

Irish Society for Autism - Autism Survey 2020

Questionnaire for Parents / Family Member

Only complete if you are over 18 years of age

Introduction: Thank you for taking the time to complete this survey. This is an important survey, aimed at capturing the views of People with Autism, their Parents / Families and professionals in Ireland today.

Your name is not required, as we wish for this survey to be anonymous.

If there is more than one person with Autism in your family, please complete one questionnaire per family member with Autism.

Terms: The terms People with Autism and Person with Autism are used throughout this survey. There are many different views at present with regard to terms. Some people prefer to be referred to as People with Autism, whereas others prefer to be referred to as Autistic. We do not wish to offend anyone in using the terms People with Autism and Person with Autism, but have chosen these for the purpose of this survey.

What is your preferred term?

- A) Person with Autism
- B) Autistic Person
- C) Other (Specify):
- D) Don't Mind

Section 1 Details of your family member (Person with Autism)

- 1.1 Their current age:**
- | | | |
|---------------|---------------|---------------|
| 0 – 3 years | 4 – 12 years | 13 – 15 years |
| 16 – 17 years | 18 – 35 years | 36 – 50 years |
| 51 – 65 years | 66 – 80 years | 81 + years |

- 1.2 Are they:** Male: Female: Other (Specify):

1.3 What county does the person live in? (Please Specify):

1.4 Do they access services?

In the Republic of Ireland (Specify County):

Outside the Republic of Ireland

Or Nowhere at present

1.5 Is where they currently live? Urban Or Rural

Section 2 Your Details

2.1 Your relationship with your family member (Person with Autism)?

Mother

Sister

Father

Brother

Other (specify):

2.2 Your age:

18 – 35 years

36 – 50 years

51 – 65 years

66 – 80 years

81 + years

2.3 Are you:

Male:

Female:

Other

(Specify):

2.4 Do you live in?

Munster

Leinster

Ulster

Connaught

2.5 Is where you live? Urban Or Rural

Section 3 Initial concerns

3.1 Did you have initial concerns about your family member's development?

Yes

No

Not Applicable

Comment:

3.2 If yes, what age was your family member when you initially had concerns?

3.3 What prompted your concerns?

3.4 Who did you raise these concerns with (e.g. G.P / Public Health Nurse, other)?

3.5 Did you feel that your concerns were taken seriously?

Yes

No

Not Applicable

Comment:

3.6 Please rate your satisfaction with the response you received when you raised these concerns
(Please tick the response you most agree with below)

Totally Satisfied

Reasonably Satisfied

Neither Satisfied or Dissatisfied

Reasonably Dissatisfied

Totally Dissatisfied

Not Applicable

Comment:

Section 4 Your family member's diagnosis

4.1 Has your family member received a formal diagnosis of Autism?

Yes

No

Don't Know

Not Applicable

Comment:

4.2 If yes, what age was your family member when s/he first received the diagnosis?

4.3 What year was the diagnosis made?

4.4 Was it difficult to get a diagnosis?

Yes

No

Don't Know

Not Applicable

Comment:

4.5 If yes, how difficult was it to get a diagnosis?

Very Difficult

Reasonably
Difficult

Neither Difficult
or Easy

Reasonably
Easy

Very Easy

Not Applicable

Comment:

4.6 How long did it take to get a diagnosis? (Please specify in years / months)

Years / Months

Don't Know

4.7 Did you access this diagnosis...

Privately

Publicly

Don't Know

Not Applicable

Comment:

4.8 If you accessed this privately, was this done by...

Choice

Necessity

Don't Know

Not Applicable

Comment:

4.9 What type of professional made the diagnosis?

A Psychologist

A Psychiatrist

Other (please specify)

Not Applicable Don't Know

Comment:

4.10 Was this professional part of a wider team carrying out an assessment?

Yes

No

Don't Know

Not Applicable

Comment:

4.11 Which diagnostic assessment tool(s) did they use? (If you do not know, please state this)

4.12 Did the professional who made the diagnosis explain the diagnosis in a way that you could understand?

Yes

No

Don't Know

Not Applicable

Comment:

4.13 Was the diagnosis delivered in a caring manner?

Yes

No

Don't Know

Not Applicable

Comment:

4.14 When given the diagnosis, were you given information about autism?

Yes

No

Don't Know

Not Applicable

Comment:

4.15 If yes, were you given this information...

Verbally

In writing

Verbally and in writing

Comment:

4.16 If yes, was this information helpful?

Yes

No

Not Applicable

Comment:

Section 5 Early Intervention

Note: For the purpose of this questionnaire, Early Intervention refers to young children with Autism receiving early supports prior to reaching primary school age (typically from 2.5 to 3 years of age), to assist with their development.

