

# Autism care pathway in Europe

**Maria Andreina Mendez, Antonia San Jose Caceres, Bethany Oakley,  
Roberto Canitano, Michela Tinelli, Martin Knapp, James Cusack,  
Mara Parellada, Pierre Violland, Jan Roderik Plas, Declan Murphy,  
Vinciane Quoidbach, Celso Arango**

*Autism working group lead: Professor Celso Arango, Hospital General  
Universitario Gregorio Marañón, Madrid, Spain*

## Background

Autism is a lifelong complex neurodevelopmental condition of early onset that affects brain development and behaviour, characterized by difficulties in social communication, restricted and repetitive patterns of behaviour, interests or activities, and sensory issues which have significant consequences in daily life<sup>1</sup>.

Early intervention can play a crucial role in the earlier social-communicative and emotional development which will act as a bridge for other more complex abilities<sup>2</sup>. The primary goal of early intervention is to maximize functional independence and quality of life<sup>3</sup>. Despite its great societal and personal impact, Europe-wide consensus and support for early detection, diagnosis, and intervention of autism are lacking<sup>4</sup>.

The objectives of this study were:

1. To analyse autistic children care pathway and early journey in three European countries: Italy, Spain and the United Kingdom.
2. Propose policy recommendations on how to improve the care pathway (i.e. minimise treatment gaps).

## Methods

The care pathway of autistic children was analysed from a carer, autism community and professional perspective to identify major barriers (treatment gaps) preventing carers of autistic children from receiving information, support, timely screening/diagnosis and treatment/intervention.

We conducted a very rapid literature review of the existing care pathway in Europe. We also conducted a survey aimed at carers of autistic children ages 0 to 18 living in Italy, Spain and the UK. Additionally, members of the working group met in Brussels and remotely (due to the COVID-19 pandemic) between 2019 and 2021 to identify the main treatment gaps and their causing factors, prepare a survey to evaluate service users unmet needs, discuss results, and propose policy recommendations.

Survey was approved by local ethics committees in Italy, Spain and the UK.

The following critical points of the care pathway were addressed:

1. Screening/diagnosis after carers raise first concerns to health professionals.
2. Intervention/treatment once diagnosis is confirmed.
3. Information about access to services and support for families and carers of autistic children.

### Sample characteristics

Autistic child's age at time of survey, mean (SD)	10.17 (4.39)
Sex of autistic child (% male, % female)	76,8%, 23,2%

Country	Male	Female	Total
Italy	129	29	158
Spain	222	65	287
UK	158	60	218
<b>Total sample</b>	<b>509</b>	<b>154</b>	<b>663</b>

### Quotations from survey respondents (parents or carers):

*"No one from health services mentioned a possibility of autism until my child was 11 years old."*

*"Health professionals are not trained in autism."*

*"There are not enough diagnostic clinics/services."*

*"Never received any early intervention programme."*

*"Early intervention is crucial."*

*"I was given minimal information after diagnosis."*

# Treatment Gaps/Unmet Needs

Current care pathways (split by treatment gap) averaged across data sources and countries. For specific country data, please see figures on the right.

## 1. Delayed screening and diagnosis:

- 70% of family members raised first worries about their child’s development and/or behaviour, 19% were raised by school/nurseries staff while only a concerning 6% were raised by health staff.
- 28% of respondents stated it took them over a year after first worries were raised to be offered a screening visit.
- 44% of respondents reported it took them over one year after the screening visit to have a diagnosis assessment.

## 2. Delayed or no access to intervention once diagnosis has been confirmed:

- 36% of respondents stated that the autistic children did not receive any intervention after diagnosis. Despite the high percentage of people in Spain and Italy receiving intervention after diagnosis, a good proportion of these relied on private funding or a combination of both private and public funding.

