

# asdeu

Autism Spectrum Disorders  
in the European Union



## **Autism Spectrum Disorders in the European Union (ASDEU)**

**ASDEU is a pilot project funded by the European Parliament and  
managed by the European Commission**

**Action scheme: Call for tender n° SANCO/2014/C2/035**

**Executive summary**

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**Project website: <http://asdeu.eu>**

## Introduction

Autism Spectrum Disorders in Europe (ASDEU) was a three-year (2015-2018) programme funded by the European Parliament to research autism prevalence, costs, diagnosis and interventions throughout Europe. Its overall aim was to find ways to improve care and support for people with the condition and their families.

It is the most comprehensive clinical and policy autism spectrum disorder (ASD) research ever done in Europe, generating important findings that will impact the development of future policies both within European Union (EU) member states and at the European Commission level. ASDEU is also the first multi-national prevalence study of ASD in Europe.

ASD research has risen dramatically in recent decades in the UK and USA, but at much lower levels in the EU. The United Nations and World Health Organization's acknowledgment that ASD is an emerging public health issue demanded an immediate and organised EU response – which ASDEU provided.

Conducted by a network of 22 groups from 14 European countries, ASDEU serves as a foundation for future investigation into ASD, with information-sharing across the network increasing efficiency and cost-effectiveness.

Specifically, ASDEU aimed to:

1. provide an ASD prevalence for Europe
2. estimate the economic costs of autism, ASD disease burden across Europe, and costs of early detection programmes
3. gather information about and make recommendations to improve diagnosis, early detection and intervention, and treatment for children
4. create a framework to improve services and care for autistic adults

5. review autism policies in all European countries and come up with recommendations for an EU public health plan to support member states to respond to the needs of autistic people and their families.

This summary highlights ASDEU's main findings in these five areas, accompanied by recommendations for policy-makers.

You can read comprehensive details about methods and results in the project's full final report at <http://asdeu.eu>.

## **ASDEU key findings and recommendations for policy-makers**

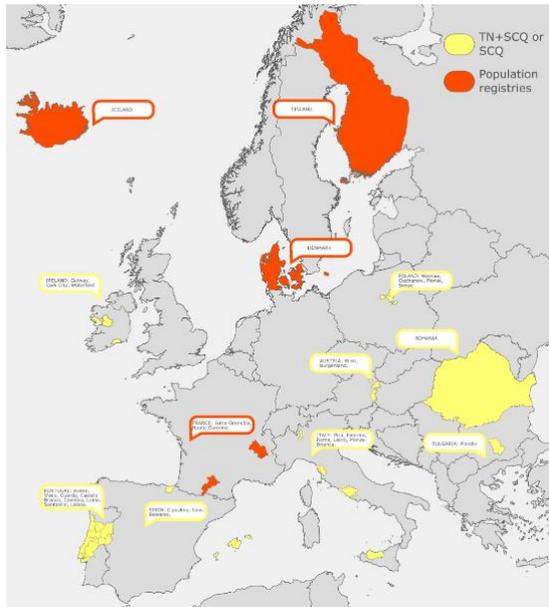
### **1. ASD prevalence**

The first key aim of ASDEU was to provide an estimate of ASD prevalence in Europe. The programme also sought to test and identify the best method to implement an ASD surveillance programme in Europe, which could provide standardised prevalence estimations.

The programme scrutinised 631,619 children, with an average estimated prevalence of 12.2 per 1,000 (one in 89) children aged 7-9 years. Overall ASD prevalence estimates varied among European countries, from 4.4 - 19.7 (percentiles 10 and 90) per 1,000 aged 7-9 years.

ASDEU tested three methods to estimate ASD prevalence: i) screening in two phases – teachers nominating children via a form, then a parent questionnaire ii) screening in a single phase with parent questionnaire only and iii) looking at data from national registries. In total the three methods were tested in 23 regions in 12 European countries.

