



European Autism Information System (EAIS) Project

Design of a Prevalence Study Questionnaire on health care, educational and social facilities and patients' organizations for Autism Spectrum Disorders (ASD)

Team member (name/s and surname/s): _____

Associated partner, EAIS:

Collaborating partner, EAIS:

Area of influence (please name appropriate country / region / local area):

Population size (approximately) of this area of influence:

You should consider ASDs as: Autistic Disorder, PDD-NOS (atypical autism) and Asperger's disorder.

ASD diagnosis and follow-up

1. What is the accepted standard definition of ASD used in your area of influence?

- ICD 10
- DSM IV, TR
- Other (define) _____
- There is not a standard definition

2. What sub-types are used for ASD diagnoses in your area of influence?

- Autistic Disorder
- PDD-NOS (atypical autism)
- Asperger's disorder
- Rett syndrome
- CDD
- Other (specify) _____

3. Is ASD considered as a medical, psychiatric, psychological, educational, or other (please specify) condition?

4. Is there, in your area of influence, an established protocol in the public health care system for the detection or early recognition of ASD?

- Yes Go to questions 5 and 6
- No Go to question 7

5. If yes, which is the body or institution responsible for that programme?

6. Please provide a brief description of the protocol used in your area of influence:

7. In your experience, ASD in your area of influence is mainly detected/suspected by:

	Very often (>75%)	Often (approx. 50%)	Sometimes (approx. 25%)	Seldom (approx. 10%)	Never (0%)
Public health care system (paediatrician, family physician, GPs, etc.)					
Educational system (teachers, school psychologists, etc.)					
Social services (other disability- related institutions)					
Day care/pre-school programmes					
Private services (psychologists or other private professionals)					
Other (specify:.....)					

8. In your experience, ASD in your area of influence is mainly diagnosed by:

	Very often (>75%)	Often (approx. 50%)	Sometimes (approx. 25%)	Seldom (approx. 10%)	Never (0%)
Health care system (hospital psychiatrist, psychologist, etc.)					
Educational system (school psychologists, interdisciplinary teams, etc.)					
Social services (other disability- related institutions)					
Day care/pre-school programmes					
Private services (psychologists or other private professionals)					
Other (specify:.....)					

9. Is there any ASD Case Registry in your area of influence?

Yes Go to question 10
No Go to question 12

10. If yes, this ASD-PDD Registry is:

National
Regional
Local/Provincial/County

Municipality
 Health service area
 Other (specify:

11. Approximate population size or number of births per year of the area:

Population size		Number of births per year	
Less than 50,000	<input type="checkbox"/>	Less than 10,000	<input type="checkbox"/>
50,000-75,000	<input type="checkbox"/>	10,001-20,000	<input type="checkbox"/>
75,001-100,000	<input type="checkbox"/>	20,001-50,000	<input type="checkbox"/>
100,001-500,000	<input type="checkbox"/>	50,001-75,000	<input type="checkbox"/>
500,001-1,000,000	<input type="checkbox"/>	75,001-100,000	<input type="checkbox"/>
More than 1,000,000	<input type="checkbox"/>	More than 100,000	<input type="checkbox"/>

Centre responsible for the Case Registry: _____

Institution: _____

Name of person responsible: _____

Number of cases registered: _____

Starting year: _____

12. In your experience, what is the average age at which diagnosis of autism is obtained in your area of influence?

	Age (in years)	Range (+/- months)
Autistic Disorder		
Asperger Disorder		
PDD-NOS		

13. How are cases included in the registry?

Only participants who consent
 Compulsory reported cases
 Voluntary reporting

If cases are included after some type of reporting, please, provide a description of the registry to be returned with the questionnaire, including information collected by the registry.

14. Are identifiers maintained in the registry?

Yes
 No

15. List other possible data bases that might be available with ASD diagnosis information and may be used for estimating ASD prevalence in your area of influence:

16. Has there been an epidemiologic study of ASD prevalence in your area of influence?

Yes
 No

18. If the answer is yes, could you provide us with the following information about that study?

It was conducted by: _____
Geographic region: _____
Age of subjects: _____
Study years: _____
Case ascertainment and verification method: _____
Prevalence results: _____

19. Any comments on Autism diagnosis in your area of influence?

Health care system

20. Does the public health care system in your area of influence provide universal coverage?

Yes
No

21. Child's age at each visit included in the well-child surveillance protocol in your area of influence:

1 _____ 3 _____ 5 _____
2 _____ 4 _____ 6 _____

22. Is there in your area of influence any regional/national reference hospital or centre in charge of diagnosing ASD?

Yes
No

23. When a family chooses a private diagnostic service, does the public health care system reimburse (totally or partially) diagnosis expenses?

Yes, always
No
Sometimes
(depends on the service and the existence of a previous agreement with public authorities)

24. Do the public health authorities gather data regarding all ASD diagnosis?

- Yes, always (no matter whether the person has been diagnosed in a public or a private service)
- No, only when the person has been diagnosed by a public centre
- No, not always (depends on the diagnostic service and the kind of agreement with it)
- No, never (even if public authorities are subsidising private services, their data are not available)
- Don't know

25. If the answer to question 24 is yes, please provide the following information:

Where data are located: _____
Under whose authority: _____

What kinds of data are included:

- Diagnostic
- Medical
- Demographic
- Personal identifiers
- Services received

26. How are ASD symptoms and diagnoses documented? Are there evaluation records that describe symptoms for ASD and possibly related childhood disorders?

