

## Irish Society for Autism - Autism Survey 2020

## **Questionnaire for People with Autism**

#### 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.

Terms: The terms People with Autism and Person with Autism are used throughout this survey.

**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?

Δ١	Person	with	<b>Dutism</b>
$\neg$	r el soli	WILLI	Autisiii

B) Autistic Person

C) Other (Specify):

D) Don't Mind

#### **Section 1** Your Details

**1.1 Your current age:** Are you?

18 – 35 years of age 36 – 50 years

51 - 65 years 66 - 80 years

81 + years

**1.2 Are you?** Male: Female: Other (Specify):

**1.3 What county do you live in?** (Please specify):

	-					
	In the Republic o	of Ireland	(Spe	ecify coun	ty):	
	Outside the Rep	ublic of Ireland				
Or	Nowhere at pres	sent				
	romere at pres					
1.5 ls \	where you live?	Urban		Or	Rural	
Secti	on 2 Your	Diagnosis				
2.1		ived a formal dia	agnosis of Autio	sm?		
			.g., 65, 5	••••		
	Yes	No	Don't Know		Not Applicable	е
Comment	:					
2.2	If was what as			محمدا	aia of Austinus ?	
2.2	ii yes, what ag	e were you whe	n you received	i a diagno	SIS OI AUUSIII!	
2.3	wnat year wa	s your diagnosis	made?			
2.4	144 ta disco- ta	the make disc	-:-2			
2.4	Was it difficult	t to get a diagno	sis?			
	Yes	No	Don't Know		Not Applicable	
Comment:						

1.4 Where do you access services?

2.5	If yes, ho	w difficult	was it to	get a	diagnosis?
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	Very Difficult	Reasonably Difficult	Neither Difficult or Easy	Reasonably Easy	Very Easy	Not Applicable
Commen	t:					
2.6	How long did it ta	ke to get a dia	gnosis (please spe	ecify in years / r	months)?	
	Years / Months		1	Don't Know		
2.7	Did you access yo	ur diagnosis				
	Privately	Publicly	Do	on't Know	Not Ap	plicable
	·	·			·	
Comm	ent:					
2.8	If you accessed th	is privately, wa	as this done by			
	Choice	Necessit	y Do	on't Know	Not Ap	plicable
Comme	ent:					
2.9	What type of pro	fessional made	the diagnosis?			
5	A Psychologist		the diagnosis.			
	A Psychiatrist					
	Other		(spec	ifv)		
				Know		
	Not Applicable		Don t	KIIUW		

Comment:

2.10	Was this profe	essional part of a	wider team carrying or	ut an assessment?
	Yes	No	Don't Know	Not Applicable
^- ·- ·- · · · ·				
Comment	:			
2.11	Which diagnost	ic assessment to	ool(s) did they use? (If yo	ou do not know, please state this)
2.12	Did the profes could understa		e the diagnosis explain	the diagnosis in a way that you
	Yes	No	Don't Know	Not Applicable
Commen	t:			
2.13	Was the diagn	osis delivered in	a caring manner?	
2.13	_	osis delivered ii	-	
	Yes	No	Don't Know	Not Applicable
Commen	<b>+</b> ·			
Commen				
2.14	When given th	aa diaanasis wa	ra vau givan informatia	n about autism?
2.14	when given tr	ie diagnosis, we	re you given informatio	n about autism?
	Yes	No	Don't Know	Not Applicable
Commen	<del>t</del> ·			
Commen				

	Verbally	Ir	n writing	Verbally and in writing
Commen	t:			
2.16	If yes, was this	information he	lpful?	
	Yes		No	Not Applicable
Comment	t:			
Autisr	For the purpos	ly supports pric	onnaire, Early Interve or to reaching primary	ention refers to young children with school age (typically from 2.5 to 3
3.1	Was Early Inte	rvention recom	mended for you, as a cl	nild?
	Yes	No	Don't Know	Not Applicable
Comme	nt:			
3.2	If Early Interve	ention was recor	nmended for you as a o	child, did you receive this?
	Yes	No	Don't Know	Not Applicable
Commer	nt:			
3.3	•	l early intervent when you need	· · · · · · · · · · · · · · · · · · ·	receive this in a timely manner?
	Yes	No	Don't Know	Not Applicable
Commer	nt:			

2.15

If yes, were you given this information...