**Figure 1: European areas involved in the ASD prevalence study**



*TNF: Teacher nomination form*  
*SCQ: Social communication questionnaire for parents*

A large amount of data was collected and individual site studies need to be analysed carefully. At present the best ASDEU recommendation on ASD prevalence is that building population-based registries with the capacity to routinely monitor and oversee larger cohorts of children is the optimal way to monitor ASD prevalence in Europe.

**ASD prevalence: Recommendation for policy-makers**

Establishing 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.

## 2. ASD burden

Another of ASDEU’s key aims was to estimate the health and economic burden of ASD. This is useful to work out what people with the condition need, and to assess the impact of future policies and interventions.

Findings included:

- **Health burden of ASD:** ASDEU estimated this in terms of disability-adjusted life years (DALYs) – years of life lost due to premature death and years lived in disability. Our results showed that total DALYs for ASD in the 14 European countries

participating in ASDEU are 207,771, (153,153 DALYs for males and 54,618 for females).

- **Costs of ASD:** To estimate the costs of ASD, ASDEU conducted an anonymous online survey for children and adults with the condition, collecting individual data on resources and costs. Estimations of direct costs ranged from €797 in Romania to €11,189 in Denmark per individual for six months.

Special education services are the costliest resources, followed by tutorial support, especially among younger people. Costs of other services are notable in older populations. Some health and social services are a significant part of the cost individuals with ASD and their carers pay directly.

The costs of productivity losses among carers, for six months, range from €307.70 per carer in Poland to €4,467.40 per carer in Austria.

From the results we can conclude that type of ASD, age, and comorbidities – intellectual disability especially – are important drivers of the costs of autism.

- **Economic impact of an ASD screening programme:** In several countries in Europe ASDEU also aimed to estimate the economic impact of a screening programme for ASD, looking at the transferability of a Spanish screening programme, estimating the hypothetical cost of implementing it in the rest of the countries. ASDEU found that the total cost of universal screening would range from €43,000 per year in Iceland to €5 million per year in France.

It concluded that a screening programme, such as the Spanish one, could be transferable to other countries. This is because all countries have regular medical check-ups of children under two in primary care, and because all countries except Denmark have a version of the Modified Checklist for Autism in Toddlers, the instrument for autism screening.

#### **ASD burden: Recommendation for policy-makers**

- 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
- Although an ASD screening program in young children is feasible, long-term assessment of local experiences is required to provide information on the effectiveness and cost-effectiveness of ASD screening programmes
- Just as it happens in other health technology assessment programs, where the effectiveness and cost-effectiveness information are yet not completed, both ASD screening effectiveness and cost-effectiveness could be analyzed depending on the decisions of the policy-makers in each country

### **3. ASD early detection, intervention and treatment**

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

ASDEU did systematic reviews of current evidence on autism early detection and intervention programmes in Europe, as well as systematically reviewing biomarkers and non-social markers (behaviours, cognitive functions and personal characteristics) for early detection.

The programme also held several focus groups and did a large survey of families and professionals to hear about their experiences and ideas.

ASDEU found that:

- **Diagnosis is still a big problem in Europe, and more resources are needed to facilitate early detection:** Research showed that the average age first concerns about autism are identified is 25.3 months, while on average, diagnosis does not happen until 44.4 months – 19 months later. Most parents (68.8%) indicated delays of more than six months to access a diagnostic service. Only 44.8% of families reported that professionals informed them about their child’s specific needs and 20% of families said they did not receive any information at the time of diagnosis. Families evaluated detection services negatively in terms of the attention professionals gave to parents’ concerns.

- **Early detection projects could be improved:** Although ASDEU found early detection projects in nine European countries, only two are currently active, in Spain and Norway. The Modified Checklist for Autism in Toddlers has been the most-used tool. ASDEU's systematic review proposes biomarkers and non-social signals that could be used in future early population screening programmes. However, it did observe some doubts about the usefulness and feasibility of specific biomarkers among EU clinicians.
- **European practitioners are using up-to-date procedures in early intervention – but parents still say there are problems:** European practitioners reported using up-to-date procedures, based on techniques that combine behavioural developmental perspectives, and involve caregivers in the intervention process as active agents to improve the effectiveness of programmes.

