



January 2018

## Welcome to the ASDEU quarterly newsletter

This e-newsletter is being sent to you as the Autism Spectrum Disorders in Europe (ASDEU) programme reaches its final stages. The conclusion of this unique three-year programme will be marked by a conference in Madrid on 29 and 30 January, where an invited audience of politicians, policy makers and other influencers will hear about the programme's findings and discuss them with the ASDEU's consortium of 20 groups from 14 countries.

The next and final ASDEU e-newsletter will outline the findings and discussions at the conference. Most importantly, it will set out how the ASDEU programme is set to influence the development of autism practice and policy across Europe.

This newsletter links you to summaries of progress and early findings, where these are available, covering investigations into: the prevalence of autism and its costs; early detection and improved training; effective support for autistic adults and senior citizens; and the development of EU-wide policies on autism.

Please forward this e-newsletter to colleagues, autistic individuals and their families, and the groups and professionals who provide support. We want to ensure that we share the range of information generated at every stage of the ASDEU programme with the wider communities concerned with improving understanding of autism.

Many thanks

Manuel Posada  
**Coordinator of the ASDEU programme**

### Prevalence and cost

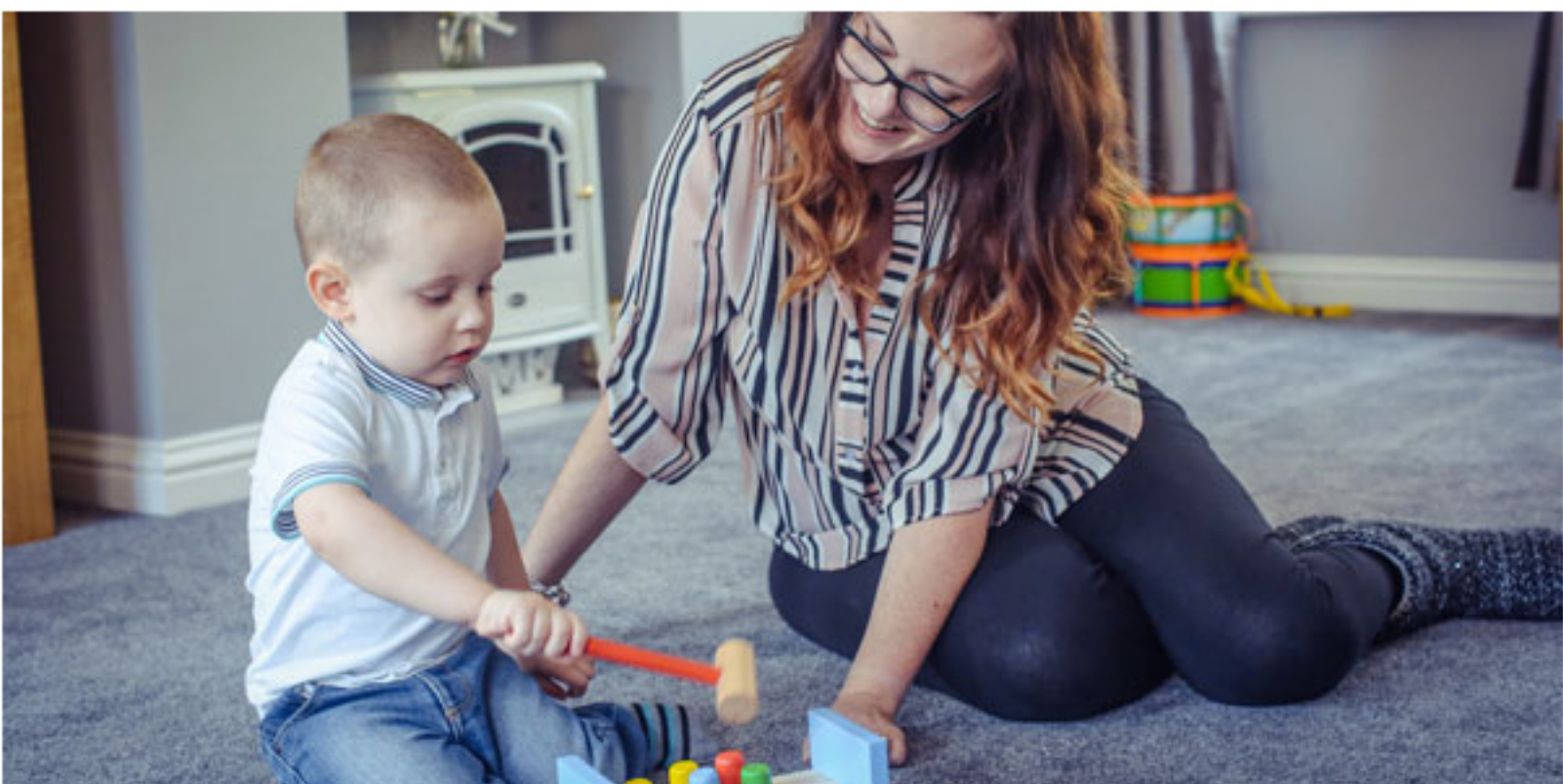
The ASDEU programme's final estimate of the prevalence of autism across Europe and its related costs will be fundamental to establishing an evidence-based, EU-wide response to the growing societal needs of autistic individuals.

