: the prevalence of autism and its costs; early detection and improved training; and effective support for autistic adults and senior citizens. Our findings are set to influence the development of autism practice and policy across Europe.

We have presented our final report and discussed findings with officials from the European Commission, which managed the programme funded by the European Parliament. In particular, we considered the potential for establishing accurate measures of autism prevalence across Europe, the need for better understanding of autism across autistic people's lifespan – as an eventually aging adult as well as a child – and the vital importance of improved training for professionals, such as teachers, and health and social care workers.

The Commission has acknowledged the vital importance of the work carried out by everyone involved in the programme and share our ambition to ensure it leaves a strong legacy which has a direct impact on the lives of autistic people across Europe.

The programme's most important legacy will be its contribution to the development of future autism research, policy and practice. Through discussions with member states, we are using the ASDEU findings to work towards the inclusion of autism on the agenda of the [Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases](#). To support this, we have placed programme reports and findings on the Steering Group's Europa [best practice portal](#). This also means that ASDEU information can be accessed by academics, practitioners, policy and decision makers across Europe.

As well as its legacy in terms of policy and practice frameworks, the [programme's website](#) will remain online until the end of 2019 as a vital source of information for autistic individuals and their families, as well as for the groups and professionals who provide support. The website includes [the executive summary](#) and summaries of all the [work](#)

support. The website includes [the executive summary](#) and summaries of all the [work programme findings](#).

We want to ensure that we share the wide range of information generated by the programme so please forward this e-newsletter to your colleagues and contacts.

I want to conclude my introduction to this final newsletter by thanking the many wonderful and [expert individuals](#) who led and contributed to the different work packages within the programme.

Many thanks to them – and to all of you who have shared this journey with us and who I hope will benefit from the programme's work in the future.

Manuel Posada  
**Coordinator of the ASDEU programme**

## Prevalence and cost



The ASDEU programme's final estimate of the prevalence of autism across Europe and its related costs will be fundamental to establishing an evidence-based, EU-wide response to the growing societal needs of autistic individuals. It was based on both screening and analysis of data from population registries.

The prevalence of autism in the different countries where the programme's research took place varied widely. Overall, the programme scrutinised 631,619 children, with an average estimated prevalence of 12.2 per 1,000 – one in 89.

**The programme's main recommendations for policy makers about prevalence, the cost of autism and the effectiveness of screening are:**

- Establish population-based registries with the capacity to routinely monitor and oversee larger cohorts of children is the optimal approach to monitor ASD prevalence in Europe.
- More research is needed about the implementation of support and services which meet the specific needs of autistic individuals, taking into account their age, intellectual ability and any other conditions.

**You can find a summary of findings from the different prevalence studies and the cost study on the 'updates' page of the [ASDEU website](#).**

### Early detection and intervention



The ASDEU evaluated screening, diagnosis and treatment strategies for autistic children throughout Europe – finding that there was much room for improvement.

This concluded that diagnosis is still a big problem in Europe, and more resources are needed to facilitate early detection. Also, even though the study identified that professionals were using good early intervention practice, parents are critical of the current situation. They highlighted a lack of resources, access problems depending on where they live, lack of professionals and insufficient training of professionals. Only 30% of families reported occasional active participation and treatment.

**The programme's main recommendation for policy makers about early detection and intervention are:**

A European-wide autism screening programme in young children is feasible, but first long-term assessment of local experiences is required of existing local programmes to provide information on country-wide screening programmes.

**You can link through to a summary of findings from early detection and intervention studies on the 'updates' page of the [ASDEU website](#).**

## Autistic adults





Relatively little is known in the EU and globally about existing services and care for adults on the autism spectrum. Creating a framework to improve services and care for autistic adults in the EU was another ASDEU goal.

In this area, ASDEU began by researching current policies and organisation of services. In particular it identified that there were problematic gaps between good practice guidance and autistic adults' actual experience of support.

**The programme's main recommendation for policy makers about autistic adults are:**

- Develop activities to reduce the gap between recommendations for autistic adult services provision and actual community practices.
- Develop activities to diminish uneven capacities and gaps in autistic adult services provision across different services areas, especially in healthcare and managing the transition from adolescent to adult.
- Implement training programmes about autism for staff in adult services, including healthcare staff.

