



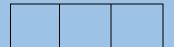








CONFIDENTAL QUESTIONNAIRE



The Economic Costs for Families Raising a Child with an Autism Spectrum Disorder National Survey 2015

National University of Ireland, Galway

Please return the completed questionnaire to Áine Roddy, the researcher over the study, by the **23rd October 2015 or as soon as is possible for you** in the FREEPOST return envelope provided.

Áine Roddy, J.E. Cairnes School of Business & Economics, Room 238, First Floor, St. Anthony's Building, National University of Ireland, Galway, FREEPOST FGA 442 Co. Galway

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	provide	d is strictly conf	idential and	Áine Roddy	will]	have	sole	owne	ershij	p of t	
Γ	NAME:	will need to conta	act the winne	ers of the five	1Pad	s tha	it are	beinş	g rati	iled.	
-	ADDRE	CSS:									
-	Email address	:									
-	Tel. nur	nber									
The older The For	Could y box below the person fire details of the details of the column B, column E	lling the form should the child or children gest anyone else living in if date of birth is not please tick just one b	d put their detadiagnosed with the house shout available pleas ox that describe	on on each me ails in the first re an ASD should be ld be put in the ne se give the age at es best the person	ember ow oe put i ext rov	in the v(s) rthday	next ro	w(s) s	tarting		
	(A)	(B)	(C)	(D)				(E)			
No	Sex M F	Date of Birth dd mm yr	Does this person have an ASD	Relationship of each member of the household to the child e.g. mother,	Pre-school	School/Education	At Work/ Training	Unemployed	Retired	Home Duties	Other
1			Yes No	father etc.							
2											

1. Could the person filling the form please fill in their contact details below in

SECTION 1:

Background Details

				Married		Partner			Widow
4. W	hat is your n	narital status?	· 🗆	Separate	ed 🗆	Divorced			
	·								
5. What County do you live in?									
5 4 DI				1		D 1			TT 1
5.1 PI	lease select th	e type of area	that you	ı live in?		Rural	Suburbar	1	Urban
6. Do you or your partner have your own transport?									
7. W	hat type of a	ccommodatio	n do you	live in?					
	Owner occupi				Rente		Rented from	i	Other
	(with or witho mortgage)	out _ pur a lo	chased fr	om _	priva	tely	Local Authority		
	mortgage)		thority				Aumorny		
8. A	re you or you	r partner a m	nember o	f an ASI	D suppo	rt group (or organisatio	n?	
Г	Yes 🗆	No If yes, p	olease list	t the nar	ne(s) of	the organ	isation(s):		
an c			4.7						1
SEC	CTION 2:	Child 1 v	vith an A	utism S	pectrun	n Disorder	•		
		uestions abou		•					
		s. It is import							
•	ound helpful iated with it.	and who par	ents rely	on to pi	covide t	ne services	s and the cost	S	
		MORE THAN	NONE C	HILD V	VITH A	N ASD A	GED RETWI	EEN	
		OF AGE PLE				· ·			
		N ASD FOR							
CH	ILD 2 ON PA	GE 9.							
1. Please fill in what age your child was when first diagnosed with an									
		gth of time wa	U		red for	a diagnosi	s. Once refer	red	
how Child	y long did it ta	ake to get a di Age when diag			g time to	he O	nce referred, ho	w long	\neg
Ciliu		with an ASD	gnoseu	referre			d it take to get a	_	
				diagnos	sis	dia	agnosis		
Child 1	1								
1.1 W	as your child	diagnosed in	the pub	lic syste	m e.g. H	ISE	Yes N	lo 🗆	
2. Wł	nat diagnosis	did you recei	ve for yo	ur child	?				
Child	Autism	Asperger's	Childh	ood	Perva	sive	Retts	Not	
	disorder	disorder	disinte			pmental	syndrome	sure	
			disorde	_	disord	-	_		
Child 1			1 -	_					

2.1 It is very important to answer the severity of your child's ASD. Please tick the white box to show whether your <u>child's ASD is SEVERE, MODERATE or MILD</u>. You may find the tables on this page helpful to answer the question. If you are still unsure please contact Áine at <u>a.roddy1@nuigalway.ie</u> or 087 7694521

Severity level	Social communication	Restricted, repetitive behaviours
Level 3 Requiring very substantial support SEVERE	Severe deficit in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 Requiring substantial support MODERATE	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 Requiring support MILD	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

	2.3 Is yo	our child verbal?	Yes No							
	3 If vo	ur child also has an	intellectual disability	v nlease ti	ck how	affecte	d voi	ır chil	d	
	is		microcian disabilit	picase ti	CK HOW	uncete	u you	ar Ciii	·	
	Child	Mild	Moderate	Se	vere		Pro	found	l	
	Child 1									
4.	4. Does your child also have another medical condition(s) e.g. epilepsy, ADHD, anxiety disorders, sleep disorders, gastrointestinal problems (Please specify)									
5	Ц од уду	ır ahild haan haanita	llised in the past year	Y	es 🗆	No [
5.	nas you	ir ciniu been nospita	insed in the past year	[.						
5.1	l How ma	any nights was this f	or? Please enter '0' i	f none						
				_						
6.			ast 12 months when,			•			1	
			ervices, therapies or	an interv	ention	treatmo	ent(s)	for		
	their AS	SD but he/she did no	t receive it?	Yes	No		n't k	now		
	6.1 In v	our oninion, does vo	ur child still need m	edical car	e. servi	ces, the	ranie	es or a	n	
		rvention treatment(s	· ·	Yes	No		n't k			
	6.2 Why	y did your child not	get the medical care,	service, 1	herapi	es or in	terve	ntion		
	trea	tment for their ASD	? Please tick Yes or I	No for eac	h box:					
(a) You (couldn't afford to pay	,			Yes	Ιп	No	Ιп	
(b			e/therapy/intervention	treatmen	<u></u> t	Yes		No		
	wasn	't available to you								
(c	′	oo far to travel to	20 1 1 1 1			Yes		No		
(d			f work to visit the hea		sional	Yes		No		
(e			e if the problem got b			Yes	H	No		
(f)			octor/health profession	nai		Yes	片	No		
(g		is on the waiting list				Yes		No		
(h	<i>'</i>	re of child's needs	oc ovoiloble in our em	20		Yes		No		
(i)		*	es available in our are	a		Yes Yes		No No		
(j)	Other	•				168		INO		

6.3 Please fill in which medical care/services/therapy/intervention treatment you consider your child <u>needed in the past 12 months but did not receive it</u>? If it is not listed below, please add it under "Other". Please enter Yes or No for each treatment listed & the number of sessions needed per month.

Medical care/therapy/intervention treatment	Did your child need it in the past 12 months?	Number of sessions needed per month in the last 12 months	Does your child still need it?	Number of sessions needed per month for the next 12 months
Applied behavioused	No		Yes or No	
Applied behavioural				
analysis (ABA)				
Speech & language				
therapy				
Occupational therapy				
Physiotherapy				
Cognitive behavioural				
therapy				
Relationship development				
intervention (RDI)				
The SCERTS model				
Sensory integration				
therapy				
Horse riding				
Play therapy				
Respite care				
Neurodevelopmental				
therapy				
Social skills				
training/group				
Other				
(1)				
(2)				
(3)				
(4)				
()				
Has a health professional(s) intervention treatments?		led that your child	receives any	of the therapies

	Social skills								
	training/group								
	Other								
	(1)								
	(2)								
	(3)								
	(4)								
or (Ii a c	6.4 Has a health professional(s) recommended that your child receives any of the therapies or intervention treatments? Yes No Commended that your child receives any of the therapies or intervention treatments? Yes No Commended that your child receives any of the therapies or intervention treatments? Yes No Commended that your child receives any of the therapies or intervention treatments?								
6.5 If yes, what qualification do they have?									
6.6	Did you see them in the pub	olic system e	g. HSE?	Yes	□ No □				
			5						