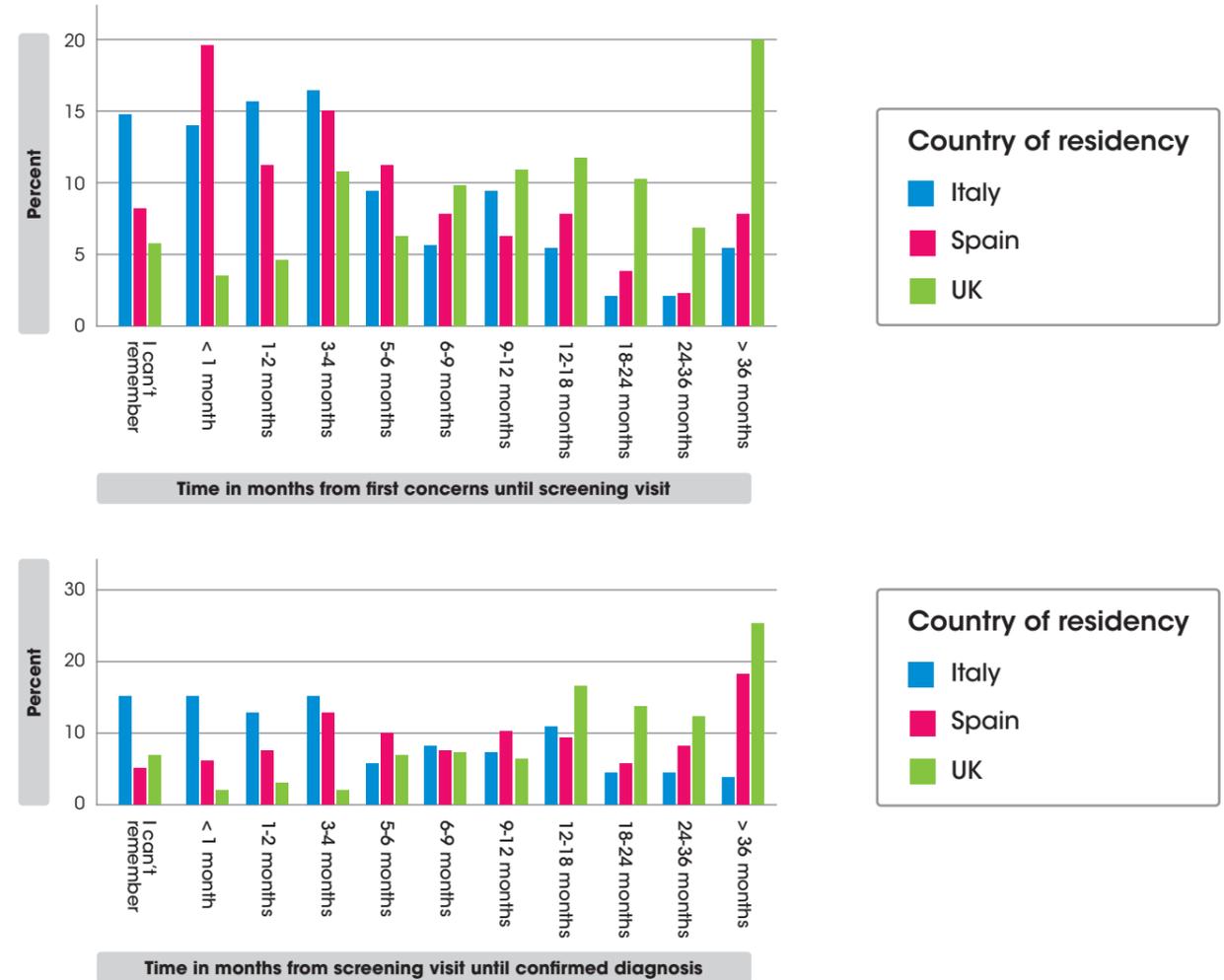
## 3. Limited information about autism and how to access early detection services:

- 62% of respondents reported that it was not easy to access information about early detection services.

