



July 2017

Welcome to the ASDEU quarterly newsletter: the programme progress issue

This issue of the newsletter updates you about our progress before we start collating findings from across this unique programme, which brings together experts from across Europe to fill in the gaps in our understanding of autism spectrum disorder (ASD). The final findings from the programme will be presented in a major conference in Madrid in early 2018, as well as reported through the newsletter and on [the ASDEU website](#).

The last issue of our newsletter in January was a survey special – linking professionals, autistic people and families to a range of questionnaires. These surveys are a key part of our efforts to encourage as many people as possible to contribute to ASDEU's programme to increase understanding of autism in Europe.

My colleagues in the programme and I would like to thank everyone who has shared the surveys or completed a survey. So far we've had surveys completed by 4,632 people from 18 European countries, as well as by others from beyond Europe. There is more information about the surveys and responses in the detailed updates about the different areas of the programme's work below.

[The surveys remain open on the ASDEU website](#) until the end of October and we would encourage everyone reading this newsletter to complete the surveys if you haven't already done so, and to share the link with your networks.

Many thanks

Manuel Posada
Coordinator of the ASDEU programme

Prevalence and costs

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.

The studies considering prevalence in our project fall into two types: field studies in eight countries 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.

The field studies identify children using, broadly, a three-stage process: teachers identify children who they think may have autism using Teacher Nomination Forms (TNF); parents are asked to complete a Social Communication Questionnaire about their children; and finally, those children are screened using established clinical protocols.

The school participation rate shows a mean of 60.8%. The parental participation rate is even higher, ranging from 40% to 100%. A total of **39,324** school children have been involved in the process so far in seven countries. As well as establishing prevalence figures, by going through a three-stage process, the studies are also allowing the programme to evaluate the relative accuracy of teachers', parents' and clinicians' identification of ASD in children.

In those countries where population registries include data on children with an autism diagnosis, data collection is relatively straightforward and already in hand or in preparation. These will cover two areas in France and nationwide in Iceland, Denmark and Finland.

The programme is also gathering data on the costs of living with ASD using questionnaires for autistic people and their families. So far there are results from 12 countries, as well as feedback from partners across Europe about the potential unit costs of a screening programme.

Next steps:

The analysis of the outcomes of both prevalence and cost studies will take place in the coming months. Final reports will be presented at the ASDEU conference in Madrid in early 2018.

You can find out more about progress from the different [prevalence studies](#) and the [cost study](#) on the ASDEU website.

Early detection and intervention

The ASDEU is identifying 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 will be fed into guidance and training modules.

In the past months, as well as reviewing published information, the programme has been consulting with parents of autistic children and with professionals, through focus groups and surveys. Up to now, more than a thousand European families have contributed their experiences and opinions.

Our preliminary analysis of the scientific literature indicates that in both Comprehensive Treatment Models – such as ESDM, TEACCH, LEAP, PACT – and interventions focused on specific difficulties, high intensity interventions, intervention duration, and parent involvement seem to play an important role in positive outcomes.

The results from the focus groups indicate the importance of: more information for and collaboration with families; more universal access to diagnosis and interventions – regardless of economic status or location; and the importance of institutions supporting training for professionals in early detection and diagnosis.

Next steps:

Results from the surveys and literature reviews are being analysed and reports will be drafted and circulated to partners in the coming months. There will be updates outlining these results in the next issue of this newsletter and the final results will be presented at the Madrid conference.

You can find out more about progress from the [early intervention studies](#) on 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.

To achieve a better understanding of services for autistic adults in the EU, a survey on knowledge about and experiences with services and care practices for adults was announced in February 2017. The survey was developed in versions for adults on the autism spectrum, caregivers of autistic adults, and professionals providing services for autistic adults.

The survey is now available in eight languages (English, Danish, Spanish, German, Italian, Polish, Icelandic and French); Romanian, Finnish and Portuguese language versions will be available soon. The survey asks about the respondent's background; general knowledge of autism services; awareness of autism in the workplace (only the professional version); diagnosis and medical services; non-medical services (residential, employment, educational, financial, social); services during major life transitions such as from adolescent to adult services; and services for elders with autism.

The response rates increased markedly after the surveys were announced by large autism advocacy organisations for autistic people, their families and professionals in a variety of different media, such as Facebook. The response rates also increased where it was possible to tailor the invitation to the organisation, for instance ensuring the organisation only had to deal with one survey, or encouraging them to make an individual approach to a few people, rather than a blanket approach. Finally, response rates increased when both a personal link (requiring an email address) and a general link (no email address required) were made available. To date, 600 respondents from 21 countries have participated in the surveys.

Next steps:

Analysis of the survey results will begin in the autumn for preparation of the draft final report by November 2017. Analyses will focus on overall responses by type of respondent in each topic area, as well as by the characteristics of the respondents, such as their country. The final report will also include results of information searches that the sites conducted prior to the launch of the survey.

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

Autism policies in the European Union



Delegates at the Autism-Europe Annual General Assembly, held in May 2017 at Zagreb (Croatia)

Autism-Europe is responsible for this work and has elaborated on its literature review and report about existing autism policies throughout the EU. Further consultation with stakeholders in key national ministries and civil society groups has been undertaken to verify the findings in the report.

Autism-Europe has also begun the consultation process to draft the foreseen proposal for a public health plan addressing the needs of the autism community to be submitted to the European Commission and European decision-makers. With the help of its members across Europe, Autism-Europe is currently identifying experts and specialists to assist in jointly pooling knowledge and experience to support the development of this EU public health plan. The results of the various ASDEU surveys will also feed into the future plan.

Next steps:

The literature review of policies will be concluded, incorporating the latest feedback.

Further rounds of consultation with relevant stakeholders across Europe will support the drafting of the proposal for a public health plan for autism.

You can find out more about progress with [autism policies](#) on 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.

Activities have included tailored communications being sent out to around 40 clinical and research centres in 10 different European countries, encouraging them to complete the ASDEU surveys in order to ensure they reach a wide audience of autistic individuals, parents and clinicians. And, in the other direction, invitations to EU-AIMS' webinars were distributed across ASDEU programme partners.

Furthermore, database procedures of the EU-AIMS data pooling initiative were aligned with the ASDEU prevalence study database to allow comprehensive capture, co-ordination and standardisation of information by sharing protocols, core clinical measures, and discussing future database access.

You can find out more about progress 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 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

Five 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



Please do not reply to this email.

If you no longer wish to receive emails from The National Autistic Society or wish to choose the types of email we send to you, please click here: [Want to unsubscribe or change your details?](#)

You can resubscribe at any time by visiting [our website](#) to register your details, or, if you already have an account with us, you can [sign in to our website](#) and change your contact preferences.

[View our privacy policy.](#)

© 2017 The National Autistic Society, 393 City Road, London EC1V 1NG, United Kingdom, VAT registration number: 653370050; registered as a charity in England and Wales (269425) and in Scotland (SC039427).