5.1 Was Early Intervention recommended for your family member with autism, as a child?

Yes No Don't Know Not Applicable

Comment:

5.2 If Early Intervention was recommended for your family member with autism, did they receive this?

Yes No Don't Know Not Applicable

Comment:

5.3 If your family member received early intervention as a child, did they receive this in a timely manner? (That is to say, when they needed it)

Yes No Don't Know Not Applicable

Comment:

5.4 Please rate your satisfaction with access to Early Intervention

Totally Satisfied **Reasonably Satisfied** **Neither Satisfied or Dissatisfied** **Reasonably Dissatisfied** **Totally Dissatisfied** **Not Applicable**

Comment:

5.5 Please rate your satisfaction with the quality of Early Intervention

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

5.6 What would you change, if anything, to improve Early Intervention in Autism?

Comment:

Section 6 Primary and Secondary School Experience

6.1 Does / did your family member with Autism receive an education?

Yes	No	Not Applicable
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Comment:

6.2 If yes, do/did they go to (tick all that apply)

- A Mainstream School
- An Autism Specific Class in a Mainstream School
- A Special Education School
- An Autism Specific School
- Home School
- Other (please specify)

Comment:

6.3 Please rate your satisfaction with access to Primary School education for your family member

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

6.4 Please rate your satisfaction with the quality of your family member's Primary School education

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

6.5 Please rate your satisfaction with the overall Primary School Experience for your family member

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

6.6 In your view, do primary schools in the area that you live in adequately meet the needs of children with Autism?

Yes	No	Don't Know	Not Applicable
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Comment:

6.7 If No, what is required?

6.8 Please rate your satisfaction with access to Secondary School education for your family member

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

6.9 Please rate your satisfaction with the quality of the Secondary School education for your family member

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

6.10 Please rate your satisfaction with the overall Secondary School Experience for your family member

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

6.11 In your view do secondary schools in the area that you live in adequately meet the needs of children with Autism?

Yes	No	Don't Know	Not Applicable
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Comment:

6.12 If No, what is required?

Section 7 Post School Experience

This section deals with the following areas: -

7.1 Day Services

7.2 Supported Employment Services

7.3 Post Leaving Certificate Courses (other than University or Institute of Technology Programmes)

7.4 Third Level (University or Institute of Technology Programmes)

7.5 Employment

7.6 Residential Services

7.7 Respite Services

Please complete any of the following sub-sections that apply with regard to your family member with Autism

7.1 Day Service

Currently Attending	Has Attended in the Past	Has Never Attended	Not Applicable
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Tick the box or boxes on the right that apply (if they apply)

7.1.1 Is / was this service Autism Specific (i.e. Just for people with autism)?

Yes	No	Don't Know
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Comment:

7.1.2 Please rate your satisfaction with access to the Day Service

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.1.3 Please rate your satisfaction with the quality of the Day Service

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.2 Supported Employment Service

Currently Attending	Has Attended in the Past	Has Never Attended	Not Applicable
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Tick the box or boxes on the right that apply (if they apply)

7.2.1 Please rate your satisfaction with access to the Supported Employment Service

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.2.2 Please rate your satisfaction with the quality of the Supported Employment Service

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.3 Post Leaving Certificate (PLC) Course

Currently Attending	Has Attended in the Past	Has Never Attended	Not Applicable
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Tick the box or boxes on the right that apply (if they apply)

7.3.1 Please rate your satisfaction with access to the Post Leaving Certificate Course

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.3.2 Please rate your satisfaction with the quality of the Post Leaving Certificate Course

Totally Satisfied Reasonably Satisfied Neither Satisfied or Dissatisfied Reasonably Dissatisfied Totally Dissatisfied Not Applicable

Comment:

7.4 Third Level (Institute of Technology or University) Education

Currently Attending Has Attended in the Past Has Never Attended Not Applicable

Tick the box or boxes on the right that apply (if they apply)

7.4.1 Please rate your satisfaction with access to Third Level Education

Totally Satisfied Reasonably Satisfied Neither Satisfied or Dissatisfied Reasonably Dissatisfied Totally Dissatisfied Not Applicable

Comment:

7.4.2 Please rate your satisfaction with the quality of Third Level Education

Totally Satisfied Reasonably Satisfied Neither Satisfied or Dissatisfied Reasonably Dissatisfied Totally Dissatisfied Not Applicable

Comment:

7.5 Employment

Currently Employed Self Employed Currently not Employed, but has been employed in the past Has Never Been Employed Does Not Require Employment

Tick the box or boxes on the right that apply (if they apply)

7.5.1 In general, is it difficult for your family member with autism to get employment?

Yes No Not Applicable

Comment:

7.5.2 If you have answered yes to question 7.5.1, what are the main barriers to your family member with autism getting employment?