0.7 What therapies of inte	er vention tree	timent(s) the	they recor	micia.					
6.8 How long did they recommend your child should receive the medical care, therapies or									
intervention treatment for	r?								
7. Has your child with an	7. Has your child with an ASD received any intervention treatments?								
7.1 If was what ago wore t	thoy whon the	w started it	how long d	id they receiv	o it for was it				
7.1 If yes, what age were they when they started it, how long did they receive it for, was it helpful & who provided it? (e.g. HSE, voluntary organization, paid for it yourself etc.) If									
•	you feel you would like to provide more information on this you can provide more								
information in the addition	_		•	-	e more				
	71441 1111 01 1114V	Child 1							
Interventions		Age when	How long	Was it	Who provided it?				
		started	did they	helpful					
			receive it	Yes/No/Not					
Applied behavioural analysis (A	(BA)			sure					
Floortime									
Gluten free/casein free diet									
Occupational therapy									
PECS									
Relationship development interv	vention (RDI)								
The SCERTS model									
Sensory integration therapy									
Speech therapy									
TEACCH approach									
Other (please specify)									
(1)									
(2)									
(3)									
(4)									
(5)									
8. Please specify what me	dications or s	upplements y	our child	with an ASD	is currently				
taking.					·				
Medication	Strength	No. of times pe	er day Hoy	v long is the chil	ld on this medication				
	and a gr								

9. <u>Please specify the services & interventions used by your child with an ASD in the past 12 months</u>. Who paid for the service(s) e.g. HSE, voluntary organization, health insurance, paid for it yourself etc. *Please enter '0' if your child had no visit*.

Child 1									
Services	No. of visits	Distance from your home to service (in Km)	Who paid for the service/intervention(s)?						
Dentist									
GP									
Practice nurse									
Optician									
Dietician									
Speech & language therapist									
Occupational Therapist									
Physiotherapist									
Applied Behavioural Analysis									
Sensory integration therapy									
Cognitive behavioural therapy									
Play therapy									
Psychiatrist									
Psychologist									
Social worker									
Behavioural therapist									
Neurologist									
Gastroenterologist									
Accident & Emergency									
Social skills training/group									
Other (please specify)									
(1)									
(2)									
(3)									
(4)									
(5)									

10. What type of school does your child with an ASD attend? Please tick the box(es) for your child. If your child attends both a mainstream school and a special needs school please write how many days per week they attend each type of school.

Type of schoolin	ıg		Child 1	Number of days per week that they attend		
Pre-school/crèch	ne					
Special pre-scho	ol					
Mainstream pri	mary					
Special needs sc	hool					
ASD unit						
Mainstream seco	ondary					
Home educated	by parent	S				
Private school						
10.1 Please fill in how many hours per week your child has a special needs assistant in school 10.2 How many hours has your child being granted under the home tuition grant? 10.3 Does the teacher in school/home tuition have a qualification in teaching children with an ASD? Yes No Don't know 10.4 If yes, what method do they use e.g. Applied behavioural analysis, TEACCH approach, eclectic approach etc.?						
10.5 Does your child use special transport to school, special equipment or special training devices? Please list them.						
10.6 Does your	10.6 Does your child receive the July Provision or July Education Programme?					
10.7 Please tick	whether	they receive it in scho	ol or at home	☐ School ☐ Home		

SECTION 2:	Child 2 with an Autism Spectrum Disorder	
PLEASE GIVE THE	DETAILS OF YOUR SECOND OLDEST CHILD WITH AN A	SD
FOR CHILD 2. If vo	ou don't have a second child with an ASD please skip to p.22	

1. Please fill in what age your child was when first diagnosed with an ASD and the length of time waiting to be referred for a diagnosis. Once referred how long did it take to get a diagnosis?