- Yes, always
- No
- Don't know

27. In your opinion, what role do private diagnostic services play in your area of influence regarding ASD?

- Not important, most cases are diagnosed in the public health care system
- Rather important, many families choose a private service or want a second opinion
- Very important, most cases are diagnosed by private professionals or ASD associations
- Don't know

28. Any comments on the health care system in your area of influence:

Education system

29. At what age does compulsory education begin in your area of influence?

When children are _____ years old or when they are this age during the school term/year

30. When the child is younger, is there a public network of pre-school institutions, such as kindergartens or any other day-care facility?

- Yes
- No

31. If yes, is this public network enough to meet demand?

- Yes
- No

32. What percentage of children attend public pre-school centres in your area of influence?

_____ % of children (age range between _____ and _____ years old)
No available data

33. Amongst these children, which is the percentage attending public day-care facilities?

_____ % of children (age range between _____ and _____ years old)
No available data

34. Is there any public database where all the information regarding children attending government dependent (or subsidised) private nursery schools is gathered?

Yes **Go to question 35**
No

35. Could you provide some description about that database?

(For example, where it is located, under whose authority, what kinds of data are included: diagnostic, demographic, personal identifiers, services received, etc.):

36. Are there any special schools specifically meant for children with an ASD in your area of influence?

Yes
No

37. If yes, are they: *(more than one choice may be made)*

Private
Public
Private non-profit subsidized
Managed by parents' support groups
Other (specify:.....)

38. Until what age can children with an ASD stay on at school?

Until they are _____ years old

39. Do all children with ASD participate in public education programmes?

Yes
No

40. If not, where else would they spend their days?

41. Does the school maintain evaluation records describing symptoms and diagnoses or classification labels?

Yes
No

42. What kind of documentation of ASD behaviours is available?

43. What kind of schooling patterns for ASD are there in your area of influence regarding special educational needs (SEN)?

(Mark the choice that would be available in your own area of influence. You can make more than one choice)

- a. **Inclusive education** (same school, same classroom, specific human support for pupils with SEN)
- b. **Integration within mainstream education** (same school, different class-rooms, sharing some hours and subjects)
- c. **Combined** (different schools, SEN school for certain subjects and mainstream school for other)
- d. **Multi-track option** (variety of services between mainstream and special education needs)
- e. **Separate education**(special schools and mainstream schools)

44. Which official body or institution in your area of influence is in charge of deciding which is the most appropriate educational plan for children with SEN?

45. Any comments regarding your area of influence in relation to identifying and providing educational services for children with ASD:

Social services

46. Once the child has been diagnosed, are there any public institutions in your area of influence responsible for:

	Yes	No
Early intervention (0-3)		
Economic support		
Domestic/Household support		
Respite programmes		
Individual therapy		
Speech therapy		
Family education and counselling		
Physical therapy		
Social work services		
Case management (co-ordination of all services provided)		
Follow-up services		

47. Do these public services meet demand in your area of influence?

- Yes
- No

48. Does access to these social services depend only on the ASD diagnosis?

- Yes, families only need an ASD diagnosis
- No, they need an ASD diagnosis and a disability certificate
- Depends on the services demanded
- Others

49. Does access to these services depend on fulfilling certain requirements (income, residence, disorder severity)?

- Yes
No
If yes, please specify _____

50. If access to social services depend on the previous existence of a disability certificate, which is the body or institution in charge of issuing such a document:

51. Does that institution gather data regarding all ASD diagnosis?

- Yes, always (no matter whether the person has been diagnosed in a public or a private service)
- No, only when the person has been diagnosed by a public centre
- No, not always (depends on the diagnostic service and the kind of agreement with it)
- No, never (even if public authorities are subsidising private services, their data are not available)
- Don't know

52. If the answer to question 52 is yes, please provide the following information

Where data are located: _____

Under whose authority: _____

What kinds of data are included:

- Diagnostic
- Medical
- Demographic
- Personal identifiers
- Services received

53. How long on average does it take in your area of influence from the time a family demands these services until they receive them or they can enrol into a programme?

54. Any comments on the social services in your area of influence:

Parents' support groups / patients' organisations for ASD

55. Are there any national (covering the whole country) parents' support groups/patients' organizations for ASD in your country?

- Yes
No

56. How many of these organizations are there in your area of influence?

57. Do these organizations provide services, programmes or facilities regarding:

	Yes	No
Diagnosis		
Intervention		

58. Do parents' support groups/patients' organizations for ASD in your area of influence have accurate databases with information (what type?) concerning their members?

Yes
 No
 Don't know

59. How many families belong to one of these organizations in your area of influence?

_____ families

Data not available

60. Comments on parents' support groups/patients' organisations for ASD in your area of influence:

Access to data

61. In order to conduct a study of autism prevalence, if a research team involved in a European project asked for data or access to databases regarding autism diagnoses, how likely would it be to get that information from the following institutions?

		Very likely	Likely	Unlikely	Very unlikely
Health care system	Public				
	Private				
	Mixed				
Educational system	Public				
	Private				
	Mixed				
Social services	Public				
	Private				
	Mixed				
Associations					

62. What national legislation and ethical requirements would need to be fulfilled to gain access to the data at each of the institutions?

63. Are there any laws, regulations, or permissions that apply to the collection of individually-identifying information on children to identify ASD?

- Yes
- No
- Don't know

64. Would it be possible to access information on children with special needs who do not have a diagnosis or classification of ASD to identify children with behaviours associated with ASD?

- Yes
- No
- Don't know

65. Any comments on the accessibility of data in your area of influence:
