

17th
International
ESCAP Congress
TRANSITION
Child and adolescent psychiatry
in a world of change
+ Geneva, Switzerland
9-11 July 2017

Autism Spectrum Disorders: supporting people to transit trough science, lives and services




















Joaquin Fuentes, MD

Child and Adolescent Psychiatry Unit
Policlínica Gipuzkoa & Gautena Autism Society
Donostia / Sebastián, Spain



DISCLOSURES

July, 2014 - 2017

SOURCE	RESEARCH FUNDING	PRO BONO CONSULTANT	SPEAKER BUREAU	MEETINGS ATTENDANCE	HONORARIES AS SPEAKER IN OTHER MEETINGS	COMPENSATION FOR THIS PRESENTATION
EU Commission - ASDEU						
Policlínica Gipuzkoa Foundation						
Hoffman-La Roche						
Shire						
Eli Lilly						
IACAPAP						
MGH Psychiatry Academy						
Gautena						
AEPNYA						
AACAP						
ESCAP						

Joaquín Fuentes, MD

GRATITUDE

July, 2014 - 2017

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EU Commission - ASDEU	<input type="checkbox"/>					
Policlínica Gipuzkoa Foundation	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>		
Hoffman-La Roche	<input type="checkbox"/>					
Shire			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Eli Lilly			<input type="checkbox"/>	<input type="checkbox"/>		
IAC P&AP				<input type="checkbox"/>		
MGH Psychiatry Academy					<input type="checkbox"/>	
Gaunina	<input type="checkbox"/>	<input type="checkbox"/>				
AEPNYA					<input type="checkbox"/>	
AACAP					<input type="checkbox"/>	
ESCAP						<input type="checkbox"/>

Thank You!

Joaquín Fuentes, MD



Simon Baron-Cohen

“Neurodiversity”



Severe
Autism

Autism

High-Functioning Autism
Aspergers Syndrome

Disease – Disorder/Condition - Disability - Difference



OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

2016 SUMMARY OF ADVANCES

in Autism Spectrum Disorder Research



<https://iacc.hhs.gov/publications/summary-of-advances/2016>

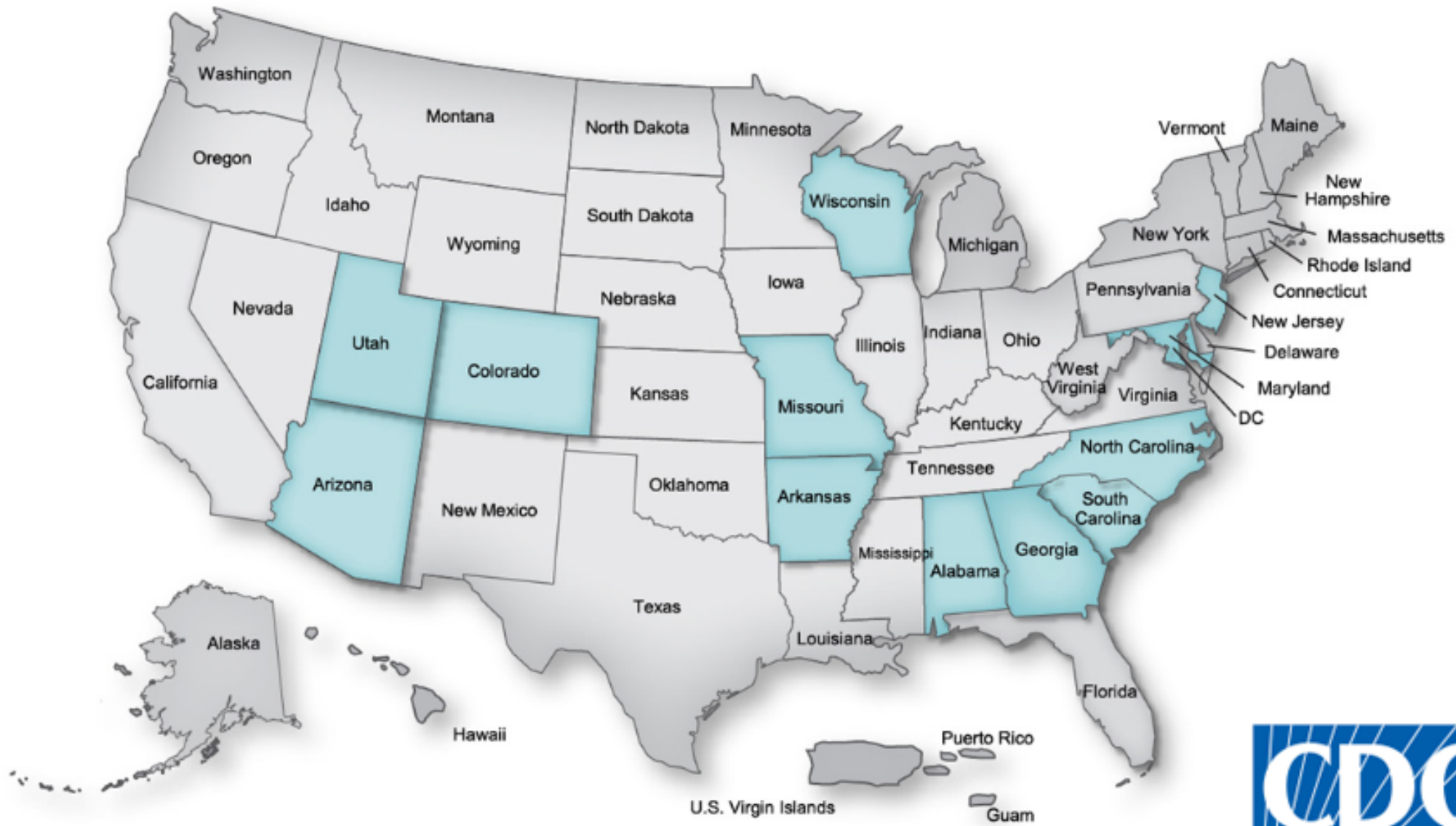
WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?



Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012

We emphasize the important role of the schools in enabling early detection. Continued surveillance of ASD prevalence is required to target education, outreach, and policy efforts.

Autism and Developmental Disabilities Monitoring (ADDM) Network Sites



Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000-2010
Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.3 - 9.9)	1 in 150
2002	1994	14	6.6 (3.3 - 10.6)	1 in 150
2004	1996	8	8.0 (4.6 - 9.8)	1 in 125
2006	1998	11	9.0 (4.2 - 12.1)	1 in 110
2008	2000	14	11.3 (4.8 - 21.2)	1 in 88
2010	2002	11	14.7 (14.3 - 15.1)	1 in 68

1 / 42 

1 / 189 

¿1/45?



**Autism prevalence in 55,000 students, aged 7 to 12
in Seoul, South Korea: 2.64% **1 per 38****

New sex distribution in this sample: 2.5 M / 1 F

Kim YS et al. (2011) J Am Acad Child Adolesc Psychiatry, 168:904-12

Kim YS et al. (2014) J Am Acad Child Adolesc Psychiatry. 53:500-8



European Parliament

2014 - 2019

WRITTEN DECLARATION ON AUTISM

Calls on the European Union and its Member States to adopt a **European Strategy for Autism** that will:

- Support accurate detection and diagnosis across Europe
- Promote evidence-based treatment and support for all ages
- Foster research and prevalence studies
- Encourage the exchange of best practices

418 MEPs
(September 2015)

Moving forward for the adoption of a European Strategy for autism in Europe

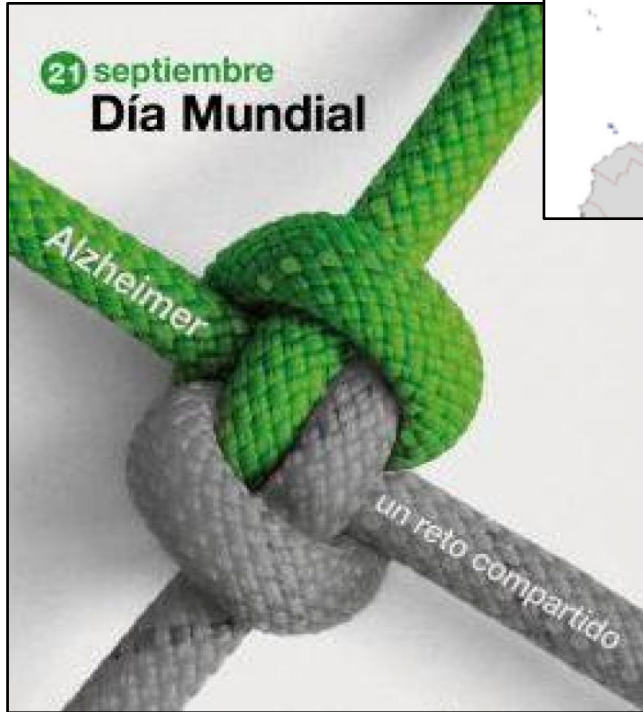


29 September 2015

28 Countries



Population: 508 M

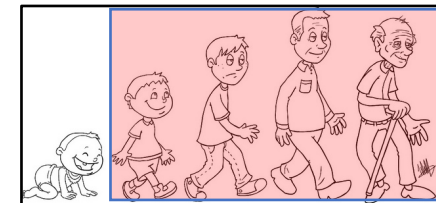
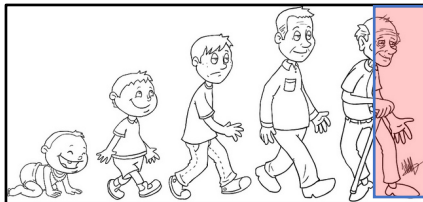


=



Dementias: 6.3M

Autism: 5 – 7.2 M?



Quiénes somos

Misión y visión

Funciones

Estrategia

Organización

Comunicación

Noticias y actos

Notas de prensa

Presentaciones

Documentación institucional

Portal de videos

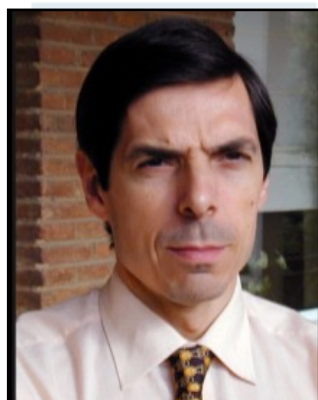
Estás en: Instituto de Salud Carlos III >> El Instituto >> Comunicación >> Noticias y actos >> De tres años de duración

Comunicación
Noticias y actos

Call for tender nº SANCO/2014/C2/035

03/02/2015

El Instituto de Salud Carlos III y la Comisión Europea firman un acuerdo para avanzar en las políticas de salud para el autismo en Europa



Manuel Posada
PI



Foto: Álvaro Millán

El proyecto, dotado con 2 millones de euros, comenzará formalmente el 15 de febrero.

Contará con la participación de diferentes representaciones de 14 países europeos y será liderado por Manuel Posada, Director del Instituto de Enfermedades Raras del ISCIII.

