



December 2016

Welcome to the ASDEU quarterly newsletter



Welcome to the second issue of the ASDEU newsletter, where you can catch up with our progress on this unique Europe-wide programme as it reaches its halfway point. The newsletter aims to update professional colleagues, autistic individuals, families and others about the ASDEU programme and how it will contribute to a better understanding of autism spectrum disorder (ASD) in Europe.

The ASDEU programme partners welcome contributions from everyone with an interest in autism and the next issue of the newsletter will come out in January 2017, and will be a 'survey special'. This will link readers to the questionnaires gathering data to support this comprehensive exploration of autism.

This newsletter provides a chance to find out in brief what each area of the programme has done and discovered to date, after the programme partners got together at the XI Autism European Congress in Edinburgh in September. [More detailed updates are on the ASDEU website.](#)

We are already learning a great deal about autism prevalence, practice and policies through this powerful collaborative programme: it is set to leave an important legacy for the European Union and individual member states. We hope that you will find the newsletter of interest and look forward with us to the next half of the programme, as the different strands of work start reporting in earnest on their findings.

Manuel Posada
Coordinator of the ASDEU programme

Prevalence and cost

The studies considering prevalence fall into two types: those identifying children on the autism spectrum aged 7 to 9 in schools; and those using existing registries of children of the same ages with an autism diagnosis. There is also related research looking at the costs associated with an autism diagnosis.

The school-based prevalence studies are taking place across 23 areas in eight different countries. The findings will emerge in the second half of the programme, but studies have already screened over 13,000 children and 2,035 have been nominated as potentially on the autism spectrum, with some preliminary prevalence results from Bulgaria, Romania and Italy. You can see updates from each of the prevalence studies on [the ASDEU website](#).

The studies assessing prevalence using population registries which include data on children with an autism diagnosis, are being carried out in two areas in France and nation-wide in Iceland, Denmark and Finland.

The programme is already establishing its legacy. New autism diagnosis expert teams established in Bulgaria, Poland and Austria and the teacher nomination and social communication questionnaires have been translated into eight languages.

Next steps:

The population-based studies will start generating their results in the coming months and school-based studies will be completing screening and evaluating and validating their initial screening results.

The questionnaires to gather data about costs will be launched shortly. You'll be able to access the questionnaire from January's 'Survey Special' issue of this newsletter.

You can find out more about progress from the different prevalence studies in a PDF from [the ASDEU website](#).

Early detection and intervention

The main objective of ASDEU's work in this area is to create guidance on early screening, diagnosis and intervention. This is being explored in two main strands: the first is examining the effectiveness of screening, diagnosis and early intervention; and the second that of non-genetic biological markers and non-social behavioural features for autism.

Both strands have systematically reviewed thousands of articles, and fully analysed key studies, which form the basis of more detailed investigation via focus groups and questionnaires for professionals and families.

Exploration of existing studies around diagnosis and follow-up focus groups have already identified that: there needs to be greater coordination between clinical and research expertise in planning screening and diagnostic programmes, professionals want more training, and families want more support around diagnosis – particularly away from urban centres.

In terms of non-genetic markers that could potentially support early diagnosis and intervention in the future, some of the more promising biomarkers identified are: larger total brain volume, brain function and electrophysiology, and immune function deficiency. The most promising non-social behavioural features are: motor functioning and repetitive/stereotyped behaviour.

Next steps:

The online surveys of professionals about biomarkers, screening and early intervention will be available from the January issue of this newsletter. Responses will be analysed in March 2017, with the final report in preparation from May.

You can find out more about progress from the early intervention studies in a PDF on [the ASDEU website](#).

Autistic adults



Professor Diana Schendel of Aarhus University, Denmark, is leading the studies into prevalence in Denmark and adult treatment and care.

There is relatively little known in the European Union, or globally, about existing services and care for autistic adults or about the readiness of communities to provide for them. The objective of this area of ASDEU's work is to create a framework for improving services and care for autistic adults.

Through analysing information about service provision in seven sites and through literature reviews, the study has already confirmed how underdeveloped the research base about services for autistic adults is. From analysing site-specific reports, it has identified that private organisations (including charitable and not-for-profit) are the main providers of services, although the balance in the split of public/private provision varies between and within countries. Within countries, there's also a wide variation in the range of services available and those that exist tend to cluster in large urban areas. There are also early indications there may be limited development and specialisation among services offered by the non-public sector.

Next steps:

Surveys on knowledge and experiences with adult services and care practices for autistic adults, caregivers and professionals are being finalised. The English versions will be available via the January issue of this newsletter. Other language versions will be launched as they become available. Preliminary survey results will be analysed from February 2017, and the final report should be prepared by August.

You can find out more about progress from the autistic adults studies in a PDF on [the ASDEU website](#).

Autism policies in the European Union



Zsuzsanna Szilvassy, President of Autism-Europe, with Mark McDonald MSP, Minister for Childcare and Early Years, and Mark Lever, Chief Executive of The National Autistic Society, at the XI Autism-Europe International Congress in Edinburgh.

Autism-Europe completed a comprehensive literature review of autism-specific and autism-related policies and legislation in place throughout the EU. A related survey was made available in 15 languages, with responses from over 900 people, representing every EU member state. The findings of the survey were also explored through stakeholder consultation in May 2016, with 50 representatives from European autism associations.

Some of the key tendencies observed in autism-related policies were: the uneven response to the needs of autistic people throughout Europe, slow but gradual deinstitutionalisation, and measures for employment taking shape, although implementation is still unsatisfactory.

Several common challenges were identified: late or inadequate diagnosis, social exclusion and lack of awareness, lack of implementation of existing legislation and the need for better training for professionals.

Over the last decade, some countries and regions have adopted autism-specific policies, which vary from single policies to all-encompassing national autism plans or strategies. The study has identified that successful autism strategies have a practical approach, are designed in close partnership with autism organisations, and generally after public consultation. They also have the flexibility to allow for revision without resorting to formal processes.

Next steps:

The results of this mapping exercise will feed into draft recommendations for a European public health plan for autism. Autism-Europe will then carry out further consultation with a wide range of key stakeholders, to establish final recommendations to present to the European Commission and national decision makers at the final ASDEU conference.

You can find out more about progress about autism policies in a PDF on [the ASDEU website](#).

ASDEU and EU-AIMS

The ASDEU programme liaises with the EU-AIMS – part of the Innovative Medicines Initiative private/public funding partnership – which is doing pre-clinical research on potential pharmaceutical interventions around autism. Many ASDEU partners are part of the EU-AIMS extensive clinical network and co-ordination between the two programmes supports sharing of relevant data and tools, dissemination and communications. You can find out more about coordination between the two programmes by [downloading a PDF document from 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 towards the end of 2017 or in early 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
- Policlínica Gipuzkoa, Spain

About this newsletter

Four 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 nearly a decade ago. He is autistic and has been working as a Senior Content Editor for The National Autistic Society for over three 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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