Child	Age when diagnosed with an ASD	Waiting time to be referred for a diagnosis	Once referred, how long did it take to get a diagnosis
Child 2			

2. What diagnosis did you receive for your child?

Child	Asperger's disorder	Childhood disintegrative disorder	Pervasive developmental disorder	Retts syndrome	Not sure
Child 2					

2.1 It is very important to answer the severity of your child's ASD. Please tick the white box to show whether your <u>child's ASD is SEVERE</u>, <u>MODERATE or MILD</u>. You may find the tables on this page helpful to answer the question.

Level 3 Requiring very substantial support SEVERE Level 2 Requiring substantial support MODERATE Moderate sentences, whose interaction is limited to narrow special interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication Requiring support MODERATE Mithout supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions, For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with behaviours extreme difficulty coping with change, or other restricted/repetitive behaviour difficulty coping with change, or other restricted/repetitive behaviour all spheres. Great distress/difficulty coping with change, or other restricted/repetitive behaviours appear of requiring similated to narrow special interests, and who has markedly odd nonverbal communication Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours appear of the part of t			
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Level 1 Requiring support			action.
Level 1 Requiring support			
Requiring support interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.			•
Requiring support interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.	Level 1		\mathbf{c}
support or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with			interference with functioning
of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with	Requiring		
MILD interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with	support	•	
a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with			
sentences and engages in communication but whose to-and-fro conversation with	MILD		<u> </u>
but whose to-and-fro conversation with			hamper independence.
others fails, and whose attempts to make			
<u>friends are odd and typically unsuccessful.</u>		<u>triends are odd and typically unsuccessful.</u>	

