

Professional 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 mean for you. Please take the time to read this information carefully. For more information, do not hesitate to contact Ricardo Canal (rcanal@usal.es).

This 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 professional who currently works, or has worked in recent years, in the field of autism and knows firsthand the kind of services provided to children under 6 years of age in their community.

The objective of the survey is to assess 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. More 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 respondents; opinions on the organization of services for young children with ASD; and suggestions on ways to improve these type of services.

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

If you provide personal information this will only be used to contact you in case we need more detailed information or a clarification. Completing the survey will take 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 check all the following items:

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 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 work, your age, your job, and two more questions about your experience with children with autism.

1. How old are you?

2. Gender

- Male
- Female

3. What country and city do you work in?

Country

City

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

- Less than 10.000.
- Between 10.001 to 50.000.
- Between 50.001 to 150.000.
- Between 150.001 to 1.000.000.
- More than 1.000.000.

5. What job or career title fits you best? (Select only one, whichever is your main job)

- Counsellor
- Department head or chief
- Director of an organization
- General practitioner
- Psychiatrist
- Nurse
- Other medical professional, please specify _____
- Psychologist
- Social worker
- Teacher
- Teaching assistant
- Mental health therapist
- Physical or occupational therapist
- Other, please specify _____

6. Do you work or have you worked in recent years with children with ASD under six years?

- Yes
- No

7. How many years in total have you been working in jobs that brought you into contact with young children with autism (younger than 6 years old)?

- < 1 year
- 1 - 3 years
- 3 - 5 years
- > 5 years

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 segment, there will be another one specific for the diagnostic process.

8. Do you participate or have participated in the last 6 years in an ASD early detection program?

- Yes
- No

We would like to contact you directly so that you can describe the program in detail. Can you provide us with an email address?

We would like to contact someone directly involved in the ASD early detection program. Could you provide us with an email address to get more details on how the detection is carried out in your organization?

9. Does the centre / institution where you work provide any specific services for early detection of children with ASD?

- Yes
- No

Please specify (You can select more than one option):

- Training for awareness raising for families
- Awareness aimed at professionals
- Developmental surveillance
- Search for early signs during routine consultations
- Application of a standardized questionnaire. Name of the questionnaire _____
- Other, please specify _____

10. Does the centre/organization provide information about early ASD signs and/or early detection programs running in the area or region where your centre provides services?

- Yes
- No

Please specify (select at least one from each row)

| | | | | |
|---|---|--|--|--------------------------------|
| Target audience | <input type="checkbox"/> Families | <input type="checkbox"/> Professionals | <input type="checkbox"/> Media | <input type="checkbox"/> Other |
| Promoting institutions | <input type="checkbox"/> Educational services | <input type="checkbox"/> Health services | <input type="checkbox"/> Social services | <input type="checkbox"/> Other |
| Resources | <input type="checkbox"/> Written material | <input type="checkbox"/> Meetings and seminars | <input type="checkbox"/> Posters / brochures | <input type="checkbox"/> Other |
| Most used media for disseminating information | <input type="checkbox"/> Email / website | <input type="checkbox"/> Post mail | <input type="checkbox"/> Phone | <input type="checkbox"/> Other |
| Frequency | <input type="checkbox"/> Only once | <input type="checkbox"/> Seasonal (campaigns) | <input type="checkbox"/> Permanently | <input type="checkbox"/> Other |

If you have selected other target audience, please, specify

If you have selected other promoting institutions, please, specify

If you have selected other resources, please, specify

If you have selected other media for disseminating the information, please, specify

If you have selected other frequency, please, specify

11. Does your centre/organization collaborate with any other agencies/institutions in your region or country of residence to improve ASD early detection?

- Yes
- No

12. Do you know how much time passes, on average, from the parent's first concerns until they request an appointment at your centre/service?

- Less than 1 month
- 1-2 months
- 3-4 months
- 5-6 months
- 7-8 months
- 9-10 months
- 11 months or more
- I do not know

13. Do you have information on the average age at which you or other professionals in your institution usually identify ASD early signs in the population area where you are attending?

- Less than 12 months
- 13-18 months
- 19-24 months
- 25-32 months
- 33-39 months
- 40-46 months
- 47-53 months
- 54-60 months
- 61 months or more
- I do not know

14. Does your region or country have any practice guidelines to serve people with autism in the detection and identification phase?