Joaquín Fuentes, de Policlínica Gipuzkoa, de Donostia / San Sebastián, España, actuará como Asesor

Científico del Coordinador de la Red de Investigación ASDEU.



Sede electrónica



Directorio



Información al ciudadano



Registro Nacional de Biobancos

Accesos directos

Biblioteca Nacional de Ciencias de la Salud

CENTROS ISCIII

RE-LAB

Alianza por la Investigación y la Innovación en la Salud

Espacios ISCIII

Fundaciones



European
Commission



MINISTERIO
DE ECONOMÍA
Y COMPETITIVIDAD



Instituto
de Salud
Carlos III

(2015 – 2018)

asdeu

Autism Spectrum Disorders in the European Union

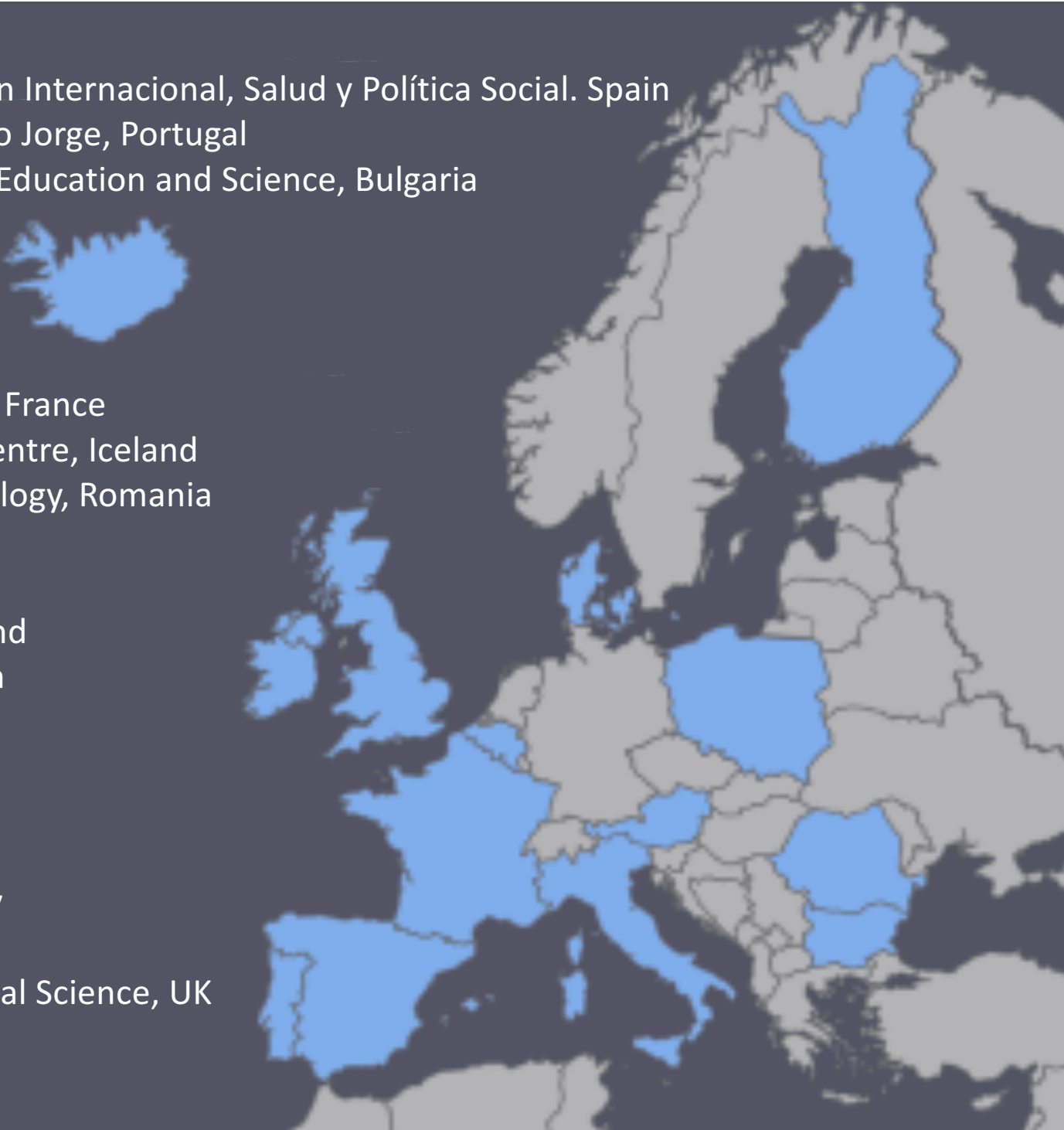
14 COUNTRIES



- IIER, ISCIII, Spain

- Fundación Española para la Cooperación Internacional, Salud y Política Social. Spain
- National Health Institute Doutor Ricardo Jorge, Portugal
- Bulgarian Association for Promotion of Education and Science, Bulgaria
- Medical University of Vienna, Austria
- Ghent University, Belgium
- Aarhus University, Denmark
- University of Oulu, Finland
- University Toulouse 2 Jean Jaurés UT2J, France
- The State Diagnostic and Counselling Centre, Iceland
- Victor Babes National Institute of Pathology, Romania
- Autism Europe, Belgium
- University of Warsaw, Poland
- Dublin City University, Republic of Ireland
- Fundación Bio-Advance, Canarias, Spain
- Universidad de Salamanca, Spain
- Fundación Policlínica Gipuzkoa, Spain
- National Autistic Society, UK
- King's College London, UK
- The IRCCS Stella Maris Foundation, Italy
- Instituto Superior de Sanitá, Italy
- London School of Economics and Political Science, UK

22 TEAMS





European
Commission



Work Package 1

**PREVALENCE AND SOCIAL AND
ECONOMIC COSTS**



Work Package 2

**EARLY DETECTION, DIAGNOSIS AND
EVIDENCE BASED INTERVENTION**



Work Package 3

ADULTS TREATMENT AND CARE



Work Package 4

ASD POLICIES IN THE EU



Work Package 7

COORDINATION OF ACTIVITIES WITH THE EU-AIMS CONSORTIUM



Work Package 5

IMPACT & DISSEMINATION



Work Package 6

EVALUATION



Work Package 8

COORDINATION & MANAGEMENT

Help us to build a better understanding of autism spectrum disorder (ASD) in Europe!

A straightforward way to contribute is to complete one of our on-line information-gathering surveys.

By sharing your experiences, you will also help to speed up the development of more effective services and interventions for autistic people and their families.



[QUESTIONNAIRE ABOUT COSTS](#)

[SURVEY ABOUT EARLY INTERVENTION, DIAGNOSIS AND INTERVENTION](#)

[SURVEY AND SUPPORT FOR AUTISTIC ADULTS](#)



You can find out more and participate in ...

SURVEY OPENED UNTIL OCTOBER 1st. 2017



European
Commission



Work Package 1

PREVALENCE AND SOCIAL AND
ECONOMIC COSTS



Work Package 2

EARLY DETECTION, DIAGNOSIS AND
EVIDENCE BASED INTERVENTION



Work Package 3

ADULTS TREATMENT AND CARE



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Work Package 6

EVALUATION



Work Package 8

COORDINATION & MANAGEMENT

Prevalence: countries

FIELD STUDIES

Austria
Bulgaria
Spain
Ireland
Italy
Poland
Portugal
Romania

vs.

POPULATION REGISTRIES

Denmark
Finland
France
Iceland

12 Countries

ASD Prevalence Study across Europe: Cross sectional study design versus population-based registries approach.

P. García Primo (Spanish Foundation for International Cooperation, Health and Social Policy – FCSAI-), **A. Vicente** (Instituto Nacional de Saúde Doutor Ricardo Jorge), **D. Schendel** (University of Aarhus), **E. Partner** (University of Aarhus), **C. Rasga** (PhD, Instituto Nacional de Saúde Doutor Ricardo Jorge), **C. Café** (Centro Hospitalar Universitário de Coimbra), **B. Rogé** (University Toulouse 2 Jean Jaurès UT2J), **C. Arnaud** (University Toulouse 3 Paul Sabatier), **E. Saemundsen** (State Diagnostic and Counselling Centre), **F. Muratori** (IRCCS Stella Maris Foundation), **A. Narzisi** (IRCCS Stella Maris Foundation), **A. Boilson** (Dublin City University, School of Nursing and Human Sciences), **G. Oliveira** (Centro Hospitalar Universitário de Coimbra), **J. Fuentes** (Fundación Policlínica Gipuzkoa), **L. Poustka** (Medical University of Vienna), **M.L. Scattoni** (Istituto Superiore di Sanità), **M. Gissler** (University and University Hospital of Oulu), **M.R. Sweeny** (Dublin City University, School of Nursing and Human Sciences), **M. Budisteanu** ("Victor Babes" National Institute of Pathology), **Rafal Kawa** (University of Warsaw), **R. Canal-Bedia** (University of Salamanca), **R. Stefanov** (Bulgarian Association for Promotion of Education and Science), **ME Van Bakel** (REOP) & **M. Posada** (Institute of Rare Diseases Research, ISCIII)



Gipuzkoa County

Gipuzkoa Field Study

All the children aged 7 to 9 years

(DOB between 09/01/2007 and 08/31/2009)

- Attending mainly **2°**, **3°** or 4° grade

Schools: 182 / Head teachers: 1.041

- Attending 1st grade, but complying with DOB

Schools: 182 / Head teachers: 356

Gipuzkoa Field Study (2016-2017)

1. Warning

NOVEMBER - APRIL

2. Screening

MAY - SEPTEMBER

3. Diagnosis

OCTOBER - DECEMBER

PROYECTO ASDEU-GIPUZKOA: DETECCIÓN DE PROBLEMAS DEL DESARROLLO COMUNICATIVO Y SOCIAL EN LA INFANCIA

FORMULARIO DE NOMINACIÓN PARA EL PROFESORADO

CÓDIGO DEL CENTRO EDUCATIVO CURSO AULA

Estamos realizando una encuesta para detectar dificultades sociales y comunicativas en los centros de educación primaria de Gipuzkoa y le agradecemos se tome unos minutos revisando la siguiente descripción:

- A) Es socialmente torpe
- B) Parece no comprender los sentimientos de otros o de otras
- C) Habla mucho sobre sus propios intereses, pero no le sale bien llevar una conversación
- D) No se comunica con el fin de resultar únicamente amistoso con los demás
- E) No es muy flexible – tiende a insistir en ciertas normas y rutinas
- F) Se interesa marcadamente en solo unos pocos temas o actividades

1. ¿Hay algún alumno o alumna en su clase que encaje con esta descripción?

Si No (Si marca No, pase a la pregunta 3)

*Nota: No es necesario que todas y cada una de estas características del listado encajen con el alumno o alumna para marcar "SI". Si usted cree que, de manera general, esta descripción encaja con un alumno o alumna determinado, marque "SI". En su reflexión considere también al alumnado con necesidades específicas de apoyo educativo (por ejemplo, alumnado con TEA, TDAH, Discapacidad Intelectual, etc.).