	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
3.5	Please rate y	our satisfaction	with the quality	of Early Interve	ntion	
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
3.6	What would	you change, if a	anything, to impro	ove Early Interv	ention in Autisr	m?
<u>Sect</u>	ion 4 Prin	nary and Sec	condary Schoo	ol Experienc	<u>e</u>	
4.1	Did you recei	ve an educatio	n?			
	Yes	No		Not Applio	cable	
Comment:						

Please rate your satisfaction with  $\underline{access}\ to\ Early\ Intervention$ 

4.2	If yes, was this (ti	ck any of the	following that ap	ply)		
	A Mainstream Sch	nool				
	An Autism Specifi	c Class in a M	ainstream School			
	A Special Education	on School				
	An Autism Specifi	c School				
	Home School					
	Other (please spe	cify)				
Comment:						
4.3	Please rate your	satisfaction w	rith your <u>access</u> to	Primary Schoo	l education	
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:	Please rate your sa	atisfaction wit	th the quality of v	our Primary Sch	nool education	
4.4						
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						

	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	d Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
4.6	In your view, children with		nools in the area t	that you live in	adequately me	et the needs of
	Yes	No	Don't Know	Not A	pplicable	
Comment:						
4.7	If No, what is	required?				
4.8	Please rate yo	ur satisfaction	with your <u>access</u>	to Secondary So	chool education	ı
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
4.9	Please rate y	our satisfactior	n with the <u>quality</u>	of your Second	dary School edu	cation
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
4.10	Please rate y	our satisfactio	n with your <u>over</u> a	all Secondary Se	chool Experienc	e
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable

Please rate your satisfaction with your <u>overall</u> Primary School Experience

Comment:

		of children wit	h Autism?		
		Yes	No	Don't Know	Not Applicable
Com	ment:				
	4.12	If No, what is r	equired?		
	Section	on 5 Post S	School Exper	<u>rience</u>	
	This se	ection deals wit	h the following	g areas: -	
	5.1 Da	y Services			
	5.2 Տսլ	oported Emplo	yment Services	5	
		st Leaving Cert mmes)	ificate Courses	(other than Universit	ry or Institute of Technology
	5.4 Thi	ird Level (Unive	ersity or Institu	te of Technology Proչ	grammes)
	5.5 Em	ployment			
	5.6 Res	sidential Servic	es		
	5.7 Re	spite Services			

In your view do secondary schools in the area that you live in adequately meet the needs

# Please complete any of the following sub-sections that are applicable to you

5.1	L Day S	Service .		Have		
			•	Attended	Have Never	Not
	Tialiska ka		Attending in	n the Past	Attended	Applicable
	the right th	ox or boxes on				
	(If they app					
5.1.	1 If you	ara attanding or h	ava attandad a Da	v Comico Is	/was this samina	Autiem Enocific
3.1.	•	are attending or h st for people with		iy service, is	/ was this service i	Autism Specific
	Yes		No	Don't k	(now	
	163	'	10	Don't k	(IIOW	
Comme	ent:					
5.1	.2 Please	rate your satisfac	tion with access t	n the Day Se	rvice	
3.1		-				
	Totally Satisfied		Neither Satisfied or Dissatisfied	Reasonably Dissatisfied		Not Applicable
Comment:						
Comment.						
5.1	.3 Please	rate your satisfac	tion with the <u>qual</u>	<u>ity</u> of the Da	y Service	
	Totally Satisfied		Neither Satisfied	Reasonably Dissatisfied		Not Applicable
	Satisfied	3 Satisfied	or Dissatisfied	Dissatisfied	Dissatisfied	Applicable

## **5.2 Supported Employment Service**

J.2 <u>J</u>	<u>upported</u>	<u> </u>				
the	k the box or k right that ap hey apply)		Currently Attending	Have Attended in the Past	Have Never Attended	Not Applicable
5.2.1	Please rate	your satisfact	tion with <u>access</u> t	o the Support	ed Employment S	Service
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
5.2.2	Please rate	your satisfact	tion with the <u>qua</u> l	ity of the Sup	ported Employm	ent Service
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
5.3	Post Leav	ving Certifi	cate (PLC) Cou	<u>ırse</u>		
th	ick the box or ne right that a f they apply)		Currently Attending	Have Attended in the Past	Have Never Attended	Not Applicable
5.3.1	Please rate	your satisfact	tion with <u>access</u> t	o the Post Lea	ving Certificate C	course
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable

Comment:

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

Totally	Reasonably	<b>Neither Satisfied</b>	Reasonably	Totally	Not
Satisfied	Satisfied	or Dissatisfied	Dissatisfied	Dissatisfied	Applicable

Comment:

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

## 5.4 Third Level (Institute of Technology or University) Education

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

## 5.4.1 Please rate your satisfaction with access to Third Level Education

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

Comment:

### 5.4.2 Please rate your satisfaction with the quality of Third Level Education

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

Comment:

5.5	Employment	l am Currently	l am	I am not Currently Employed, but Have Been Employed in	l Have Never Been	I Do Not Require
Tick the bo on the right apply (If they app	t that	Employed Self-Employed		the Past	Employed	Employment
5.5.1	In general, is it	difficult for yo	ou to get employn	nent?		
	Yes		No	Not Appl	icable	
Comment:						
5.5.2	If you have answering employment?	wered yes to o	question 5.5.1, wl	nat are the main b	arriers to you ge	etting
5.5.3	If you have ans	wered yes to o	question 5.5.1, wl	nat would help yo	u to get employr	ment?
5.5.4	If you are curre employment?	ntly employed	d, what is most us	seful to you, in sup	porting you in y	our