- Yes
- No

15. Which professionals (most frequently) assist the children during the process of identifying the first signs in your service/institution? You can select more than one option

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

16. In the absence of an ASD screening program in your region or country: please describe briefly how early ASD signs are detected in young children

17. 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 professionals involved in the process listen and take into account the concerns of parents | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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

DIAGNOSIS In this section you will be asked questions about the diagnostic process of ASD. We are interested in your perception of the centers or institutions that have cared for the 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 children with ASD.

19. Are you directly involved or have you been involved in the last 6 years in conducting diagnostic processes for children with ASD?

- Yes
- No

We would like to contact you directly for more details on how the diagnostic process is carried out in your organization. Can you provide us with an email address?

We would like to contact someone directly involved in the diagnostic process. Could you provide us with an email address to get more details on how the diagnostic process is carried out in your organization?

20. What are the institutions/services that most frequently provide diagnoses of ASD in your country?

| | Psychiatry | Pediatrics | Neurology | Psychology | Other |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Public Hospital/Centre | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Private Hospital | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Local/regional parent organization | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Private consultation with a specialist | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other. Please, specify | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

21. Does your centre/service (You can select more than one option):

- Conduct diagnostic assessments
- Refer clients to other services to make a diagnosis
- Take the evaluations conducted by other services or centers

22. Who refers (most frequently) children under 6 years of age with autism or possible autism to your service/institution? You can select more than one option:

- The pediatricians or nurses from public health services
- The pediatricians or nurses from private health services
- Teachers or school staff from public education services (nursery, kindergarten, school, etc.)
- Teacher or school staff from private education services (nursery, kindergarten, school, etc.)
- Professionals from public social services (agencies or other)
- Professionals from private social services (agencies or other)
- Other. Please, specify _____

23. Which professionals (most frequently) assist the children during the process of diagnosis? You can select more than one option:

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

24. Does your centre have a specific requirement regarding the type of professional who must take part in the diagnostic process (e.g., a doctor, teacher or psychologist)?

- Yes
- No

Please, specify. You can select more than one option

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

25. Does your centre require that any specific instrument be used during the diagnostic process?

- Yes
- No

Please, specify. You can select more than one option

| | | | | | | |
|-----------------------------|---|---|--|---|--|--------------------------------|
| Autism Symptomatology | <input type="checkbox"/> Autism Diagnostic Observation Schedule (ADOS-2) | <input type="checkbox"/> Social Communication Questionnaire (SCQ) | <input type="checkbox"/> Autism Spectrum Quotient (AQ) | <input type="checkbox"/> Autism Diagnostic Interview Revised (ADI-R) | <input type="checkbox"/> Social Responsiveness Scale (SRS) | <input type="checkbox"/> Other |
| IQ measures | <input type="checkbox"/> Wechsler Preschool & Primary Scale of Intelligence (WPPSI-R) | <input type="checkbox"/> Mullen Scales of Early Learning (MSEL) | <input type="checkbox"/> Merrill-Palmer-Revised Scales of Development (MP-R) | <input type="checkbox"/> Leiter International Performance Scale- R (Leiter-R) | <input type="checkbox"/> Bayley Scales of Infant Development (BSID-II/III) | <input type="checkbox"/> Other |
| Behaviour & Comorbid traits | <input type="checkbox"/> Vineland Adaptive Behaviour Scales (VABS-II) | <input type="checkbox"/> Child Behaviour Checklist (CBCL) | <input type="checkbox"/> Strengths & Difficulties Questionnaire (SDQ) | <input type="checkbox"/> Conners' Rating Scale (CRS) | <input type="checkbox"/> Other | <input type="checkbox"/> Other |

If you have selected other instrument for autism symptomatology, please specify

If you have selected other instrument for IQ measures, please specify

If you have selected other instrument for behaviour & comorbid traits, please specify

26. Do you know the average age of the children to whom a diagnosis of ASD occurs in your centre / service?

- Less than 12 months
- 13-18 months
- 19-24 months
- 25-32 months
- 33-39 months
- 40-46 months
- 47-53 months
- 54-60 months
- 61 months or more
- I do not know

27. Do you know how much time passes, on average, from the first meeting with the specialist on ASD detection until the child receives a diagnosis of ASD?