2. ¿Cuántos alumnos y alumnas de su clase encajan en esta descripción?

3. A continuación, incluyendo este alumnado que encaja en la descripción, rellene la tabla siguiente, nombrando hasta un máximo de 4 niños o niñas de su clase, y detalle cuál o cuáles características (A-F) presentan y cuál sería la más relevante. Ponga en primer lugar a quien tenga el mayor número de características, identificándolo o identificándola con el código numérico asignado por el Centro (no incluya nombre ni otros datos personales).

Código asignado por el Centro) como identificador del alumno o alumna	Indique let(s) característico(s) que presenta						Indique la letra de la lista A-F que sería la característica más relevante para cada uno de los nominados o nominadas	¿Hay otras dificultades, no incluidas en la lista A-F que haya observado en cualquiera de estos alumnos? ¿Sebe si han recibido un diagnóstico? ¿Cuál?
	A	B	C	D	E	F		
1:							Característica más relevante <input type="checkbox"/>	
2:							Característica más relevante <input type="checkbox"/>	
3:							Característica más relevante <input type="checkbox"/>	
4:							Característica más relevante <input type="checkbox"/>	

4. Hasta donde usted conoce, ¿Alguno de estos alumnos o alumnas se beneficia de alguna medida específica de atención educativa? Si la respuesta es afirmativa ¿cuál es o cuáles son esas medidas? (ACI: escolarizado en aula ordinaria con apoyo; acude en ocasiones a un aula de apoyo; escolarizado en centro ordinario, pero básicamente en un aula estable...).

Alumno 1: Alumno 2:
Alumno 3: Alumno 4:

5. ¿Cuántos alumnos y alumnas hay en total en su clase?

Por favor, una vez respondido, guarde el formulario pulsando en este botón

Envíe el formulario pulsando en este botón

¡MUCHAS GRACIAS POR SU PARTICIPACIÓN!

ASDEU-GIPUZKOA PROIEKTUA: GARAPEN KOMUNIKATIBO ETA SOZIALEKO ARAZOEN DETEKZIOA HAURTZAROAN

IZENDAPEN-FORMULARIOA IRAKASLEENTZAT

IKASTETXEAREN KODEA IKASTURTEA IKASGELA

Gipuzkoako Lehen Hezkuntzako zentzuetan sozializazio eta komunikazio zailtasunak antzemateko galdeteka bat burutzen ari gara. Ondorengo deskripzioa aztertzen minutu batzuk har ditzazun eskertzen dizugu:

- A) Sozialki inaketsa da
- B) Badirudi ez dituela ulertzen bestearen sentimenduak
- C) Asko hitz egiten du bere interesei buruz, baina elkarriketa bat jarraitzeko zailtasunak ditu
- D) Ez da besteekin komunikatzeko adiskidetasun izateko helburu bakararekin
- E) Ez da oso malguia; arau eta erudira batzuk aplikatzera jotzen du
- F) Gai ezaleko jarduerak gutxi batzuetan bakarrik nabariki interesatzen da

1. Zure ikasgelako ikaslearen batek bat egiten du deskribapenarekin?

Bai Ez (EZ baldin bada, pasatu 3. galdeteka)

*Adi: "Bai" markatzeke, ez da beharrezkoa zure ikasle zahar batenik egiten duela bat "Bai" markatu. Pembatu, halaber, hezkuntza-laguntzaren premia berantziak dituzten ikasleekin (adibidez, ADN, ADNI), deagatuzun intelektualak eta abar duten ikasleek.

2. Zure ikasgelako zenbat ikasle egiten dute bat deskribapenarekin?

3. Orain, deskribapenarekin bat egiten duten ikasle hauek barne hartuz, bete ezazu taula hau ikasgelako 4 ikasle izendatuz gehienez, eta zehaztu zer ezaugarri dituzten (A-F) eta zein den ezaugarri garrantzitsua aligeratzen. Zehazten, jarri lehenengo ezaugarri gehien dituzten ikasleak, ikastetxoak ikasleari eslehitako zenbaki-kodeaz identifikatuz (ez jarri izenik, eta beste datu pertsonalik ere).

Kodea (Ikastetxoak ikasleak eslehitzeko) ikaslearen identifikaziora gisa	Adierazi zer ezaugarri erakusten dituzten						Adierazi A-F zerrendako zer ezaugarri den aligeratzen izandakoa ikasle bakoitzaren kasuan	Bada beste zailtasun-eremuren bat A-F zerrendan jaso ez dena baina zure ikaslearen balentzen ikusi duzuna? Diagnostikoa jaso duen batak? Zen?
	A	B	C	D	E	F		
1:							Zer ezaugarri den aligeratzen <input type="checkbox"/>	
2:							Zer ezaugarri den aligeratzen <input type="checkbox"/>	
3:							Zer ezaugarri den aligeratzen <input type="checkbox"/>	
4:							Zer ezaugarri den aligeratzen <input type="checkbox"/>	

4. Zuk dakizula, ikasle horietakoren bati esleitu zailo hezkuntza-erretako berantziak neurritan bat? Hala bada, zer hezkuntza-neuri edo -erantzun esleitu zarkio? (CNE: ikasgela amuntan eskolatua laguntzarekin; laguntza-gela batera joan da tarteka; ikasleak arunt baten eskolatua, baina gela egonkor baten batik...), Adierazita badago, erantzun bi puntuek, dagokion espazioan).

Resposta 1: Resposta 2:
Resposta 3: Resposta 4:

5. Zenbat ikasle daude gutxira zure ikasgelan?

Erantzun ondoren, gorde formularioa botoi hau sakabatuz:

Bidali formularioa botoi hau sakabatuz:

¡ESKERRIK ASKO PARTE HARTZEAGATIK!

PROYECTO ASDEU-GIPUZKOA: DETECCIÓN DE PROBLEMAS DEL
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ASDEU-GIPUZKOA PROIEKTUA: GARAPEN KOMUNIKATIBO ETA
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A) Sozialki inoiztas da

B) Besteak eta besteak ulertzen ez ditu bere sentimenduenak

A) Socially awkward

B) Doesn't seem to understand the feelings of others

C) Talks a lot about own interests, but not very good at conversations

D) Doesn't really chat to be friendly

E) Not very flexible - tends to insist on certain rules and routines

F) Is intensely interested in just a few topics or activities

5. ¿Cuántos alumnos y alumnas hay en total en su clase?

Por favor, una vez respondido, guarde el formulario pulsando en este botón

Envíe el formulario pulsando en este botón

¡MUCHAS GRACIAS POR SU PARTICIPACIÓN!

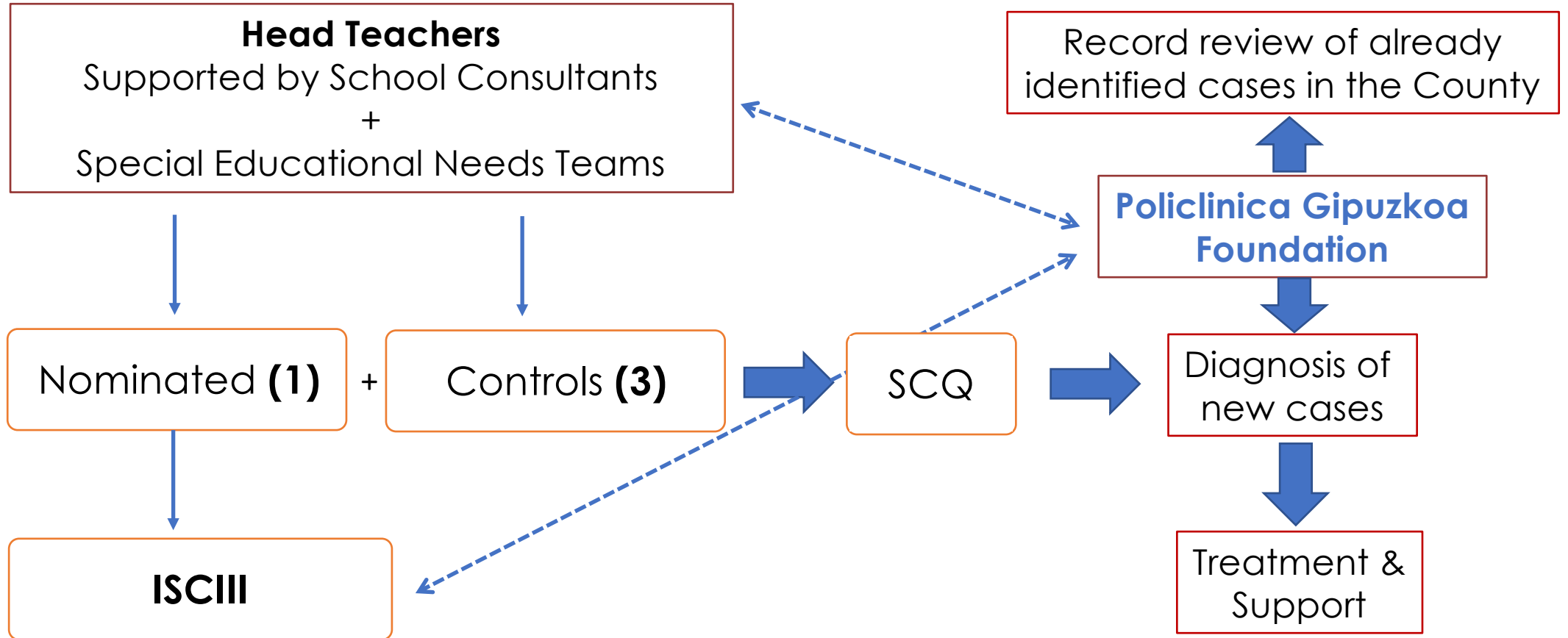
5. Zenbat ikasle daude guztira zure ikasgelan?