7.5.3 If you have answered yes to question 7.5.1, what would help your family member with autism to get employment?

7.5.4 If your family member is currently employed, what is most useful to them, in supporting them in their employment?

7.6 Residential Service

Tick the box or boxes on the right that apply (if they apply)

Currently Attending	Has Attended in the Past	Has Never Attended	Not Applicable
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7.6.1 Is / was this service Autism Specific (i.e. Just for people with autism)?

Yes	No	Don't Know
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Comment:

7.6.2 Please rate your satisfaction with access to the Residential Service

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.6.3 Please rate your satisfaction with the quality of the Residential Service

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.7 Respite Service

Currently Attending	Has Attended in the Past	Has Never Attended	Not Applicable
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Tick the box or boxes on the right that apply (if they apply)

7.7.1 Is / was this service Autism Specific (Just for people with autism)?

Yes	No	Don't Know
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Comment:

7.7.2 Please rate your satisfaction with access to Respite Services

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

7.7.3 Please rate your satisfaction with the quality of Respite Services

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

Section 8 Multidisciplinary Supports

8.1 Did / does your family member with autism require Multi-Disciplinary Supports (*e.g. Psychology, Speech and Language Therapy, Physiotherapy, other*)?

Yes	No	Not Applicable
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Comment:

8.2 If yes, is / was it possible to access the necessary Multi-Disciplinary Supports for your family member?

Yes	No	Not Applicable
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Comment:

8.3 If yes, do / did you access this...

Privately

or

Publicly

Comment:

8.4 What was the reason for your choice in accessing this privately or publicly...

Finance

Availability of Service

Other (please specify)

8.5 Please rate your satisfaction with access to required Multi-Disciplinary Supports

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

8.6 Please rate your satisfaction with the quality of Multi-Disciplinary Supports

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

Section 9 Friendships and Social Activities

9.1 Does your family member with Autism have friends?

Yes

No

Don't Know

Not Applicable

Comment:

9.2 Does your family member with autism want to have friends?

Yes

No

Don't Know

Not Applicable

Comment:

9.3 Would your family member with autism like to have more friends?

Yes

No

Don't Know

Not Applicable

Comment:

9.4 If your family member with Autism would like more friends, what would help them to have these?

9.5 Does your family member with Autism take part in social activities (e.g. clubs, sport, activities, etc.)?

Yes

No

Don't Know

Not Applicable

Comment:

9.6 Does your family member with autism want to take part in social activities?

Yes

No

Don't Know

Not Applicable

Comment:

9.7 Would your family member like to take part in more social activities?

Yes

No

Don't Know

Not Applicable

Comment:

9.8 If your family member with autism wants to take part in more social activities, what would help them to do this?

Section 10 Quality of Information Available About Autism

10.1 Please rate your satisfaction with the Information available about Autism from the statutory sector (e.g. government bodies)

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

10.2 Please rate your satisfaction with the Information available about Autism from the voluntary sector (e.g. Community and Voluntary organisations, Autism Services)

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

10.3 Please rate your satisfaction with the Information available about Autism in general

Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
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Comment:

Section 11 Advocacy

11.1 Did / does your family member require individual Advocacy?

Yes	No	Not Applicable
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Comment:

11.2 If yes, is / was it possible to access individual advocacy?

Yes

No

Not Applicable

Comment:

11.3 Please rate your satisfaction with access to individual advocacy

Totally Satisfied **Reasonably Satisfied** **Neither Satisfied or Dissatisfied** **Reasonably Dissatisfied** **Totally Dissatisfied** **Not Applicable**

Comment:

11.4 Please rate your satisfaction with the quality of individual advocacy

Totally Satisfied **Reasonably Satisfied** **Neither Satisfied or Dissatisfied** **Reasonably Dissatisfied** **Totally Dissatisfied** **Not Applicable**

Comment:

Thank you for completing this questionnaire.

How to return the questionnaire:

Please return the completed questionnaire:

By post to:

Irish Society for Autism
Unity Building
16/17 Lower O'Connell Street

FREEPOST

Dublin 1,
D01 E9W0

OR

By email to:

survey@autism.ie (please attach the survey to the email)