## 5.6 Residential Service

Have Currently Attended **Have Never** Not **Attending** in the Past Attended Applicable Tick the box or boxes on the right that apply (If they apply) Is / was this service Autism Specific (i.e. Just for people with autism)? 5.6.1 Yes No Don't Know Comment: 5.6.2 Please rate your satisfaction with access to the Residential Service Reasonably **Totally Neither Satisfied** Reasonably **Totally** Not **Applicable Satisfied** Dissatisfied Dissatisfied Satisfied or Dissatisfied Comment: 5.6.3 Please rate your satisfaction with the **quality** of the Residential Service **Totally** Reasonably **Neither Satisfied** Reasonably Totally Not **Applicable** Satisfied Satisfied Dissatisfied Dissatisfied or Dissatisfied Comment: 5.7 **Respite Services** Have Currently Attended **Have Never** Not Attending Attended **Applicable** in the Past Tick the box or boxes on the right that apply (If they apply)

	Yes	No		Don't Know		
Comment:						
5.7.2	Please rate yo	our satisfaction	with <u>access</u> to Ro	espite Services		
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
5.7.3	Please rate yo	our satisfaction	with the quality	of Respite Servi	ces	
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
Secti	on 6 Mult	idisciplinar	y Supports			
6.1	Did / do you require Multi-Disciplinary Supports (e.g. Psychology, Speech and Language Therapy, Physiotherapy, other)?					
	Yes		No	Not	Applicable	
Comment:						

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

	Yes		No		Not Applicable	
Comment:						
6.3	If yes, do /	did you access	s this			
	Privately		or	1	Publicly	
Comment:						
6.4	What was t	he reason for	your choice in acc	essing this priv	vately or publicly	<b>'</b>
	Finance		Ava	ailability of Serv	vice	
	Other	(1	olease specify)			
6.5	Please rate	your satisfact	ion with <u>access</u> to	required Mul	ti-Disciplinary Su	pports
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						
6.6	Please rate your satisfaction with the <u>quality</u> of Multi-Disciplinary Supports					
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable
Comment:						

If yes, is / was it possible to access the necessary Multi-Disciplinary Supports?

## **Section 7** Friendships and Social Activities

7.1	Do you nave tr	ienas?		
	Yes	No	Don't Know	Not Applicable
Comment:				
7.2	Do you want to	have friends?		
	Yes	No	Don't Know	Not Applicable
Comment:				
comment:				
7.3	Would you like	to have more f	riends?	
	•			
	Yes	No	Don't Know	Not Applicable
Comment:				
comment.				
7.4	If you would lil	ke to have more	friends, what would he	Ip you to have these?
7.5	Do you take na	rt in social activ	ities (e.g. clubs, sport, a	ctivities etc \2
7.3				
	Yes	No	Don't Know	Not Applicable
Comment:				

	7.6	Do you want to take part in social activities?						
		Yes	No	Don't Know	Not A	Applicable		
Com	nment:							
	7.7	Would you like	to take part in	more social activ	vities?			
		Yes	No	Don't Know	Not	Applicable		
Com	ıment:							
	7.8	If you answered	l yes to 7.7, why	do you want to	take part in	more social activ	ities?	
	7.9	If you want to t	ake part in mor	e social activitie	s, what woul	d help you to do	this?	
	Caatia	O		otion ovoilob	la abaut A			
	Section	on 8 Quali	ty of Informa	ation availab	<u>ile about A</u>	<u>lutism</u>		
	8.1 Please rate your satisfaction with the Information available about Autism from the statutory sector (e.g. government bodies)							
		Totally Satisfied	•		Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable	
Com	ment:							

8.2	voluntary sector (e.g. Community and Voluntary organisations, Autism Services)						
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable	
Comment:							
8.3	Please rate yo	our satisfaction	with the Informa	tion available a	about Autism in	general	
	Totally Satisfied	Reasonably Satisfied	Neither Satisfied or Dissatisfied	Reasonably Dissatisfied	Totally Dissatisfied	Not Applicable	
Comment:							
Sect	ion 9 Ad	vocacy					
9.1	Did / do you require individual Advocacy?						
	Yes	No		Not App	licable		
Comment:							
9.2	If yes, is / w	as it possible t	o access individua	ıl advocacy?			
	Yes	No	)	Not App	licable		
Comment:							

Please rate your satisfaction with the Information available about Autism from the

#### 9.3 Please rate your satisfaction with <u>Access</u> to individual advocacy

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

Comment:

## 9.4 Please rate your satisfaction with the Quality of individual advocacy

Totally Reasonably Neither Satisfied Reasonably Totally Not Satisfied Satisfied or Dissatisfied Dissatisfied 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,

Dublin 1, D01 E9W0

OR

#### By email to:

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