Erantzun ondoren, gorde formularioa botoi hau sakabuz:

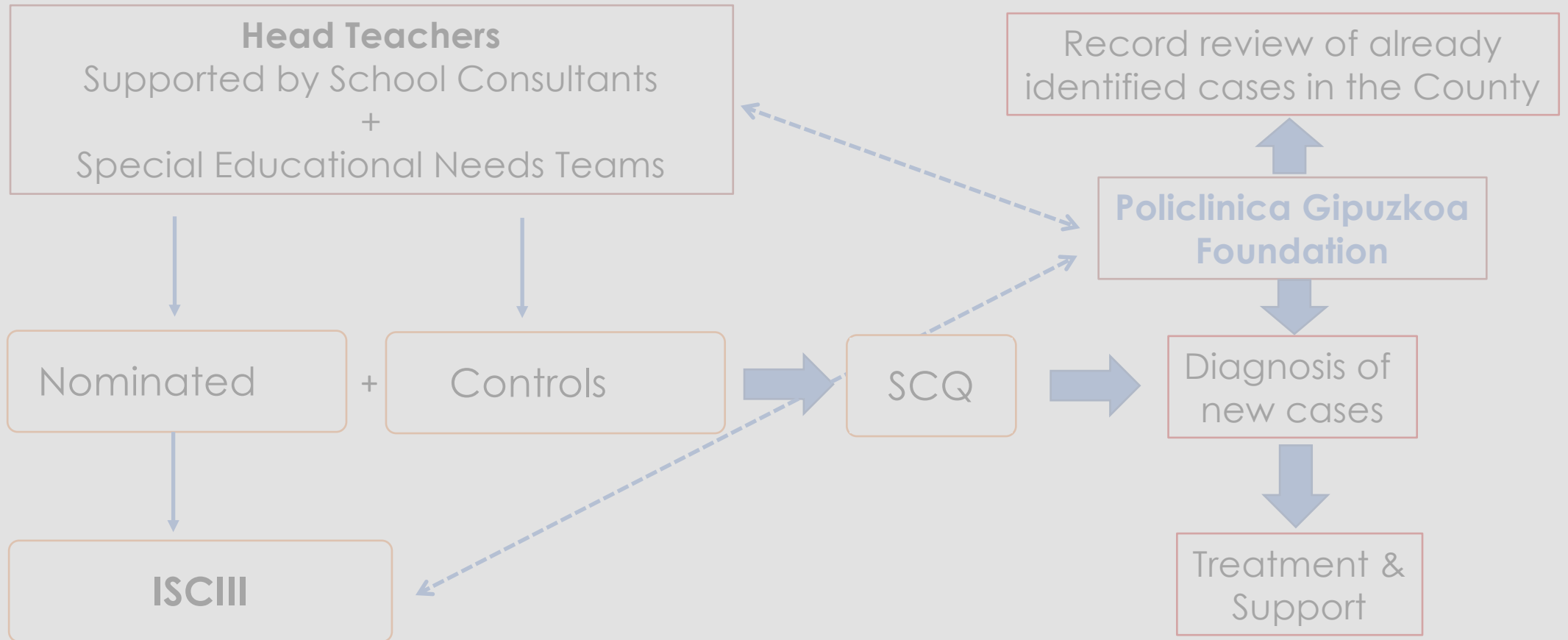
Bidali formularioa botoi hau sakatuz:

¡ESKERRIK ASKO PARTE HARTZEAGATIK!

Gipuzkoa Field Study



Gipuzkoa Field Study

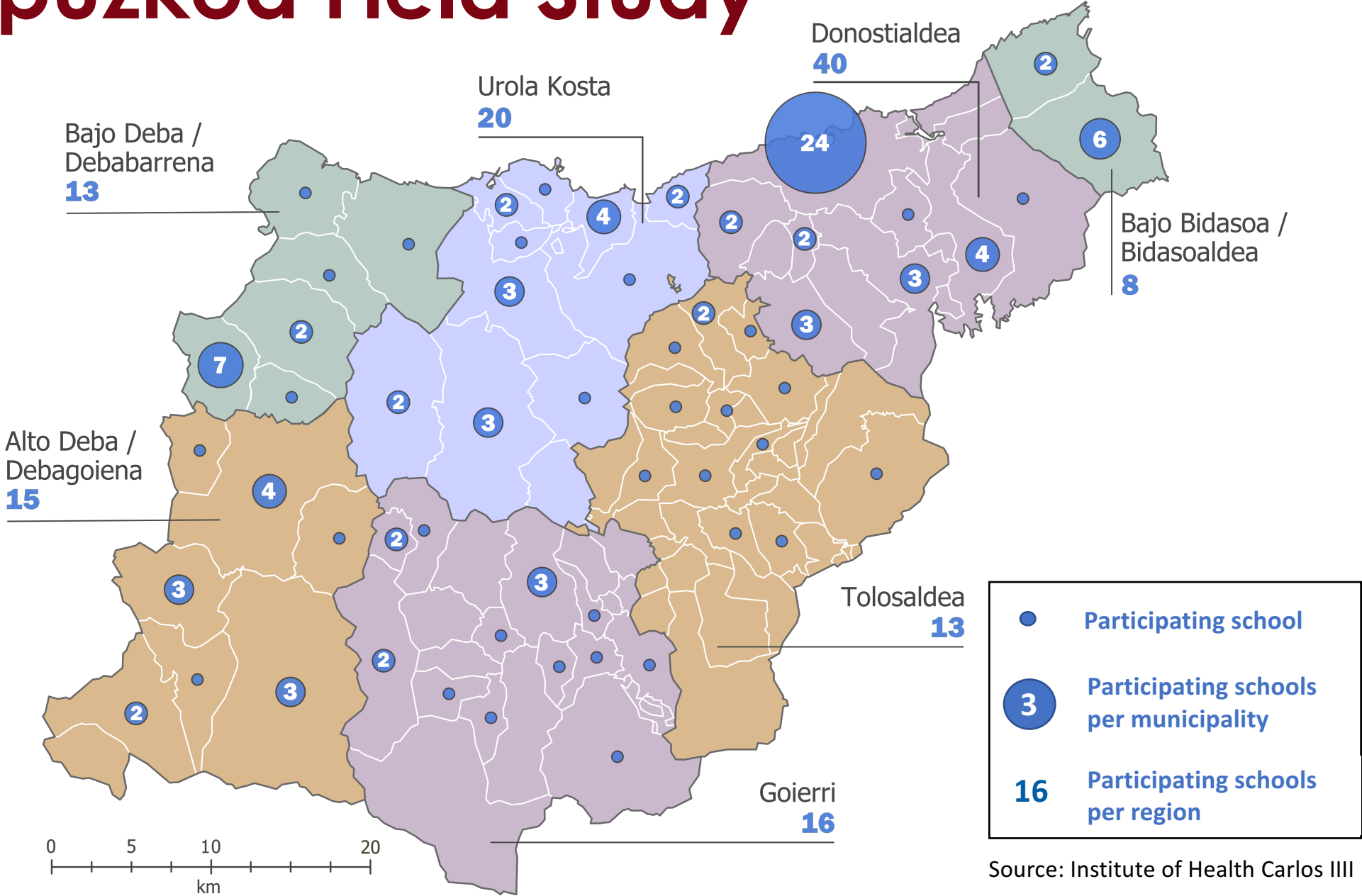


Warning

Screening

Diagnosis

Gipuzkoa Field Study



Source: Institute of Health Carlos III

Gipuzkoa Field Study

Ongoing results (regular schools):

Population: 14,830 children (age 7 to 9)

Schools participating: 125 out of 182 (69%)

Total of considered students: 10,528 (71%)

Nominated by Head Teacher: 309 (2.9%)

SCQ administration – in process...

Gautena: review of previously diagnosed cases:

Population: 52 children (age 7 to 9)

Agreed for review: 80%



MINISTERIO
DE CIENCIA
E INNOVACIÓN



ASD SCREENING IN THE NATIONAL HEALTH SYSTEM OF CASTILLA Y LEÓN

Population: 1 M

Period: 2005 -2017

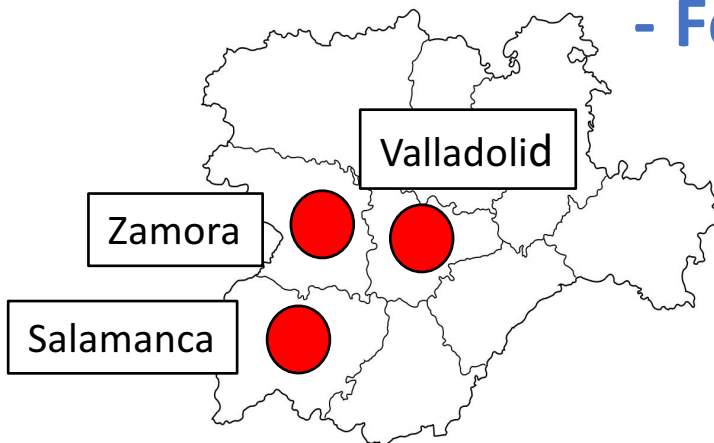
Instruments: M-Chat, M-Chat-R, App

Questionnaires: **24,378** (14 – 36 months of age)

Positives: 221 (190 assessed) (24 refused, 7 pending)

- For any developmental disorder: n. 118 / 60%

- For ASD: n. 72 / 40%

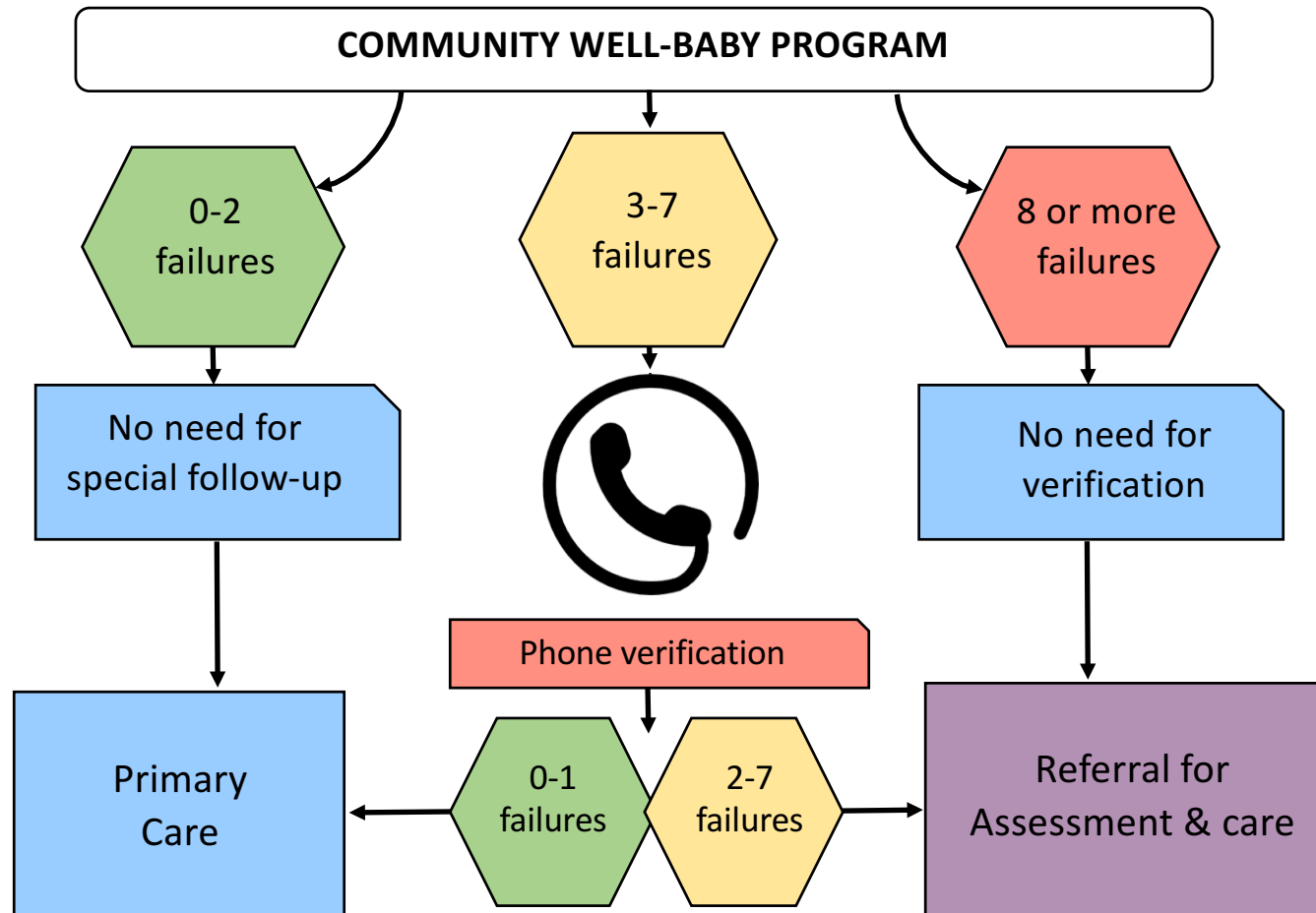


~ 22,000 children



Personal communication – Prf. R. Canal (2017) – unpublished material

Current algorithm with M-CHAT-R for ASD screening (2014-2016)