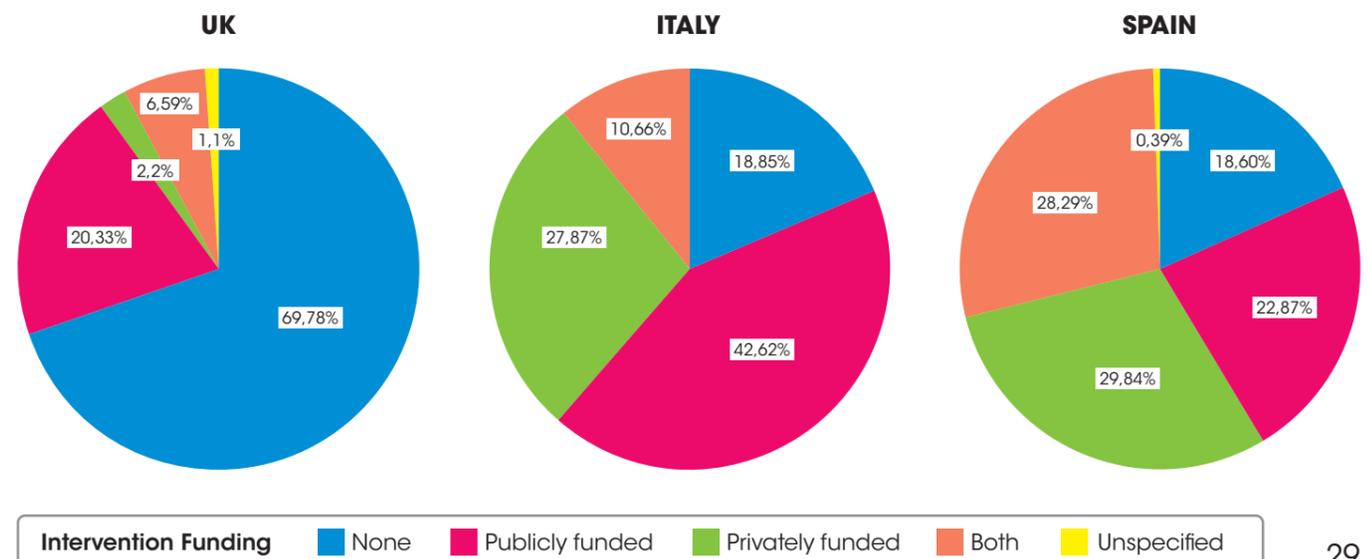
## 4. Lack of support to parents/carers of autistic children:

- 41% of respondents reported receiving no guidance or support after raising their first concerns to their assigned professional.
- 30% of respondents said they received very little or no support after the diagnosis was confirmed.
- 58% of carers that took part in our survey, said they had not received any training, coaching, or counselling to help them cope with their child’s difficulties.

# Screening/diagnosis times in each country:



# Early intervention funding:



## Recommendations

- **Raise awareness** among parents, family members, the community and primary care providers about developmental milestones, the early signs of autism and the importance of early detection and early intervention.
- **Encourage professionals to listen** to family concerns **and address** them immediately.
- **Increase autism-specific triage programmes** at well baby clinics.
- **Provide autism training** to first-line health professionals.
- **Reduce the delay in screening and diagnosis**, thus enabling children **to begin intervention programmes earlier**.
- **Increase support** to families of children diagnosed with autism.
- **The development of evidence-based interventions** for autistic people and their families must be considered a key research and clinical priority.
- **Perform further assessment** in order to identify and learn from countries/areas with better patient journey experiences.
- **Reduce economic inequality**.

## Acknowledgements:

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### References:

<sup>1</sup>World Health Organization 2018; <sup>2</sup>Myers et al 2021; <sup>3</sup>Magan-Maganto et al 2017; <sup>4</sup>Berajamo-Martin et al 2019.

# Autism with co-occurring epilepsy care pathway in Europe

Maria Andreina Mendez, Roberto Canitano, Bethany Oakley, Antonia San Jose Caceres, Michela Tinelli, Martin Knapp, James Cusack, Mara Parellada, Pierre Violland, Jan Roderik Plas, Declan Murphy, Vinciane Quidbach, Celso Arango

*Autism working group lead: Professor Celso Arango, Hospital General Universitario Gregorio Marañón, Madrid, Spain*



Comunidad de Madrid



## Background

Autism and epilepsy are frequently associated. The prevalence of epilepsy in autism is greater than in the general population<sup>1,2</sup>. Electroencephalography (EEG) has been used to investigate epilepsy in autism<sup>3</sup>. EEGs are recommended if there is clinical suspicion of epilepsy<sup>4</sup>. However, the clinical identification of seizures in autism can be challenging because some of the features of seizures such as staring spells, non-responsiveness and repetitive motor behaviours are also manifestations of autism<sup>5</sup>.

Associated conditions in autism such as epilepsy have a substantial impact on the well being of autistic people and their families, contribute to reduced quality of life and may increase premature mortality<sup>6</sup>. Despite this, there is a current lack of studies assessing the journey experienced by autistic children with co-occurring epilepsy and their families in Europe.

The objectives of this study were:

1. To analyse autistic children with associated epilepsy's care pathway in three European countries: Italy, Spain and the United Kingdom (UK).
2. To propose policy recommendations on how to improve this care pathway (i.e. minimise treatment gaps).

## Methods

The care pathway was analysed in order to identify major barriers preventing parents or carers of autistic children from receiving timely screening, diagnosis and treatment of possible co-occurring epilepsy.

