asdeu

Autism Spectrum Disorders in the European Union

European Commission

An EU Strategy for Autism to leave No One Behind

Introduction to the ASDEU programme and preliminary results of studies into prevalence and cost

Manuel Posada on behalf the ASDEU network

European Parliament

Brussels, September 25th, 2018

S&D Group of the Progressive Alliance of **Socialists & Democrats** in the European Parliament

Autism Europe

European Parliament

GOBIERNO DE ESPAÑA · MINISTERIO DE CIENCIA, INNOVACIÓN Y UNIVERSIDADES

Instituto de Salud Carlos III · Instituto de Investigación de Enfermedades Raras

Participant organization name	ACRONYM
Medical University of Vienna (Austria)	MUW
Ghent University (Belgium)	UGent
Bulgarian Association for Promotion of Education and Science (Bulgaria)	BAPES
University of Toulouse 2 Jean Jaurés UT2J (France)	UTM
Aarhus University (Denmark)	AU
Dublin City University, School of Nursing and Human Sciences (Ireland)	DCU
The State Diagnostic and Counselling Centre (Iceland)	SDCC
The IRCCS Stella Maris Foundation (Italy)	SMF
University of Oulu (Finland)	OULU
University of Warsaw (Poland)	UW
National Health Institute Doutor Ricardo Jorge (Portugal)	INSA
Victor Babes National Institute of Pathology (Romania)	INCDVB
Universidad de Salamanca (Spain)	USAL
Instituto de Investigación de Enfermedades Raras, Instituto de Salud Carlos III (Spain)	ISCIII
Fundación Española para la Cooperación Internacional, Salud y Política Social (Spain)	FCSAI
Fundación Bio-Advance (Spain)	Bio-Advance
Autism Europe	AE
King´s Colleague of London (United Kingdom)	KCL
National Autistic Society (United Kingdom)	NAS
The London School of Economics and Political Science (United Kingdom)	LSE
Policlinica Gipuzkoa	PG
Instituto Superior de Sanita, Italy	ISS

ASDEU CONSORTIUM

22 partners
14 European Member States

ASDEU Partners

Countries participating in the Prevalence Study (12 Member States)

Autism Europe (>80 members in >30 European Countries)

EU-AIMS Coordinator (>80 clinical/research centres from 37 European Countries)

Framework for action: clinical practice and European advocacy

Human framework underlying :"ASD: Ten Tips to Support Me" (Fuentes, 2014)

<u>Overall strategic objective</u>: to improve the quality of life of individuals and families affected by ASDs

ASD is an emerging public health issue

- **United Nations** http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/62/139

- **WHO** http://www.who.int/mental_health/evidence/mhGAP_intervention_guide/en/index.html

Autism Spectrum Disorders: Ten Tips to Support Me

Joaquín Fuentes, MD

Major dimensions.
Transition to policies

- **Estimation of the prevalence** and its relation with both the **social and economic burden**;

- **Early detection of ASDs** in children and **adequate interventions & biomarkers**;

- A comprehensive framework for **adult autistic treatment and care**

ASD Policies

Work packages

WP nº	WP Title	Lead Partner
WP1	Prevalence of ASDs and related social and economic costs	ISCIII
WP2	Early detection, diagnosis and evidence-based intervention	USAL
WP3	Adults Treatment and Care	AU
WP4	ASD policies in the EU	AE
WP5	Impact & dissemination	ISCIII & NAS
WP6	Evaluation	BAPES
WP7	Co-ordination of activities with the FP7 EU-AIMS consortium	KCL
WP8	Coordination and Management	ISCIII

Some Figures

- Twelve prevalence studies - in 23 different geographical areas - it has supposed 23 prevalence field studies

- More than 600,000 children involved

- More than 2,700 teachers

- More than 700 schools

- 139 new ASD diagnoses who had been not detected previously

- 29 focus groups, 226 involved from 10 European countries

- 3 systematic reviews

- 10 different surveys

- Translation into more than 10 different languages, depending of the type of survey

- Near to 6,000 people involved in the different surveys

- Dozens of regulations and laws revised

- The main European and national ASD organizations engaged

- and also Newsletters, three big meetings and several working meetings at national level, documents addressed to local authorities and committees, the website, scientific papers, tools

http://asdeu.eu

Prevalence Methods

Population-based (4 countries)