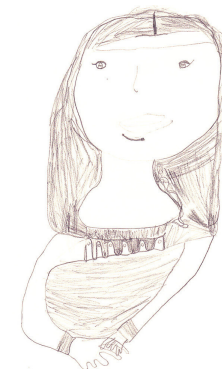


POPULATION REGISTRIES

M-CHAT-R



TEACHER NOMINATION
VS. SCQ



The Matterhorn



WHEN SHOULD I BE CONCERNED?



Reduced engagement with social stimuli in 6-month-old infants with later autism spectrum disorder: a longitudinal prospective study of infants at high familial risk

These findings suggest that high-risk infants who are later diagnosed with ASD have disrupted or delayed attention engagement for social stimuli at 6 months old. As the child ages and developmental milestones are passed, this early disruption in social attention may cascade into reduced social engagement.



2,500 HR
1,500 LR



HR Sibs  **20% ASD**



Please, screen!!



Centro de Investigación
en Neurociencia
Cognitiva del Lenguaje

Hizkuntzaren Neurozientzia
Kognitiboko Ikerketa
Zentroa



BASQUE CENTER
ON COGNITION, BRAIN
AND LANGUAGE



Lisa B. Wilson

Postdoctoral researcher
Marie Curie Fellowship 2016-2018

EEG + Infrared Spectroscopy + Dev. Assessment

Biomarkers of disordered language in infants at risk for autism

Subjects: 18, 24, 36 month old infants

- 1) HIGH RISK: Infants with an older sibling with autism
- 2) LOW RISK: Infants with a typically developing older sibling



Day 1

- Consent
- Family Interview
- Autism Measures
- Clinical Scale



Day 2

- Clinical Results
- EEG
- Brain Activity to:
 - Speech
 - Tones



Day 3

- Retest EEG



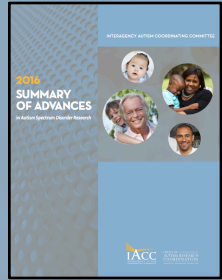
WHEN SHOULD I BE CONCERNED?



School-age outcomes of infants at risk for autism spectrum disorder

HR & LR children followed up to 9 years old. There were individual changes over time, but most were consistent. ASD related aspects ("Phenotype") was the main concern (38% HR vs.13% LR). ADHD was the second clinical concern. SRS was useful, whereas typical school focus (IQ & language) were not.

WHEN SHOULD I BE CONCERNED?



Risk of psychiatric and neurodevelopmental disorders among siblings of probands with autism spectrum disorders

Finnish Registries: 37% of ASD – SIBs had at least one disorder

	ASD - CASE	ASD - SIB	CONTROLS	THEIR SIBS
Number	3,578	6,022	11,725	22,127
ASD		10%		1%
Learning / Coordination		15%		6%
ADHD		5%		1.5%

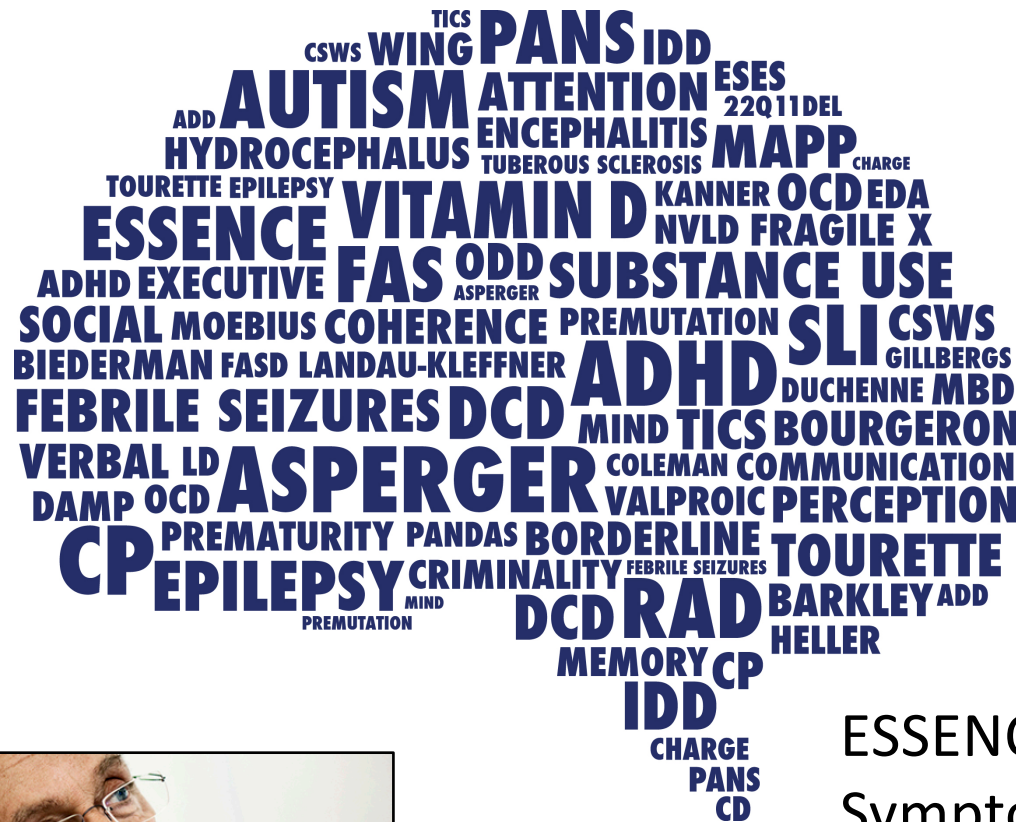
Jokiranta-Olkonieni E & col. *JAMA Psychiatry*. 2016 Jun 1;73(6):622-9.



Gillberg Neuropsychiatry Centre Sahlgremska Academy



UNIVERSITY OF
GOTHENBURG



ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) (2010)



WHICH TREATMENTS AND INTERVENTIONS WILL HELP?



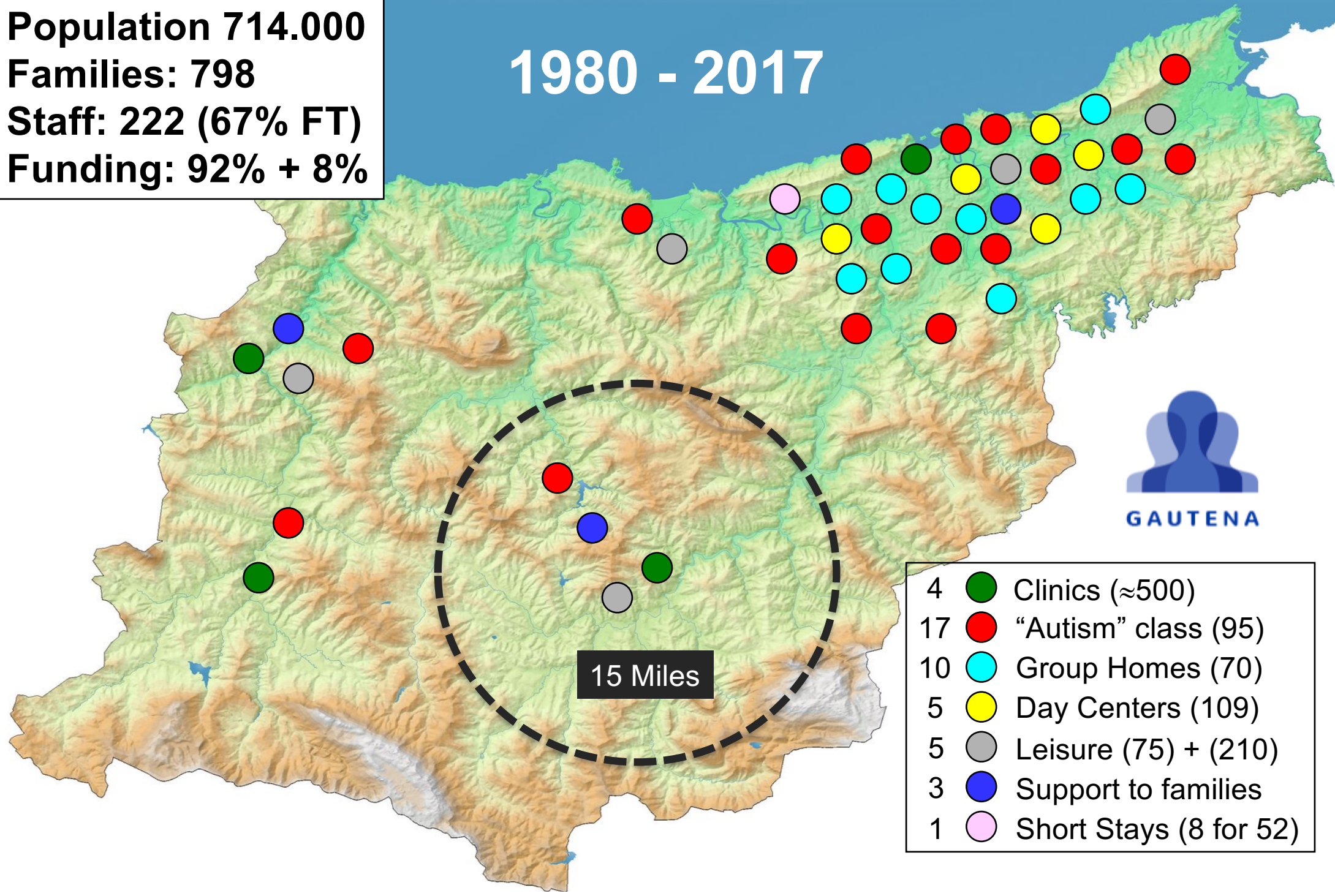
Children with autism spectrum disorder and social skills groups at school: a randomized trial comparing intervention approach and peer composition

Adult instructor school-based intervention in small-groups of students with ASD, led to more relationships than just engaging efforts. Both are needed, but the study did not consider effects in the other students.