We developed a survey aimed at parents or carers of autistic children ages 0 to 18 living in Italy, Spain or the U.K. The purpose of this survey was to collect information about carers' experience with local services from the moment they noticed difficulties with their children behaviour and/or neurodevelopment (first concerns), the time an autism diagnosis was confirmed, if an EEG was collected, time EEG was conducted, if autistic children were diagnosed with associated epilepsy and if epilepsy was treated.

Survey was approved by local ethics committees in the three countries.

## Current pathway

552 of respondents (n=663) completed the questions about an associated epilepsy diagnosis (*Table 1*).

The majority of respondents (95%) who stated their autistic children were diagnosed with associated epilepsy said their children had an EEG done. The majority of the respondents (77%) stated EEGs were publicly funded.

The average age (in years) when epilepsy was diagnosed was 5.4 (SD 3.7) in Spain, 7.17 (SD 4.3) in Italy and 10.44 (SD 4.54) in the U.K.

The average age antiepileptic medication was initiated was 6.3 (SD 3.98) in Spain, 6.5 (SD 3.9) in Italy and 10.4 (SD 4.1) in the U.K.

**Table 1.**

Sample characteristics	
Autistic child's age at time of survey, mean (SD)	10.17 (4.39)
Sex of autistic child (% male, % female)	76,8%, 23,2%

Co-occurring diagnosis of epilepsy						
			Italy	Spain	UK	Total
Diagnosis of epilepsy	No	Count	112	221	164	497
		%	94.1%	88.0%	90.1%	90.0%
	Yes	Count	<b>7</b>	<b>30</b>	<b>18</b>	<b>55</b>
		%	5.9%	12.0%	9.9%	10.0%
Total		Count	119	251	182	552

## Treatment Gaps/Unmet Needs

### 1. Delayed screening/diagnosis of epilepsy:

The average time from a confirmed autism diagnosis until EEGs were performed was six months in Spain and one and a half years in the UK. The average time from EEGs until epilepsy diagnosis was on average one year in Spain and in the UK. The Italian sample (n=7) was too small to include in this analysis (Graph 1).

### 2. Delayed treatment of epilepsy in autistic children after diagnosis of epilepsy:

The average time from epilepsy diagnosis until medication was initiated was on average fifteen months in Spain while medication in the UK was prescribed three months before an epilepsy diagnosis was confirmed by an epilepsy specialist. The Italian sample (n=7) was too small to include in this analysis.

### 3. Lack of treatment of co-occurring epilepsy:

43% of autistic children with epilepsy in Spain and 33% in the UK were not taking any antiepileptic drugs while in Italy 100% of them were on antiepileptic drugs.

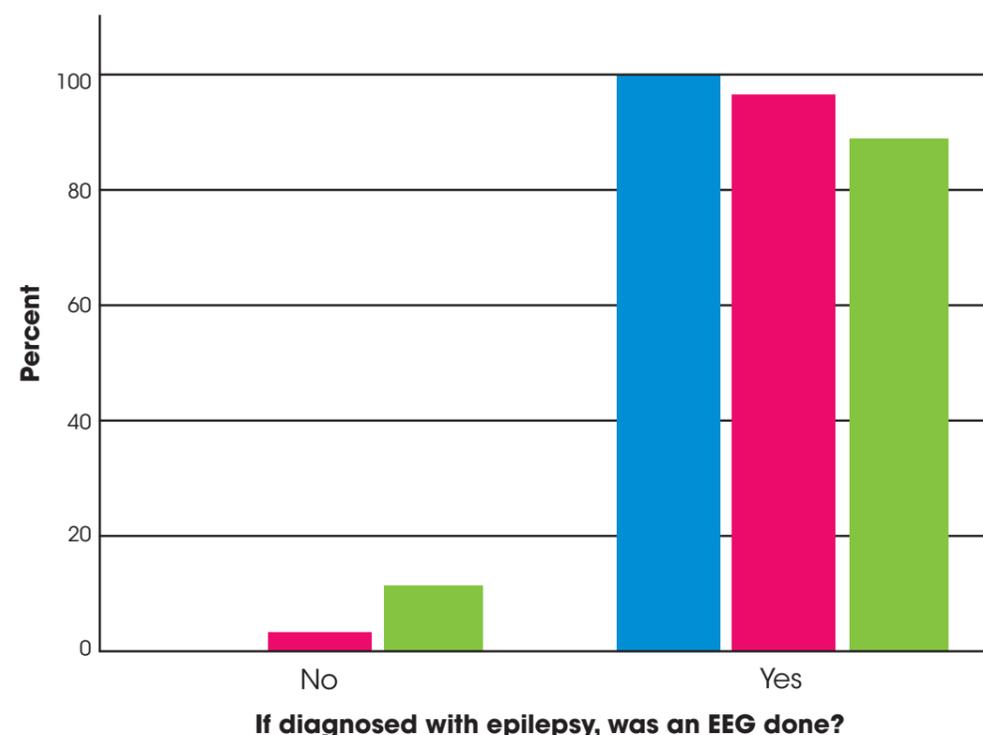
### 4. Use of multiple antiepileptic drugs:

43% of respondents in Spain stated their children were prescribed multiple antiepileptic drugs (Graph 2).