Cross-sectional prevalence studies (8 countries)

- Method 1: Screening in two phases TNF & SCQ (7 countries)
- Method 2: Screening using the SCQ (3 countries)
- Validation of the Teacher Nomination Form

NUMBER OF CHILDREN
IDENTIFIED WITH ASD

1 in 59

Methods to measure
prevalence in a population

NUMBER OF STUDENTS BEING SERVED
UNDER THE CATEGORY OF AUTISM IN VIRGINIA SCHOOLS

19,566
(2017)

18,256
(2015)

14,624
(2012)

9,719
(2004)

1,529
(1998)
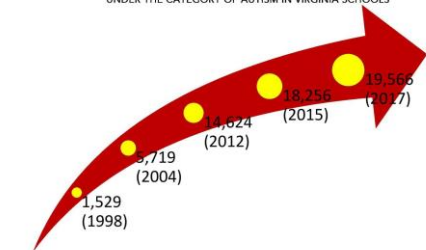
Source: Virginia Dept. of Education

Prevalence Methods -II

Prevalence – Population-based

- Denmark, France, Iceland, Finland
- 2 National ASD registries
- 2 Regional ASD registries
- 1 National Surveillance program
- 542,235 children
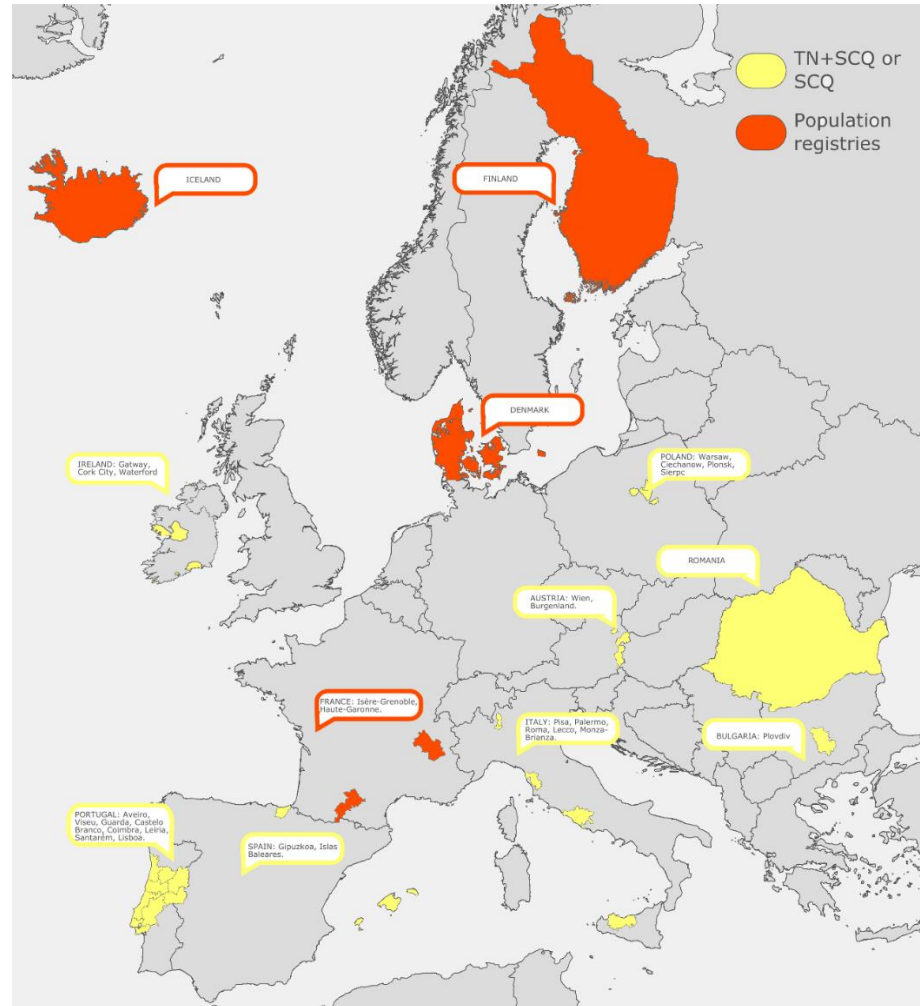- Prevalence by year (Cumulative incidence)
- Prevalence by birth year (Cumulative incidence)