Kasari C and Col. *J Child Psychol Psychiatry*. 2016 Feb;57(2):171-9. [PMID: 26391889]

Population 714.000
Families: 798
Staff: 222 (67% FT)
Funding: 92% + 8%

1980 - 2017



WHICH TREATMENTS AND INTERVENTIONS WILL HELP?



Longitudinal effects of adaptive interventions with a speech-generating devices in minimally verbal children with ASD

The data indicates that SGDs in combination with a development-based behavioral intervention can significantly improve social communication skills in minimally verbal children with ASD.

A randomized study of 61 minimally verbal 5- to 8-year-old children with ASD



Launched six years ago...

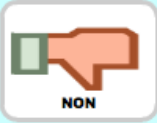
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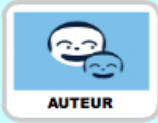
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SORTIR

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MES DONNÉES

OBJETS

ACTIONS

PERSONNES

LIEUX

INTÉRÊTS

SANTÉ

ADJECTIFS

PHRASES

ALIMENTS

APPRENTISSAGES

1

PERSONNALISATION 1

2

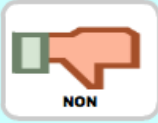
PERSONNALISATION 2



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NON



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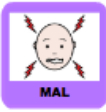
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INJECTION



MÉDICAMENT



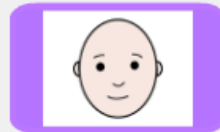
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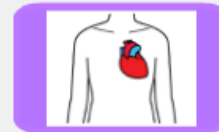
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BOUCHE



VISAGE



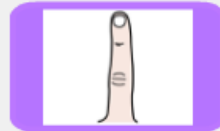
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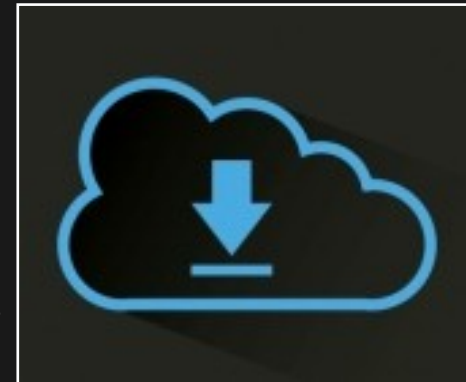
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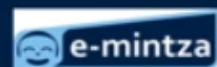
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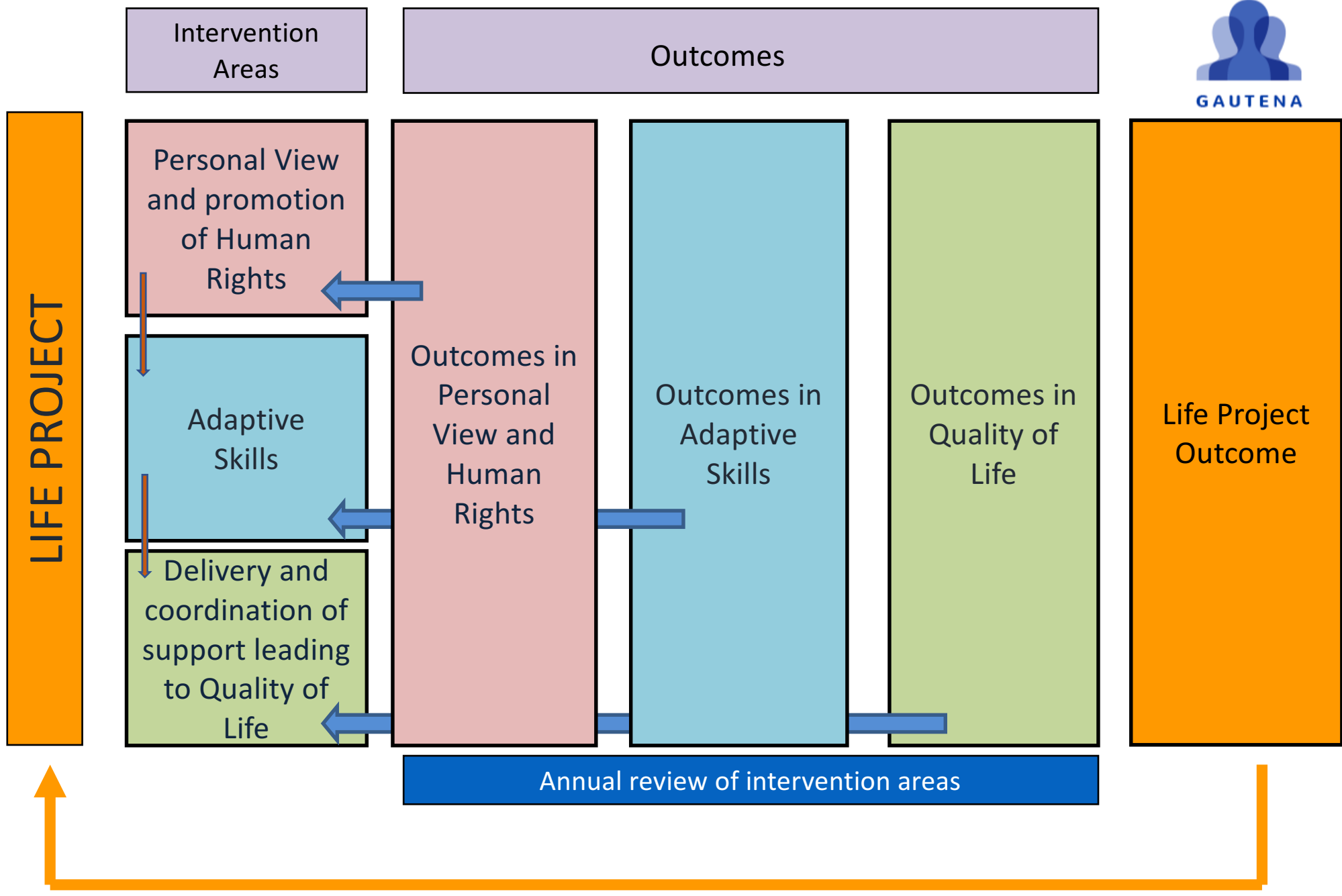


In Spanish

<http://www.policlinicagipuzkoa.com/e-mintza.php>

Transition





Intervention
Areas

Outcomes



LIFE PROJECT:

Autism only “informs”,

The person is the one to design it.

Annual review of intervention areas

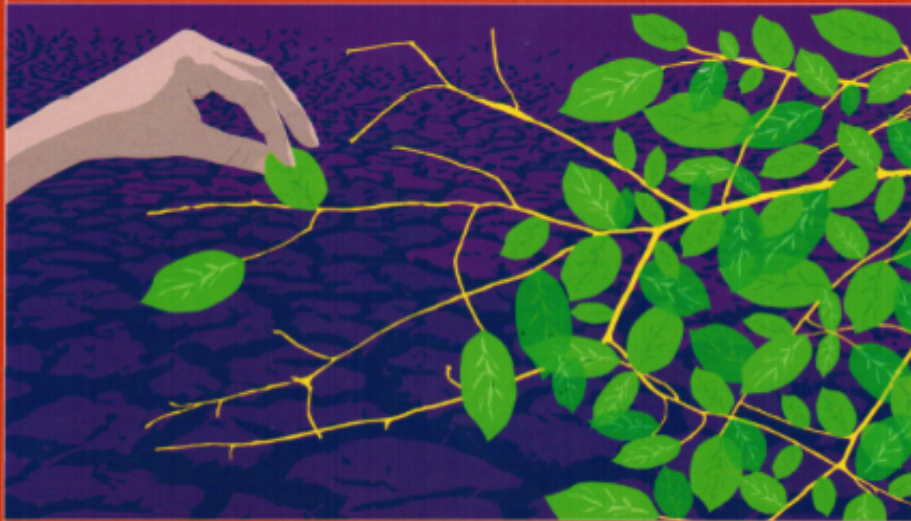
NAMED WORKER

EMPOWERMENT



Journal of the American Academy of CHILD & ADOLESCENT PSYCHIATRY

Volume 52 | Number 3 | March 2013



<p>HERE AND THERE 215 Adolescence and Adversity CLINICAL PERSPECTIVES 217 Telepsychiatry: Time to Connect TRANSLATIONS 220 Mentalization-Based Treatment: Can It Be Translated Into Practice? EDITORIALS 223 Treating Trichotillomania Across the Lifespan 225 Do Stimulants Prevent Substance Use and Misuse Among Youth With ADHD?</p>	<p>228 Tools for Effective Early Intervention for Preschool ADHD NEW RESEARCH 231 N-Acetylcysteine for Pediatric Trichotillomania 241 Age and Gender Correlates of Hoarding 250 Adolescent Substance Use in the MSA 264 PATS: 6-Year Follow-Up 279 Meta-Analysis of fMRI Correlates in ASD</p>	<p>290 Amygdala Connectivity in Adolescent GAD 300 Beyond Autism: Outcomes of High-Risk Siblings 309 Risk of Psychiatric Disorders After Late Preterm Birth LETTERS TO THE EDITOR 319 Risks Interpreting Odds BOOK FORUM 321 Electric Dreams</p>
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Advancing the science of pediatric mental health and promoting the care of youth and their families

Autism Spectrum Disorders: Ten Tips to Support Me

Joaquin Fuentes, MD

The recently revised American Academy of Child and Adolescent Psychiatry Practice Parameter for the Assessment and Treatment of Children and Adolescents With Autism Spectrum Disorder¹ highlights the importance of clinicians maintaining an active role in family and individual support. Its evidence-based recommendations coincide with those of the International Association for Child and Adolescent Psychiatry and Allied Professions, the European Society for Child and Adolescent Psychiatry, and Autism Europe.² In contrast, in Europe, there is a greater emphasis on an approach to children and adolescents with autism spectrum disorder that is based on rights, participation, and quality. Inclusion Europe³ leads a campaign for making information easily understandable as an essential mechanism to foster citizen participation, ensure informed choice, and protect human rights.

Recognizing the complementary strengths in these approaches, my colleagues and I have produced a tool to empower stakeholders, guide caregivers, and provide a rationale for advocates. The document was originally produced by its author and then reviewed, edited, and formally endorsed by a self-support group of young persons with Asperger disorder and by the Board of Families from the Gipuzkoa Autistic Society, the largest autism community program in southern Europe.

It is hoped that this document, also accessible in Basque, French, and Spanish in Supplement 1 (available online), will become a framework for clinical practice and global advocacy.

AUTISM SPECTRUM DISORDERS: 10 TIPS TO SUPPORT ME

1. I am not "autistic." I am first, foremost, and always a person, a student, a child, and I have

autism. Do not confuse me with my condition. And, please, do not use the term in a negative or inconsiderate way. I deserve to be respected.

2. I am an individual. Having autism does not make me the same as other people with autism. Make an effort to know me as an individual, to understand my strengths, my weaknesses, and me. Ask me—and my friends and my family, if I cannot reply—about my dreams.

3. I deserve services, just like all children. Services for me begin early. Autism is—or it will be, when recognized—a public health issue in many countries of the world. There are instruments to screen it. They should be applied in the framework of screening for other developmental disabilities. If you start soon, my life will be different! And remember that about one quarter of my siblings will have autism or other problems. Help them; they are an important part of my life.

4. I belong in the health care system, just like all children. Include me in regular health care. The health care system should adapt to me, limiting waiting times and ensuring that I understand what is to be done, by using, for example, easy-to-read materials, pictograms, technologic means, and so forth. Other patients also will benefit.

5. I belong with other children. Do not separate me from them because you want to treat me, educate me, or care for me. I can, and I should, be placed in regular schools and regular community settings, and special support should be provided to me in those places. I have something to teach other children and something to learn from them.

6. I belong with my family. Plan with me for my future and my transitions. I am the one who should decide, and, when my ability to do so is limited, my family and friends will speak for me. No government agency can take the



Supplemental material cited in this article is available online.



FUENTES TEN TIPS

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Cerca de 430,000 resultados (0.56 segundos)

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[Autism Spectrum Disorders: Ten Tips to Support Me ...](#)

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de J Fuentes - 2014 - [Artículos relacionados](#)

Autism Spectrum Disorders: **Ten Tips** to Support Me ... Disclosure: Dr. **Fuentes** has received research support, has served as unrestricted speaker for, or has ...

[Autism Spectrum Disorder: Ten Tips Guidance Article](#)

www.elsevier.com/.../autism-spectrum-disorder-ten-t... ▾ [Traducir esta página](#)

4 nov. 2014 - Dr. **Fuentes** said of his article, "We see in our nations a radical evolution ... The article "Autism Spectrum Disorders: **Ten Tips** to Support Me" by ...

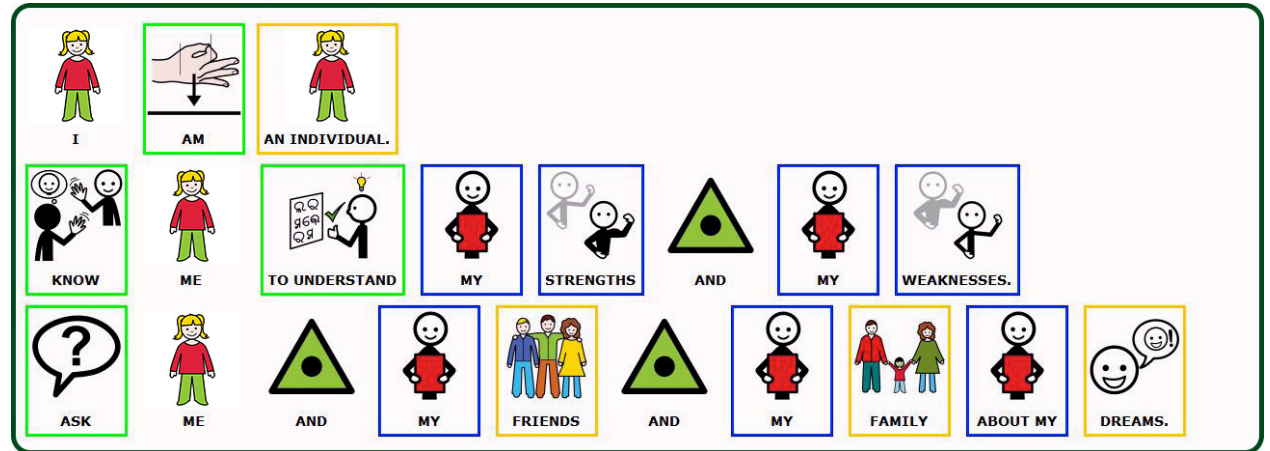
[Ten Tips to Support Me | Autism Speaks](#)

<https://www.autismspeaks.org/.../ten-tips-support-me> ▾ [Traducir esta página](#)

Ten Tips to Support Me. Google+. Be a champion for inclusion for all who have autism! A renowned autism researcher-doctor-advocate asks the autism ...

Online supplemental material in 42 languages

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Dutch	Romanian
Estonian	Russian
Farsi	Serbian
Galician	Slovak
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Hausa	Turkish
Hebrew	Ukrainian
Hindi	Urdu
Hungarian	English Pictograms
Igbo	Spanish Pictograms

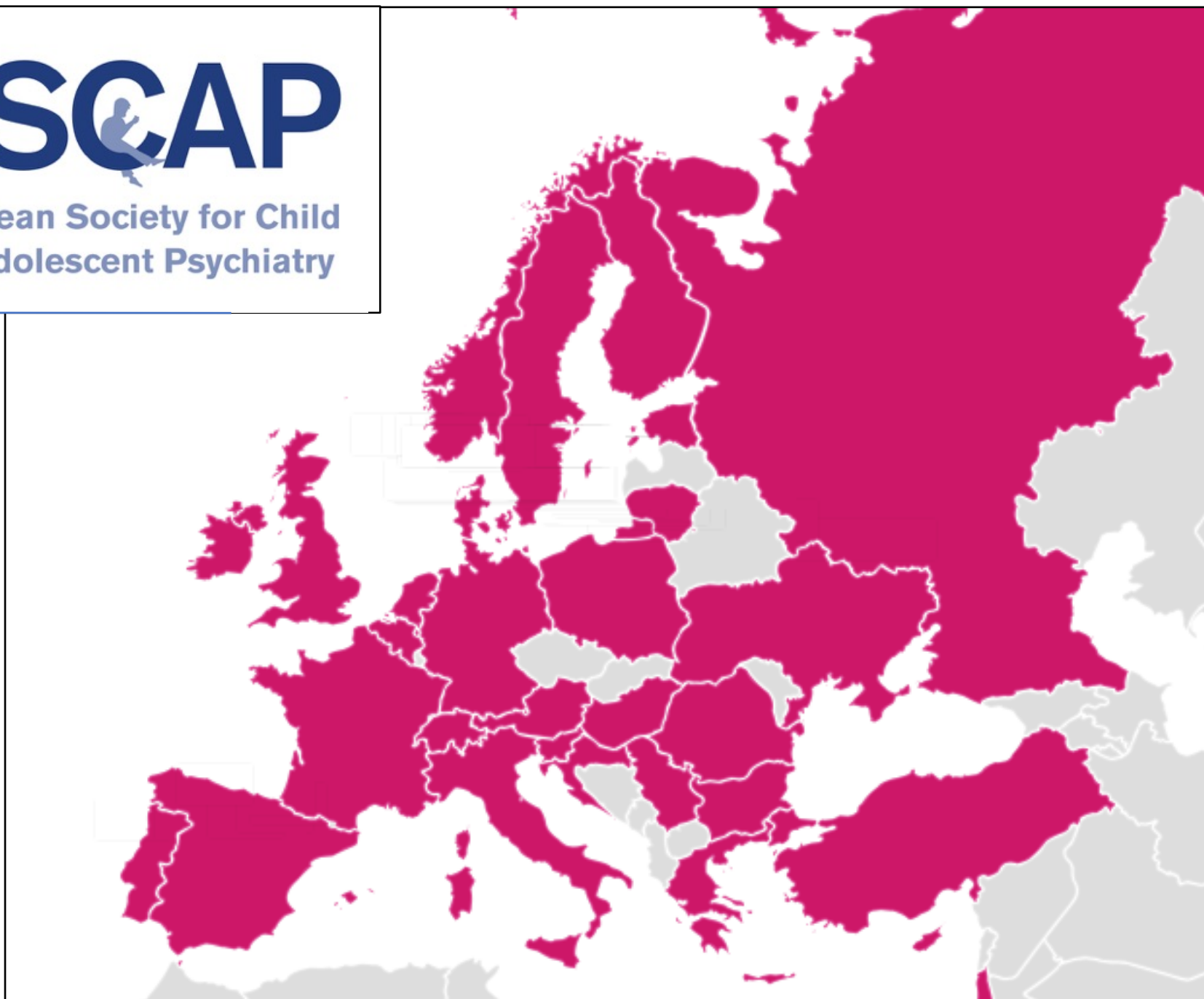


Mary K. Billingsley, ELS
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ASD TASK FORCE



Joaquín Fuentes
Spain



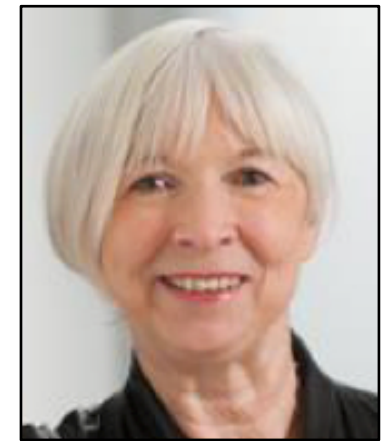
Thomas Bourgeron
France



Rutger van der Gaag
The Netherlands



Christopher Gillberg
Sweden



Patricia Howlin
United Kingdom

ESCAP

European Society for Child
and Adolescent Psychiatry

ASD TASK FORCE

CAP National Societies from 32 Countries

Projects:

- Educational video-clips (2017)
- ESCAP European Practice Guidelines on ASD (2018)



ASD VIDEOCLIPS PACKAGE





GENERAL ASPECTS OF ASD



Joaquín Fuentes
Policlínica Gipuzkoa, SPAIN



DIAGNOSTIC ASPECTS OF ASD



Rutger van der Gaag
Radboud UMC, The Netherlands



GENETIC ASPECTS OF ASD



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COMMORBIDITIES OF ASD



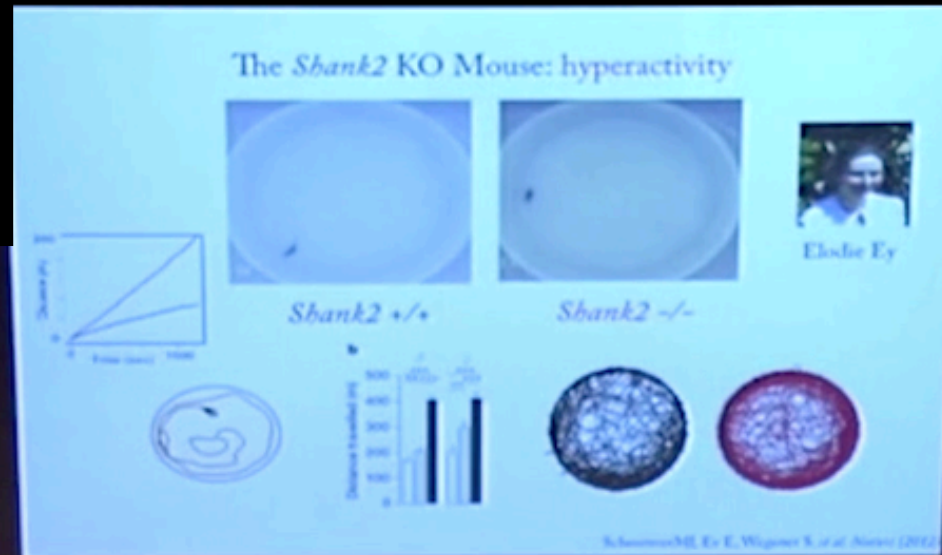
Christopher Gillberg
University of Gothenburg, Sweden



ADULTHOOD IN ASD



Patricia Howlin
King's College, United Kingdom



“...the shank 2 KO Mouse hyperactivity, opens new ways to consider interplay...”



