

Family Survey - final

Identification, diagnosis and early intervention for young children with autism spectrum disorder (ASD)

A survey study to improve support for young children with ASD

Before you respond to the survey, we want to explain the reason for this research and what it will involve for you. Please take the time to read this information carefully. For more information, do not hesitate to contact Ricardo Canal (rcanal@usal.es).

The survey is designed to collect information from people who have or have recently had any direct involvement with screening, diagnosis or treatment services for young children under 6 years of age with ASD. Direct involvement means you are a close family member of a child under 6 years of age who has received any of those services and knows firsthand this kind of services for children under 6 years of age that are provided where the child lives.

The objective of the survey is to gather the opinion of each of the respondents about the clinical services for early detection, diagnosis and treatment for children with ASD under 6 years of age. Specifically, the aim is to gather information about the personal experiences that the respondents have had in relation to these issues, including age of identification and diagnosis; demographic characteristics of families; opinions on the organization of services for young children with ASD; and suggestions for ways to improve this type of service.

Ethics approval has been given by the University of Salamanca. Copies of the ethics approval letter are available if you wish to see them.

We will not ask for any identifying information – e.g. your name, your full address
Participation will last approximately 15 minutes.

Thank you for taking the time to read this Information. If you wish to complete this survey, please check all the following items

Please read the consent form below.

I have read and understood the survey information sheet

I understand that all data collected from this survey will be anonymously coded and stored confidentially and securely

I am willing to take part in this research survey

If you wish to complete this survey, please click "I agree to participate" to continue

I agree to participate

Yes

No

BACKGROUND INFORMATION The questions in this initial section will ask you about your gender, where you live, your age, your education, the current monthly household income of the family the child with autism live in (optional), the number of people living in your home, and three more questions about age, gender and verbal ability of the child with autism.

1. Please select your country and city of residence

Country
City

2. Gender

- Male
- Female

3. How old are you?

4. What is your relationship with the child with autism?

- Mother or father
- Grandparent
- Sibling
- Other, please specify: _____

5. How many people live in the municipality where you reside?

- Less than 10.000.
- Between 10.000 to 50.000.
- Between 50.000 to 150.000.
- Between 150.000 to 1.000.000.
- More than 1.000.000.

6. Please indicate the highest level of education reached

- No formal education completed
- Primary education (or similar: elementary, middle school ...)
- Secondary school, High school
- University degree
- Professional training
- College Education (Bachelor degree or higher)

7. How many people live permanently in the household of the child with ASD?

	1	2	3	4	5	6	7	8	9	10
Number of people										

8. This question is optional: Please state the current monthly household income (currency in the relevant country)

9. What is the child's with ASD age?

10. Child's gender

- Male
- Female

11. What is the child's verbal ability?

- Does not talk
- Uses single words only (e.g. "daddy", "mommy")
- Uses two- or three- word phrases (e.g. "want cookie")
- Uses sentences with four or more words (e.g. "I want a biscuit")
- Uses complex sentences (e.g. "When we get home, can I have a biscuit?")

DETECTION In this section you are going to answer questions about the process of detecting the child's difficulties with ASD before knowing the diagnosis. After this section, there will be another specific for the diagnostic process.

12. How old was the child when you or someone else first have concerns about he/she had developmental problems?

(Table Truncated to 63 Columns)

13. What was that first concern? Apply more than one, if any

- Does not direct large smiles or expressions of joy to the adult at 6 months
- Does not exchange sounds, smiles or facial expressions since 9 months
- Do not babble at 12 months
- Does not make gestures (pointing, saying goodbye by hand, etc.) at 12 months
- Does not say simple words at 16 months
- Does not say spontaneous phrases of 2 words (not simply echoics) at 24 months
- ANY loss in ANY area (language or social skill) at ANY age
- Other. please, specify _____

14. Who was the first person who suspected that something was wrong with the child's development?

- You detected the problem
- A family member. Please, specify _____
- The pediatrician or nurse from public health service
- The pediatrician or nurse from private health services
- A teacher or school staff from (nursery, kindergarten, school, etc.)
- Other. Please specify _____

15. The person who raised the first concerns about the child's development was based on (check all that apply)

- His / her knowledge about this child with ASD
- His / her own experience and knowledge on child development in general
- A questionnaire we filled in the doctor's office/ school (name of the questionnaire if you remember it) _____
- A program specifically aimed at identifying problems on communicative and social development available in health / school / social services in my city.
- Other. Please, specify _____

16. Do you consider it was easy to have access to information about programs and early detection services where you are residing?

