

Welcome to the ASDEU quarterly newsletter [Click here to view online version](#)



February 2016

Welcome to the ASDEU quarterly newsletter



Welcome to the first issue of the ASDEU newsletter, where we aim to update professional colleagues, autistic individuals, families and others about the ASDEU programme and how it aims to contribute to a better understanding of autism spectrum disorder (ASD) in Europe.

The ASDEU programme will address many of the gaps in our understanding concerning some of the most important current questions about ASD, such as estimating prevalence, identifying the best early detection and intervention strategies and the problems faced by those with ASD as they get older, from adolescence and into

old age.

The ASDEU programme is challenging because, for the first time, experts from across a variety of fields have joined under the same banner to explore these important subjects for those affected by ASD. As ASDEU partners we will be working together, alongside other programmes such as EU-AIMS and Autism-Europe, to develop the best policy proposals, which will underpin positive health and social well being outcomes for all people with ASD and their families.

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 during early 2018.

Finally, the ASDEU programme aims to encourage professionals, people with ASD, families and organisations to collaborate and contribute to the focus groups and surveys we are running. We look forward to working with all of our partners and the wider autism community to achieve fantastic results for those we support, and I look forward to hearing from all of your organisations.

Manuel Posada
Coordinator of the ASDEU programme

Prevalence

ASDEU highlights in 2015

The first key area of work within the ASDEU programme is around calculations of prevalence and the social and economic costs of ASD. Both are essential if the right services are to be provided for autistic individuals and families and to ensure trends across time and geographical areas can be effectively tracked. The ASDEU programme represents the first time that European countries have joined together on this scale to provide prevalence data.

Twelve European countries are involved in the challenging task of assessing prevalence. Four of them are basing their data on comprehensive registries or national information systems that collate data about all people with an ASD diagnosis. The other countries are developing a standardised assessment method, to be agreed by the ASDEU consortium. This will be used to explore ASD prevalence in all schools – both mainstream and special needs - in specific geographical areas within each participating country. The general method is currently being prepared and adapted to the socio-cultural situation in each country.

Two different methods are being designed to assess the social costs and the cost to families of ASD. The involvement and contribution of parents and experts will be essential and surveys are ready to be launched soon through [the ASDEU website](#).

Coming up in 2016

This work is in its early exploratory stages, and all studies will be finished between the end of 2016 and the beginning of 2017 year. The consultative survey and updates will be published on [the ASDEU website](#) and in the next issue of this newsletter.

Because issues of prevalence and cost are so central to developing policies and the right level of service to meet needs, it is vital that health, social and education authorities, as well as stakeholders, support this study in each of countries involved.

Early detection and intervention

ASDEU highlights in 2015

After prevalence, a key area of work aims to establish recommendations on procedures for early detection and early intervention, and propose training modules for professionals and stakeholders. So far systematic reviews have been initiated with a focus on early detection, biomarkers, and early intervention. Work has already started through focus groups to discover the perspectives of families and professionals.

Coming up in 2016

The exploratory work will be used to develop surveys for professionals and families, which will make it possible to formulate concrete proposals to improve existing resources, in order to ensure that all those affected by ASD can access effective early intervention. We will also be able to develop novel training for professionals at every level, raising awareness of early signs of autism as well as teaching objectives and methods for intervention.

Interventions with adults



ASDEU highlights in 2015

The ASDEU programme will be creating a framework for improving treatment and care for adults with autism in the EU. The focus is on five areas: multidisciplinary approaches to services and treatment, management of comorbidity, access to diagnosis and post-diagnostic support, transitions during adult life and care for the autistic elder. This work is in its early stages and has so far focused on getting a better understanding of the structure and availability of services in the five areas via literature searches and key informant contacts.

Coming up in 2016

Based on the results of the adult services information searches, surveys are being developed for distribution in the coming year. The surveys are intended to collect information on current local care practice for autistic adults, examples of local best practice, suggestions for improvements in existing care strategies and perceived gaps in care strategies and provision. One version of the survey will be for experts and service providers and a second version will be for autistic adults, their families and caregivers.

We hope this work will shed new light on the state of services and care, reveal gaps in service provision, as well as highlighting good practice already in place. By documenting what is being done and what is known across these study sites, and in reference to recommended standards of care, we hope to be able to provide guidance for policy makers and service providers on what service areas need improvement and on the strategies for achieving improvement in adult autistic care.

Social policy



Antoni Montserrat and Dr Joaquin Fuentes at the Autism Europe conference on the Written Declaration on Autism

ASDEU highlights in 2015

Members of the European Parliament officially adopted *The Written Declaration on Autism* on September 2015, which was actively supported by Autism-Europe and many ASDEU partners. The declaration calls for the adoption of a European strategy for autism which will facilitate accurate detection and diagnosis, promote evidence-based treatment and support for all ages, foster research, and encourage the exchange of ideas across member states. Following the adoption of the declaration a conference organised by Autism-Europe was held in the European Parliament in Brussels, in September 2015. The conference, entitled 'Moving forward for the adoption of a European Strategy for Autism', featured a presentation of the ASDEU project by Dr Joaquin Fuentes (scientific advisor to ASDEU) and Antoni Montserrat (DG SANTE).

Coming up in 2016



Autism-Europe's 11th International Congress is approaching, and will be held in Edinburgh in September 2016, providing the setting for a consultation with European stakeholders on the ASDEU project's activities. The Congress will welcome 1,200 researchers and professionals in the field of autism, as well as parents of autistic children and self-advocates. The Congress will include a symposium on European policies, which will focus on the ASDEU collaboration with the **EU-AIMS research project**. The ASDEU mid-programme meeting will also be held in

Edinburgh, ahead of the Congress.

Autism-Europe will also be producing a report outlining and assessing health, education and social policies in Member States of the EU which support people with autism of all ages, as well as their families and communities. Autism-Europe will use this report to develop a public plan to improve the available support for people with autism in EU Member States.

Autistic people and other interested stakeholders can contribute directly to Autism Europe's research by filling out a short [online ASDEU survey](#). All individuals and organisations are invited to respond in order to help ensure a detailed account of support infrastructures in all countries and regions. The survey is available in 15 languages.

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 will: study the prevalence of autism in 12 countries of the European Union; analyse the economic and social costs of autism; review existing arrangements and develop proposals for early detection programmes; train professionals; validate biomarkers for the disorder; and improve understanding of diagnosis, comorbidity, and effective care and support for adults and senior citizens with autism.

You can find a full list of the eight programme work packages and the people leading them here 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

About this newsletter



Four issues of this newsletter will be 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 editor



Chris Pike is 22 years old, from the United Kingdom, and is proudly autistic and proudly European. He currently works for The National Autistic Society as well as for an equality and human rights charity in London.

Our partners



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