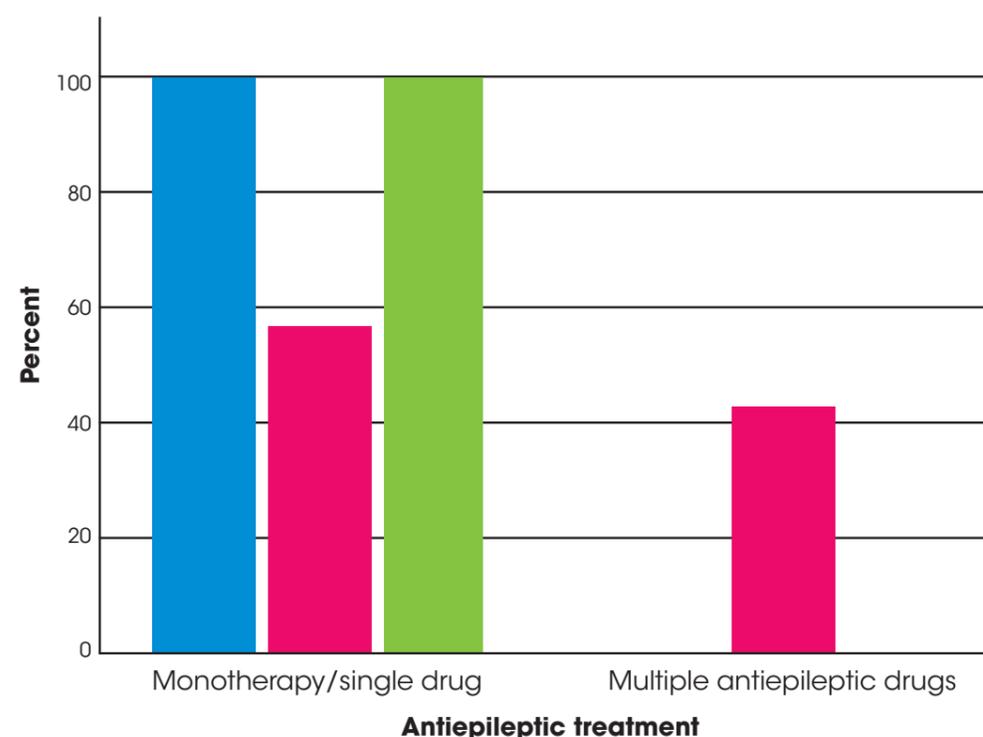
## Recommendations

- **Inform** parents/carers of autistic children and health workers about autism and epilepsy often co-occurring.
- **Provide information** on seizures characteristics, crisis management and basic life support to carers of autistic children.
- **Refer** the autistic child to an epilepsy specialist for **timely screening, diagnosis and treatment of associated epilepsy.**
- If epilepsy is suspected, **an EEG should be performed.**
- **The development of harmonized evidence-based clinical guidelines specific** to the assessment and management of epilepsy associated with autism must be considered a clinical and research priority in Europe.
- **Avoid** use of multiple antiepileptic drugs in autistic children; however, the choice of treatment should be made by the specialist (in agreement with carers) and based on seizure type and/or epilepsy syndrome.
- **Clinical monitoring** of autistic children with diagnosed epilepsy at least twice a year.

Graph 1.



Graph 2.





## Acknowledgements:

This work has received support from the EU/EFPIA/SFARI/Autistica/AUTISM SPEAKS, Innovative Medicines Initiative 2 Joint Undertaking (AIMS-2-TRIALS grant n° 777394), Servier and Roche

## References:

<sup>1</sup>Lukmanji et al 2019; <sup>2</sup>Tuchman et al., 2019; <sup>3</sup>Holler et al 2018; <sup>4</sup>NICE 2021; <sup>5</sup>Minshew et al 1997; <sup>6</sup>Mason et al 2018.