- Yes
- No

Please, explain why

17. What was the next step in the detection process?

- We ourselves had to look for a diagnostic service
- Someone gave us a phone call to refer us to a diagnostic service
- We received a letter with a medical appointment from the hospital
- The professional who had the first concern refer us directly to a specialized service
- Other. Please, specify _____

18. How much time (in months) passed from the confirmation of the first concerns until the child was attended by an autism specialist?

- Less than 1 month
- From 1 to 2 months
- From 3 to 4 months
- From 5 to 6 months
- More than 6 months
- Other. Please, specify _____

19. Did you have any professional guidance and support to address your first concerns?

- Yes
- No

Please check all that apply if it was more than one.

- Paediatrician
- Psychologist
- Psychiatrist
- Nurse
- Neuropediatrician
- Kindergarten/school teacher
- Other. Please specify: _____

20. How adequate do you consider the detection process?

	Extremely adequate	Moderately adequate	Slightly adequate	Neither adequate nor inadequate	Slightly inadequate	Moderately inadequate	Extremely inadequate
Detection process followed by the diagnostic evaluation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The staff's qualifications who attend the child during the detection process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The degree to which the professionals involved in the process listened and took into account your concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. If you have any suggestions about the detection process of early ASD signs, please specify

DIAGNOSIS In this section you will be asked about the diagnosis process of ASD. We are interested in your perception of the direct care you have been receiving at the different centers or institutions that have cared for your child during the diagnostic process. The questions incorporated in this section refer to all professionals and institutions that have been directly involved in the diagnostic process of your child, and with whom you have been in direct contact. They can be, for example, family doctors, pediatricians, nurses, physiotherapists, speech therapists, psychologists, teachers, etc.

22. Has the child received any of the following diagnoses?

- Autism Spectrum Disorder (ASD)
- Pervasive Developmental Disorder
- Autistic Disorder / Childhood autism
- Asperger's syndrome /Asperger's disorder
- Atypical autism
- Pervasive developmental disorder not otherwise specified
- Other. Please, specify _____

23. At what age was your child given an autism spectrum disorder diagnosis?

24. Do you recall how passed (approximately), from the suspicion of the child's developmental problems until the diagnosis confirmation?

- Less than 1 month
- From 1 to 2 months
- From 3 to 4 months
- From 5 to 6 months
- More than 6 months
- Other. Please, specify _____

<p>or specialized centers)? ... were they coordinated so that all the services involved provided information to arrive at a coherent diagnosis?</p>	○	○	○	○	○	○
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26. Which professionals assisted you in the diagnostic process? Apply more than one, if any

- Psychologist
- Pediatrician
- Nurse
- Neuropediatrician
- Psychiatrist
- Other. Please, specify _____

27. Did you receive advice or information from the professionals who gave you the ASD diagnosis report? (Check the box of the aspects on which you received appropriate or sufficient information) Apply more than one, if any

- Medical needs (specialists, medicine, genetic counselling...)
- Educational needs (centres, support...)
- Social needs (organizations, family support...)
- Materials (bibliography, agencies, web pages...)
- Other. Please, specify _____
- No

28. Did you receive written information about the diagnosis?

- Yes
- No

29. How adequate do you consider the diagnostic process?

	Extremely adequate	Moderately adequate	Slightly adequate	Neither adequate nor inadequate	Slightly inadequate	Moderately inadequate	Extremely inadequate
The time passed since the first suspicion of developmental problems until the confirming diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The professional level of the personnel who attended the child in the diagnostic process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information and support you received by these professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The evaluation process and diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. If you have any suggestions for the diagnostic programs, please specify