Most of the procedures and techniques they use are based on studies carried out in the US, which have provided valuable information on the effectiveness of different methods of intervention. They are mostly aimed at improving social-communicative difficulties present in young children with ASD.

On average, ASDEU found that children with ASD are receiving two to three treatment sessions per week, regardless of whether the treatment is provided by a public or private service.

Parents, however, are critical of the current situation, highlighting 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.

#### **4. ASD in adults and older people**

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, and doing an anonymous online survey.

The survey asked autistic adults, their carers, and professionals about their experiences of services, and the availability of services. Asking all three groups was important to gain a complete view of adult services in local communities. Many questions were based on published autistic adult service guidelines and the answer choices were designed to indicate how closely the respondent's actual experience aligned with the guidelines. The survey was translated into 11 languages, distributed via social media, and had 2,009 responses.

It found that:

- **Only some services are meeting guidelines:** Alignment between service guidelines and autistic people's actual experiences is evolving positively in some service areas, but not all – and there is much room for improvement. Alignment with guidelines is especially poor in the areas of staff training levels, basic services practice, post-diagnostic support and the adolescent-to-adult services transition.
- **Professionals need more knowledge:** Professional understanding of risks for poor health conditions and behaviours in autistic adults is uneven across health areas.
- **Quality varies between types of services:** Residential services provision and diagnostic services tend to have better local services, while areas most in need of good local models include healthcare and the adolescent-to-adult services transition.

ASDEU's research into current policies and organisation of services for autistic adults also found that:

- **Balance between public and private service provision varies greatly:** The balance between public and private service provision was very variable, between and within countries. However, private organisations appeared to be the core ASD knowledge base and in many cases the main providers of autistic adult services.

### **ASD in adults and older people: Recommendations for policy-makers**

- 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 adolescent-adult transition.
- Implement training programmes about ASD for staff in adult services, including healthcare staff.

## **5. Autism policies in Europe**

ASDEU's final strand of work involved assessing EU member states' health, education and social policies to support autistic people and their families – then making recommendations for a Europe-wide public health plan on autism.

As part of this, the non-profit organisation Autism-Europe mapped existing policies and legal frameworks in the field of disability and autism at the national and EU level and beyond, through a literature review and stakeholder consultation.

ASDEU also consulted civil society organisations and the Convention on the Rights of Persons with Disabilities focal points in national ministries. In addition, the programme ran focus groups and an online consultation to identify the most pressing issues for autistic people and their families across the EU, and possible ways to bridge those gaps.

Based on this work, ASDEU sent a comprehensive report to the European Commission with sections on autism-specific strategies, legislation and policies in some member states. It also included a section detailing each member state's legislation and policies relevant to autistic people in three areas: healthcare, education and access to employment.

This research found that:

- **The current response to the needs of people with autism and their families across is very diverse across the EU.** Over the last decade some countries and regions have adopted autism-specific policies. These vary from single policies to all-encompassing national autism plans or strategies.

- **Successful plans and strategies tend to follow a practical approach based on identifying the specific needs of people concerned (autistic people, but also families and carers).** They support the direction and coordination of services at national and regional levels to enhance their efficiency and benefit from adequate public funding for their implementation. They also offer enough flexibility to be revised without formal procedures, based on adequate monitoring.

#### **Autism policies in Europe: Recommendations for policy-makers**

- 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 Nations 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.
- Support research, networks of experts and partnering for progress.

#### **ASDEU in numbers**

- **12 ASD prevalence studies in 23 geographical areas**
- **600,000+ children, 2,700+ teachers and 700+ schools involved**
- **139 new ASD cases identified**
- **29 focus groups with 226 participants in 10 European countries**
- **3 systematic reviews**
- **10 online surveys, each translated into 10+ languages**
- **6,000 online survey respondents**

- **Dozens of revised regulations and laws**
- **Partnership with key European and national ASD organizations**
- **Wide information dissemination via newsletters, ASDEU website, partner meetings, several national working meetings, communication with local authorities and committees and scientific papers**

## **Annex: More about the project**

### **Impact and dissemination**

ASDEU has striven to ensure that key messages about its work have reached not only the research community, but autistic people and their families, and policy-makers.