#### Next steps:

Final reports on the prevalence, social and economic cost studies will be presented at the ASDEU conference in Madrid, uploaded on the ASDEU website and reported in the next newsletter.

You can link through to summaries outlining progress from the different prevalence studies and the cost study on the 'updates' page of the [ASDEU website](#).

### Early detection and intervention



The ASDEU is finding the information that will help families, professionals and policy makers to identify good practice in programmes for early detection, diagnosis, and intervention with children on the autism spectrum. This is being fed into guidance and training modules.

#### Next steps:

The final results will be presented at the Madrid conference, uploaded on the ASDEU website and reported in the next newsletter.

You can link through to summaries outlining progress on 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 and the readiness of communities to provide for them. The objective of the studies in this area of the programme was to create a comprehensive framework to improve support and interventions for autistic adults by adopting an adult lifespan perspective.

#### Next steps:

The final report will be presented at the Madrid conference and will summarise key findings. The limitations of the data – for example, that the survey results were derived from a convenience sample and not based on a scientific sampling frame - will be discussed. The conclusions and recommendations will serve as a guide for designing future studies addressing specific topic areas in autistic adult services.

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

### Autism policies in the European Union

Autism-Europe is responsible for this work which aims to assess existing social and health policies in EU Member States to support autistic people of all ages and in all communities, as well as their families. From this assessment it has developed recommendations for an EU public health plan addressing autism.

Having a public health policy at the EU-level would help address EU-wide challenges in relation to access to diagnosis and evidence-based interventions, as well as general healthcare. Additionally, promoting the health and well-being of autistic people requires a cross-sectoral approach to autism, including non-health public policy areas.

#### Next steps:

Autism-Europe's findings and recommendations relating to autism policies and a potential public health plan will be discussed at the Madrid conference, uploaded on the ASDEU website and reported in the next newsletter.

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](#).

### ASDEU and EU-AIMS

The ASDEU programme liaises 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.

### Key facts about ASDEU

Autism Spectrum Disorders in Europe (ASDEU) is a three-year programme run by a consortium of 20 groups from 14 countries. It is studying 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 will be submitting our final proposals to the European Commission based on the best scientific evidence of what will achieve the optimum results. All our results will be presented in a final European conference at the end of the project in Madrid from 29-30 January 2018.

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
- Policlinica Gipuzkoa, Spain

### About this newsletter

Six issues of this newsletter are being produced over the course of the programme to keep interested professionals and others up-to-date with the ASDEU programme as its work takes shape and findings emerge. It is distributed by each of the ASDEU partners (see Key Facts above), and **you can also sign up to the newsletter on the [ASDEU website](#)**.

### About the newsletter's designer



Flynn Hagerty is from San Francisco, California and moved to the UK over a decade ago. He is autistic and has been working as a Senior Content 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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