EARLY INTERVENTION In this section of the survey you will be asked about the type and quantity of Early Intervention services that your child has received in the last 12 months. You will be asked to say the time that passed since they received the diagnosis of their child until the treatment began, type of intervention your child receives, how many hours of treatment your child usually receives per week (For example, if your child receives 1 hour of therapy every 2 weeks, you should enter 0.5 hours per week), the degree of your involvement in the treatment, and your opinion about the treatment your child receives

31. Does the child currently receive early intervention?

- Yes
- No, but the child has received until less than 12 months
- No

31.1. Do you remember how much time passed since your child's diagnosis until the intervention program started?

- Yes. Please, specify (in months) _____
- No

31.2. Could you say what type of intervention, both private and public, the child currently receives?

- Public. Please, specify _____
- Private. Please, specify _____

31.2.1. How many public intervention sessions does the child receive on a weekly basis? Please indicate how long each session lasts on average

31.2.2. How many private intervention sessions does the child receive on a weekly basis? Please indicate how long each session lasts on average

31.3. How are the intervention sessions? (You can select more than one option)

- In group
- Individual
- Other. Please, specify _____

32. To what extent do you participate in the intervention sessions with your child?

- Very actively
- Actively
- Occasional participation
- I don't participate

Please, explain why

33. How far is the centre where your child with ASD receives regular interventions?

34. How long does it take you to get to that service?

31.1. How long the child does not receive early intervention?

- Less than a year
- Between 1 and 2 years
- Between 2 and 3 years
- More than 3 years
- The child has not received any intervention

31.2. Do you remember how much time passed since your child's diagnosis until the intervention program started?

- Yes. Please, specify (in months) _____
- No

31.3. Could you say what type of intervention, both private and public, the child received?

- Public. Please, specify _____
- Private. Please, specify _____

31.3.1. How many public intervention sessions did the child receive on a weekly basis? Please indicate how long each session lasted on average

31.3.2. How many private intervention sessions did the child receive on a weekly basis? Please indicate how long each session lasted on average

31.4. How were the intervention sessions? (You can select more than one option)

- In group
- Individual
- Other. Please, specify _____

32. To what extent did you participate in the intervention sessions with your child?

- Very actively
- Actively
- Occasional participation
- I don't participate

Please, explain why

33. How far was the centre where your child with ASD received regular interventions?

34. How long did it take you to get to that service?

35. Has your child received

	Yes	No
Behavioural treatment (e.g. Applied Behaviour Analysis (ABA); Pivotal Response Training (PRT); Lovaas; Discrete Trial Training (DTT) ...)	<input type="radio"/>	<input type="radio"/>
Developmental treatment (e.g. Relationship Development Intervention (RDI); Early Start Denver Model (ESDM) ...)	<input type="radio"/>	<input type="radio"/>
Relationship-based treatment (e.g. Developmental Individual Difference Relationship based (DIR Model) Floortime; Thérapie d'Echange et de Développement (TED) ...)	<input type="radio"/>	<input type="radio"/>
Portage intervention	<input type="radio"/>	<input type="radio"/>
Psychoanalytic treatment	<input type="radio"/>	<input type="radio"/>
Speech and language therapy	<input type="radio"/>	<input type="radio"/>
Occupational therapy / physiotherapy	<input type="radio"/>	<input type="radio"/>
Parent training / coaching /counselling to help you with your child	<input type="radio"/>	<input type="radio"/>
Another psychological / educational / behavioural treatment (not previously specified)	<input type="radio"/>	<input type="radio"/>

36. How adequate do you consider the intervention process?

	Extremely adequate	Moderately adequate	Slightly adequate	Neither adequate nor inadequate	Slightly inadequate	Moderately inadequate	Extremely inadequate
The waiting time to receive a public/private intervention program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The number of sessions that the child receives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your level of participation in the intervention sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information that you received about the intervention programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. If you have any suggestions for early intervention programs, please enter it below