12 - 15 Minutes

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ASD Study Group

National Institute of Health Carlos III, Spain

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REV NEUROL 2006; 43 (7): 425 - 438

International ASD Guidelines

SIGN Scottish Intercollegiate Guidelines Network

NHS Quality Improvement Scotland

98 Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders
A national clinical guideline

1 Introduction 1
2 Definitions and concepts 3
3 Recognition, assessment and diagnosis 5
4 Principles of intervention 15
5 Non-pharmacological interventions 16
6 Pharmacological intervention 23
7 Service provision 25
8 Information for discussion with children, young people, parents and carers 29
9 Implementation, resource implications and audit 36
10 Development of the guideline 39
Abbreviations 44
Appendix 44
References 66

QI Quality Improvement Scotland
This guideline can be used in settings with the remit of ASD specific resources developed by NHS Scotland for Scotland.

July 2007

COPIES OF ALL SIGN GUIDELINES ARE AVAILABLE ONLINE AT WWW.SIGN.AC.UK

ae AUTISM EUROPE

An AE official document on autism endorsed by
Catherine Bachmann
Jonas Fombonne
Pablo Quintana
Rupprecht von Gaig

PERSONS WITH AUTISM SPECTRUM DISORDERS
Identification, Understanding, Intervention

A 2010 CONSENSUS PUBLICATION
Missouri Autism Guidelines Initiative

Sponsored by the Thompson Foundation for Autism and the Institute of Developmental Disabilities, Missouri Department of Elementary and Secondary Education and Missouri Department of Health and Senior Services

This document has been produced with the support of the European Commission. The contents of these pages do not necessarily reflect its content or views.

Autism Spectrum Disorders: Guide to Evidence-based Interventions

A 2010 CONSENSUS PUBLICATION
Missouri Autism Guidelines Initiative

Sponsored by the Thompson Foundation for Autism, the Division of Developmental Disabilities, Missouri Department of Elementary and Secondary Education, Missouri Department of Health and Senior Services and the Missouri Department of Health and Senior Services

AUTISM

THE NICE GUIDELINE ON RECOGNITION, REFERRAL, DIAGNOSIS AND MANAGEMENT OF ADULTS ON THE AUTISM SPECTRUM

NATIONAL COLLABORATING CENTRE FOR MENTAL HEALTH

Autism
Caring for Children With Autism Spectrum Disorders

A Resource Toolkit for Clinicians

American Academy of Pediatrics

Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment

A 2010 CONSENSUS PUBLICATION
Missouri Autism Guidelines Initiative

Sponsored by the Thompson Foundation for Autism and the Institute of Developmental Disabilities, Missouri Department of Elementary and Secondary Education, Missouri Department of Health and Senior Services and the Missouri Department of Health and Senior Services

NHS National Institute for Health and Clinical Excellence

Autism
Recognition, referral and diagnosis of children and young people on the autism spectrum

Issue date: September 2011

NICE clinical guideline 129
Developed by the National Collaborating Centre for Women's and Children's Health

NICE National Institute for Health and Care Excellence

Autism
The management and support of children and young people on the autism spectrum

Issued: August 2013

NICE clinical guideline 170
guidance.nice.org.uk/gip/170

NICE has accredited the process used by the Centre for Clinical Practice of NICE to produce guidance. Accreditation is valid for seven years (September 2009 and expires in September 2016) and applies to guidance produced since August 2009 using the process described in NICE's 'The guidelines manual' (2007, updated 2014). More information on accreditation can be found at www.nice.org.uk/accreditation.

IACAP OFFICIAL ACTION

Practice Parameter for the Assessment and Treatment of Children and Adolescents With Autism Spectrum Disorder

Fred Volkmar, MD, Matthew Siegel, MD, Marc Woodbury-Smith, MD, Bryan King, MD, James McGeehan, MD, Matthew Stone, MD, and the American Academy of Child and Adolescent Psychiatry (AACAP) Committee on Quality Issues (CQI)

Autism spectrum disorder is characterized by patterns of delay and deviance in the development of social, communicative, and cognitive skills that arise in the first years of life. Although frequently associated with intellectual disability, the condition is distinctive in its course, impact, and treatment. Autism spectrum disorder has a wide range of syndrome expression and its management presents particular challenges for clinicians. Individuals with an autism spectrum disorder can present for clinical care at any point in development. The multiple developmental and behavioral problems associated with this condition necessitate multidisciplinary care, coordination of services, and advocacy for individuals and their families. Early, tailored intervention and the use of multiple treatment modalities are indicated. J. Am. Acad. Child Adolesc. Psychiatry. 2015;54(2):213-229. Key Words: autism, practice parameters, guidelines, developmental disorders, pervasive developmental disorders

Since the first Practice Parameter for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and Other Pervasive Developmental Disorders was published, several thousand research and clinical articles have appeared and the diagnostic criteria for autism have changed. This Parameter revision provides the opportunity to update the previous version and incorporate new research. Because the recent body of research was performed under the DSM-IV-TR diagnostic schema, the evidence will be presented using that terminology. This Parameter is applicable to evaluation of children and adolescents (17 years of age) but often will have some relevance to adults. This document presumes basic familiarity with aspects of normal child development and child psychiatric diagnosis and treatment. Unless otherwise noted, the term child refers to adolescents and younger children, and parents refers to the child's primary caretakers regardless of whether they are the biological or adoptive parents or legal guardians.

METHODOLOGY
The first version of this Parameter was published in 1999. For this revision, the literature search covered the period from 1991 to March 19, 2013 using the PubMed, PsycINFO, Cochrane, and CINAHL (EBSCO) databases. The initial searches were inclusive and sensitive. Search terms were a combination of MeSH headings and keywords, and the MeSH headings were subject to terms used by PsycINFO and CINAHL by using their thesauri. In PubMed, the MeSH terms autistic disorder, childhood development disorder—pervasive, Asperger*, and Rett* and the keyword autism were searched. The initial search yielded 23,887 results. The results were limited to English, human, all child (0 to 18 years), and 1991 to March 19, 2013. Additional limits included classic article, clinical trial, comparative study, controlled clinical trial, evaluation studies, guideline, historical article, meta-analysis, practice guideline, unpublished study, randomized controlled trial, review, twin study.

DOI: 10.1093/aacap/aaa012
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VOLUME 54 NUMBER 2 FEBRUARY 2015 www.000099.org 337

Chapter C.2
DEVELOPMENTAL DISORDERS

AUTISM SPECTRUM DISORDER
2014 Edition

Joaquín Fuentes, Muiden Bakare, Kerim Munir, Patricia Aguayo, Naoufel Gaddour & Özgür Öner

Joaquín Fuentes MD
Child and Adolescent Psychiatry Unit, Hospital General de Ginecología, Ginecología y Obstetricia, Instituto de Diagnóstico y Referencia Epidemiológica, Secretaría de Salud, México

Muiden Bakare MD
Child and Adolescent Psychiatry Unit, Federal Neuro-Psychiatric Hospital, Enugu State University of Science and Technology, Enugu, Nigeria

Kerim Munir MD
Consultant in Autism research support from the National Institute of Health (NIH), Fogarty International Center, NIH, Grand Challenges Canada

Naoufel Gaddour MD
Child and Adolescent Psychiatry Unit, Hospital General de Ginecología, Ginecología y Obstetricia, Instituto de Diagnóstico y Referencia Epidemiológica, Secretaría de Salud, México

Özgür Öner MD
Child and Adolescent Psychiatry Unit, Hospital General de Ginecología, Ginecología y Obstetricia, Instituto de Diagnóstico y Referencia Epidemiológica, Secretaría de Salud, México

IACAPAP
International Association for Child and Adolescent Psychiatry and Allied Professions

And more...

asdeu

Autism Spectrum Disorders in the European Union

AUTISM PLANS, STRATEGIES AND DISABILITY POLICIES IN THE FIELD OF HEALTH, EDUCATION AND SOCIAL INCLUSION IN THE EUROPEAN UNION

**A REVIEW OF THE INSTRUMENTS AND MEASURES IN PLACE
TO SUPPORT PEOPLE ON THE AUTISM SPECTRUM AND
THEIR FAMILIES AT ALL AGES**



ASDEU has received funding from the European Commission by the framework European Commission. Health and Consumers, Directorate-General.

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SANCO/2014/C2/035

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Italy	Wales (UK)

ESCAP

European Society for Child
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**European Practice Guidelines
on Autism Spectrum Disorder**

2018

NICE Guidelines (UK)

DGKJP/DGPPN

Dutch Knowledge Centre for CAP

Autism Europe

EAIS

Hungarian Guidelines

ASD Info Wales

Linea Guida 21 - Italia

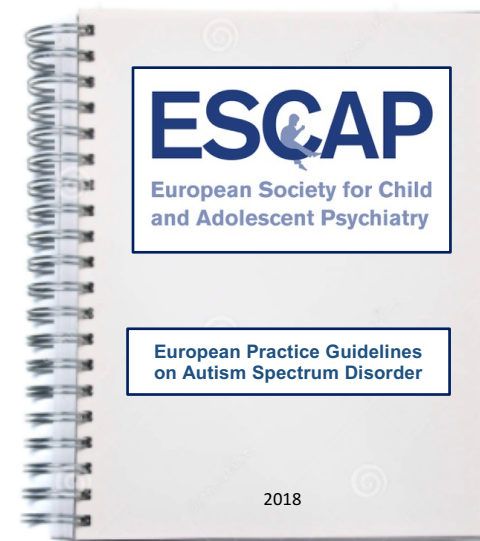
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WE NEED YOU



PLEASE, SEND US ANY RELEVANT GUIDELINE YOU KNOW OR HAVE PRODUCED

fuentes.j@telefonica.net

HOME MESSAGE FOR PROGRAM DEVELOPMENT?

1. **Embed your program in the community and ensure interdepartmental support**
2. **Follow best practice guidelines**
3. **Search for outcomes**
4. **Empower stakeholders**



(Caution: not ranked in importance!!)

17th
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TRANSITION

Child and adolescent psychiatry
in a world of change

**ESKERRIK ASKO
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