**You can link through to a summary of findings from the autistic adults studies on the 'updates' page of the [ASDEU website](#).**

## Autism policies in the European Union

This strand of the programme's work by Autism-Europe was reported to the European Commission, with sections detailing autism-specific strategies, legislation and policies in member states in: healthcare, education and access to employment.

The review of existing policy and practice identified, in particular, that successful autism plans and strategies follow a practical approach, based on identifying the specific needs of the people concerned: autistic people, but also families and carers.

**The programme's main recommendation about improving European-wide policy are:**

- Encourage member states to adopt cross-sectoral national strategies or action plans to respond to the needs of autistic people, in line with the United Nation's *Convention on the Rights of Persons with Disabilities* and international recommendations.
- Promote coordination between member states of all policies related to autism.
- Produce guidelines to harmonise practices and promote quality of support and care across Europe.
- Adopt principles of best practice and foster exchange between member states.
- Promote training of professionals across sectors.

**You can link through to summaries outlining findings about existing policies in Member States and a potential EU public health plan on the 'updates' page of the [ASDEU website](#).**

## Key facts about ASDEU

Autism Spectrum Disorders in the European Union (ASDEU) is a three-year programme run by a consortium of 20 groups from 14 countries. It studied the prevalence of autism in 12 countries of the European Union, analysing the economic and social costs of autism, reviewing existing arrangements and developing proposals for early detection programmes, training professionals, validating biomarkers for the disorder, and improving understanding of diagnosis, comorbidity, and effective care and support for adults and senior citizens with autism.

We submitted our final proposals to the European Commission based on the best scientific evidence of what will achieve the optimum results.

**You can find a full list of the eight programme work packages and the people leading them on [the ASDEU website](#).**

The ASDEU consortium associated partners are:

- **Programme lead: Institute of Rare Diseases Research (IIER), Instituto de Salud Carlos III (ISCIII), Spain**
- **Medical University of Vienna, Austria**
- **Autism-Europe, Belgium**
- **Ghent University, Belgium**
- **Bulgarian Association for Promotion of Education and Science, Bulgaria**
- **Aarhus University, Denmark**
- **University of Oulu, Finland**
- **University Toulouse 2 Jean Jaurès UT2J, France**
- **The State Diagnostic and Counselling Centre, Iceland**
- **The IRCCS Stella Maris Foundation, Italy**
- **Instituto Nacional de Saúde Doutor Ricardo Jorge, Portugal**
- **University of Warsaw, Poland**
- **Dublin City University, Republic of Ireland**
- **Victor Babes National Institute of Pathology, Romania**
- **Fundación Canaria para el Avance de la Biomedicina y la Biotecnología, Canary Islands, Spain**
- **Fundación Española para la Cooperación Internacional, Salud y Política Social, Spain**
- **Universidad de Salamanca, Spain**
- **London School of Economics and Political Science, United Kingdom**
- **King's College London, United Kingdom**
- **The National Autistic Society, United Kingdom**

Collaborating partners:

- **Istituto Superiore di Sanità, Italy**
- **Policlínica Gipuzkoa, Spain**

**ASDEU and EU-AIMS**

The ASDEU programme also liaised with [EU-AIMS](#) – a public-private consortium supported by the Innovative Medicines Initiative (IMI) aimed at developing new pharmaceutical interventions around autism.

**You can find out more about [ASDEU](#) and [EU-AIMs](#) on the [ASDEU website](#).**

## About this newsletter

Six issues of this newsletter have been produced over the course of the programme to keep interested professionals and others up-to-date with the ASDEU programme as findings emerged. It has been distributed by each of the ASDEU partners (see Key Facts above).

## About the newsletter's designer



Flynn Hagerty is from San Francisco, California and moved to the UK nearly a decade ago. He is autistic and has been working as a Senior Digital Editor for the National Autistic Society for over four years. In addition to his native English, he speaks intermediate French and a good Dutch. Illustrating the marvel of pan-European cooperation, he once inadvertently jumbled all three languages into one sentence when trying to order a beer in Belgium, but was successfully served.

## Our partners



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