- Less than 1 month
- 1-2 months
- 3-4 months
- 5-6 months
- 7-8 months
- 9-10 months
- 11 months or more
- I do not know

28. Does your centre/service give information to the family after the ASD diagnosis?

- Yes
- No

Please, specify. Check the box of the aspects on which parents usually receive appropriate or sufficient information. You can select more than one option

- Medical needs (specialists, medicine, genetic counselling...)
- Educational needs (centres, support...)
- Social needs (organizations, family support...)
- Materials (bibliography, agencies, web pages...)
- Other. Please specify _____

29. Do you follow a classification of mental disorders manual for the diagnosis of children with ASD?

- Yes
- No

Please, specify. You can select more than one option

- DSM-IV-TR
- DSM-5
- ICD-10
- Other. Please specify _____

30. 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 staff's qualifications who attend the children during 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 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"/> |

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

BIOMARKERS Biomarkers in the process of detection and diagnosis

32. Do you think it is feasible?

| | Yes, we already do this | Yes, but this is currently not common practice | Yes, but I don't think this would be useful | No, but I believe this would be useful | No, and I don't think this would be useful |
|---|-------------------------|--|---|--|--|
| To use EEG in the early detection of ASD? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| To use MRI (under sedation) in the early detection of ASD? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| To use blood assessment (e.g. to test for immune system parameters, hormone levels...) in the early detection of ASD? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| To use urine samples (e.g. to assess metabolic parameters) in the early detection of ASD? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| To use a neonatal blood draw for bilirubin testing in the early detection of ASD? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| To use eye tracking (e.g. to assess attention) in the early detection of ASD? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| To use a motor assessment in the early | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | |
|---|---|---|---|---|---|
| detection of ASD? To use questionnaires to assess temperament characteristics in the early detection of ASD? | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|

Please provide your personal email if you want to contact us for further information

EARLY INTERVENTION In this section of the survey you will be asked about the type and quantity of Early Intervention services in your region / country

33. Are there any regional / national reference service or specialized centres for ASD early intervention in your region or country? You can select more than one option

- Yes. Please, specify _____
- No. This type of services are carried out by general early intervention teams for all types of children with developmental difficulties
- There are no early intervention services for ASD

34. Are you a member or have you been a member in the last 6 years of an early intervention team that serves children with ASD?

- Yes
- No

We would like to contact you directly so that you can describe the early intervention program you are conducting for children with ASD in detail. Can you provide us with an email address?

We would like to contact someone directly involved in the ASD early intervention program. Could you provide us with an email address to get more details on how the intervention is carried out in your organization?

35. Please indicate some of the fundamental principles your early intervention model for children with ASD is based on (e.g., parent involvement, based on natural contexts, using behavioral methods, individualized objectives, etc.)?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8

36. What is the average age at which your centre often starts early intervention for children with ASD?

- Less than 12 months
- 13-18 months
- 19-24 months
- 25-32 months
- 33-39 months
- 40-46 months
- 47-53 months
- 54-60 months
- 61 months or more
- I do not know

37. Do you know how much time passes from the children's diagnosis until the intervention program starts?

- Less than 1 month
- 1-2 months
- 3-4 months
- 5-6 months or more
- I do not know

38. Would you recommend any particular treatment methods for individuals with autism?

- Yes. Please specify _____
- No

Please, specify the reason (You can select more than one option)

- Because in our team we are trained in that model of intervention
- Because it is based on the evidence
- Because we consider it appropriate for children with ASD
- Because it is the most used in our region / country
- Other reasons (specify) _____

39. How many intervention sessions and time could the children receive weekly in your service / centre?

40. How are the intervention sessions in your service / centre? (You can select more than one option)

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

41. What is the level of parent participation in the intervention programs in your service / centre?

- Very active
- Active
- Occasional participation
- Parents hardly participate

Please, explain why

42. Does your service / centre give information to the family about the ASD intervention program?

- Yes
- No

Please, specify the type of information (You can select more than one option)

- Information on evidence of program results
- Information on the suitability of the program to the characteristics of the child
- Information on the economic cost of the program
- Information about how parents will be involved
- Information about the child's progress
- Other. Please, specify _____

43. 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 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"/> |
| The level of parents' 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 the parents 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"/> |

44. If you have any suggestions for early intervention programs, please specify

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