Key to this has been developing a website, and also a logo and visual identity for the programme. ASDEU has also held several events for key audiences, and distributed a newsletter every 3-4 months. ASDEU partners have also promoted the programme via social media, their websites, press, newsletters, conferences and events.

### **Project evaluation**

Evaluation has been a key part of ASDEU throughout the programme. The final evaluation report looks at 144 evaluation indicators.

### **Coordination between ASDEU and EU-AIMS**

Throughout its three years, ASDEU coordinated and communicated with the Innovative Medicines Initiative (IMI)-funded project European Autism Interventions – A Multicentre Study for Developing New Medications (EU-AIMS), which took place between April 2012 and March 2018.

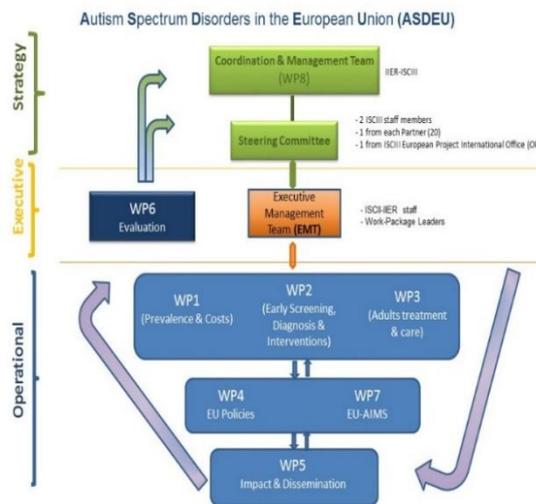
Seven ASDEU partners are applicants on the recently awarded IMI AIMS-2-Trials consortium (2018-2023), which will coordinate and run clinical trials across Europe, in partnership with industry and EU and US charities, with has a budget of €113 million.

All remaining ASDEU partners who are not part of the AIMS-2-Trials consortium will be invited to join the wider AIMS-2-Trials Clinical Network.

This collaboration is aligned with ASDEU’s goal “to create synergy between the basic and applied science ASD fields in Europe and ensure that the public policy impact of the ASDEU project is underpinned by, and in turn informs, cutting-edge science.”

## ASDEU management structure

**Figure 2: ASDEU coordination aims and management structure**



## ASDEU consortium

The ASDEU consortium comprised 22 groups representing 14 European countries. 45% of lead partners and 50% of members of the research teams were women.

**Table 1: Participating institutions and organisations**

Medical University of Vienna
Bulgarian Association for Promotion of Education and Science
Université Toulouse
University of Aarhus
Dublin City University, School of Nursing and Human Sciences
State Diagnostic and Counseling Centre
Scientific Institute Stella Maris - University of Pisa
University and University Hospital of Oulu
University of Warsaw
Instituto Nacional de Saúde Doutor Ricardo Jorge
Victor Babes National Institute of Pathology
University of Salamanca
Instituto de Salud Carlos III
Fundación Española para la Cooperación Internacional, Salud y Política Social
Canary Foundation for Advancement in Biomedicine and Biotechnology
Autism Europe
Ghent University

King's College London  
National Autistic Society  
The London School of Economics and Political Science  
Policlinica de Gipuzkoa  
Institute Superior de Sanita



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Alvaro Bejarano  
Andrew Bollson  
Anneli Yliherva  
Anthony Staine  
Antonio Narzisi  
Catherine Arnaud  
Clara Janicel Fernandez  
Eva Popova  
Galita Decheva  
Georgi Iskrov  
Gissler Mika  
Guiomar Gonçalves de  
Oliveira

Hanna Elina Ebeling  
Janet Matthews  
Johanna Kafka  
María Magán  
Maganto  
Patricia García  
Sigridur Loa Jonsdottir  
Susanne Cramer  
Tarja Parviainen  
Tracey Sellers  
Marit Vanbaker  
...