Prevalence Methods –III
Cross-sectional prevalence studies

Method 1: Screening in two phases TNF & SCQ

- 7 countries: Spain (1), Portugal (1), Poland (4), Romania (WC), Bulgaria (1), Ireland (2) and Italy (1)
- 138,483 children (population)
- 56,582 children - Range 1,401-13,690
- 702/923 schools - Range 15- 687
- 200 SEN
- 2,734 teachers - Range 54-788
- 2,142 SCQ received – Range 20 -1,401
- 212 SCQ >15 Range 10-46
- 1,358 children nominated – Range 43-342
- 61 New ASD cases/1,779 known ASD

Method 2: Screening using the SCQ

- 3 countries: Ireland (3), Austria (1) and Italy (3)
- 95,886 children (population)
- 32,802 children - Range 5,526-16,298
- 212/533 schools – Range 32 - 51
- 13 SEN
- 21,154 SCQ received – Range 1,017-6,882
- 698 SCQ >15 Range 70-230
- 39 ASD new cases/238 known ASD
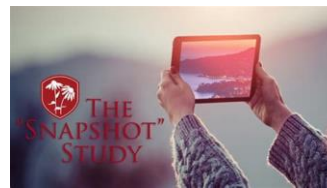
Results

Type of study design	Country	Prevalence estimation cases x 1,000	CI95% x 1,000
Population Registries	DENMARK*	12.4	11.9-12.9
	FINLAND	7.7	7.4-8.1
	ICELAND	26.8	24.2-29.6
	FRANCE**	5.4	5.0-5.9
Range	4	5.4-26.8	N/A
SCQ Screening	AUSTRIA	13.8	8.2-23.0
	ITALY-LECCO	15,4	12.7-18.5
	ITALY-ROME	12.7	9.9-16.2
	ITLAY-PALERMO	12.2	9.4-15.9
	ITALY-ALL	13.5	11.5-15.5
	IRELAND	17.9	14.7-21.8
Range	3	12.7-17.9	N/A
TNF+SCQ Screening	POLAND	6.9	5.5-8.6
	BULGARIA	2.7	1.8-3.9
	PORTUGAL	5.0	2.9-6.7
	SPAIN	4.8	3.8-6.1
	ITALY	11.5	8.3-14.6
	ROMANIA	7.2	5.3-9.7
Range	6	5.0-11.5	N/A
TNF vs SCQ	IRELAND	15.0	9.8-22.8
Range	1	15.0	9.8-22.8
TOTAL RANGE	14	4.8-26.8	N/A

ASD Costs

- **Intellectual disability is a very important driver of the costs of autism**
- **There are differences between countries in the availability of some services**
- **We observed differences in the frequency/duration of visits to some (apparently similar type of) services across countries**
- **Some services are paid directly by patients in some countries**

Screening Costs

Country	Cost per 1 child screened	Cost per 1 suspicious case detected	Annual budget impact per country (2018)
Austria	8.8 €	102.62 €	784,765 €
Belgium	7.9 €	87.06 €	935,054 €
Bulgaria	1.0 €	11.63 €	64,568 €
Denmark	7.8 €	79.70 €	410,809 €
Finland	7.3 €	81.28 €	370,597 €
France	6.9 €	72.91 €	5,047,750 €
Iceland	13.2 €	72.40 €	391,148 €
Ireland	7.0 €	129.47 €	42,761 €
Italy	6.8 €	99.62 €	3,903,753 €
Poland	2.6 €	29.26 €	975,665 €
Portugal	4.7 €	57.38 €	436,057 €
Romania	1.4 €	15.10 €	248,104 €
Spain	5.0 €	65.08 €	2,284,293 €
UK	9.1 €	100.72 €	6,668,059 €

Cost per screened child
- >9€
- 6-9€
- 3-6€
- <3€
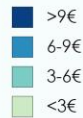
ASSUMPTIONS:
All general paediatricians in the country.
All children in the immunization program.
8.9% of suspicious cases (= pilot study in Spain).

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Main Recomendations

- **To improve the ASD registration in Europe**

- **To set up /define ASD geographical units to improve the surveillance of the prevalence**

- **To study the cost-effectiveness of the screening programs or experiences implemented in Europe.**

- **We should have effective services to satisfy the different needs of people with autism depending on their age, type of ASD and intellectual capacities.**

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