No

2.2 What is your child's IQ?

2.3 Is your child verbal?

	Mild	Moderate	Severe		Pro	found
Child 2						
disor	Ooes your child also have a rders, sleep disorders, gas use specify)	nnother medical condition(s) trointestinal problems	9 1 1		HD,	anxiet
5. H	Ias your child been hospit	alised in the past year?	Yes	No		
	ius jour emia seem nospie	unseu in the puse jeur t				
1 How	many nights was this for	? Please enter '0' if none				
Wost	hara any tima in the last 1	2 months when, in your opi	nion vous	ohild w	rith o	n ACI
	mere anv unie in the last i					
	· · · · · · · · · · · · · · · · · · ·		· · · · · · · · · · · · · · · · · · ·			
eeded 1	medical care, therapies or	an intervention treatment(s	· · · · · · · · · · · · · · · · · · ·			
eeded 1	medical care, therapies or	an intervention treatment(s	· · · · · · · · · · · · · · · · · · ·			
eeded 1 ot rece	medical care, therapies or ive it? Yes No	an intervention treatment(s Don't know) for their	ASD bi	ut he	e/she d
eeded i ot rece 1 In yo	medical care, therapies or ive it? Yes No	an intervention treatment(s Don't know distill need medical care, th) for their	ASD bi	ut he	e/she d
eeded i ot rece 1 In yo	medical care, therapies or ive it? Yes No	an intervention treatment(s Don't know distill need medical care, the) for their	ASD bi	ut he	e/she d
eeded i ot rece 1 In yo	medical care, therapies or ive it? Yes No	an intervention treatment(s Don't know distill need medical care, th) for their	ASD bi	ut he	e/she d
eeded 1 ot rece 1 In yo	medical care, therapies or ive it? Yes No	an intervention treatment(s Don't know distill need medical care, th	erapies or	ASD bi	ut he	she d
eeded in the second of the sec	medical care, therapies or ive it? Yes No	an intervention treatment(s Don't know description Don't know Don't know	erapies or	ASD bi	ut he	she d
eeded 1 In yo eatme	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yed Yed Yes No Yes Yes Yes Yes Yes Yes Yes Ye	an intervention treatment(s Don't know Id still need medical care, the No Don't know e medical care, therapies or it or each box:	erapies or	ASD bi	erven	she d
ot recent of recent of the rec	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yed did your child not get the SD? Please tick yes or no for You couldn't afford to pa	an intervention treatment(s Don't know Id still need medical care, the s No Don't know e medical care, therapies or it or each box:	erapies or	ASD be an inte	erven	/she d
eeded in the second of the sec	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yed did your child not get the SD? Please tick yes or no for You couldn't afford to pa	an intervention treatment(s Don't know Id still need medical care, the No Don't know e medical care, therapies or it or each box:	erapies or	ASD bi	erven	she d
eeded in the second of the sec	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yed Yes No Yes Yes Yes Yes Yes Yes Yes Ye	an intervention treatment(s Don't know Id still need medical care, the s No Don't know e medical care, therapies or it or each box:	erapies or	ASD be an inte	erven	/she d
1 In your eatment of the contract of the contr	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yed Yes No Yes Yes Yes Yes Yes Yes Yes Ye	an intervention treatment(s Don't know Id still need medical care, the s No Don't know e medical care, therapies or it or each box:	erapies or interventio	an inte	erven	tion No
1 In your atments of the contract of the contr	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yes did your child not get the SD? Please tick yes or no for You couldn't afford to part The necessary medical car wasn't available to you It is too far to travel to You could not take time of	an intervention treatment(s Don't know Id still need medical care, the S No Don't know E medical care, therapies or it for each box: y re/therapy/intervention treatm	erapies or interventio	an inte	ment	t for No No
2 Why eir AS (a) (b) (c) (d) (e)	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yes did your child not get the SD? Please tick yes or no for You couldn't afford to part The necessary medical care wasn't available to you It is too far to travel to You could not take time of You wanted to wait and s	an intervention treatment(s Don't know design No Don't know e medical care, therapies or it for each box: y re/therapy/intervention treatment off work to visit the health profile if the problem got better	erapies or interventio	an inte	ment	t for No No No
1 In your ceatments (a) (b) (c) (d) (e) (f)	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yes did your child not get the SD? Please tick yes or no for You couldn't afford to part The necessary medical care wasn't available to you It is too far to travel to You could not take time of You wanted to wait and s	an intervention treatment(s Don't know Id still need medical care, thes No Don't know e medical care, therapies or intervention treatment of work to visit the health professional	erapies or interventio	an inte Yes Yes Yes Yes Yes Yes	ment	tion No No No No
1 In your eatments (a) (b) (c) (d) (e)	medical care, therapies or ive it? Yes No Our opinion, does your chint(s) for their ASD? Yes did your child not get the SD? Please tick yes or no for You couldn't afford to part The necessary medical car wasn't available to you It is too far to travel to You could not take time or You wanted to wait and say The child refused/fear of	an intervention treatment(s Don't know Id still need medical care, thes No Don't know e medical care, therapies or intervention treatment of work to visit the health professional	erapies or interventio	an interest Yes Yes Yes Yes Yes Yes Yes Yes	ment	t for No No No No No

Yes

No

(j)

Other

6.3 Please fill in which medical care/services/therapy/intervention treatment you consider your child needed in the past 12 months but did not receive it? If it is not listed below, please add it under "Other". Please enter Yes or No for each treatment listed & the number of sessions needed per month.

Medical care/therapy/intervention treatment	Did your child need it in the last 12 months?	Number of sessions needed per month in the last 12 months	Does your child still need it?	Number of sessions needed per month for the next 12 months
Applied behavioural				
analysis (ABA)				
Speech & language				
therapy				
Occupational therapy				
Physiotherapy				
Cognitive behavioural				
therapy				
Relationship				
development intervention				
(RDI)				
The SCERTS model				
Sensory integration				
therapy				
Horse riding				
Play therapy				
Respite care				
Neurodevelopmental				
therapy Social skills				
training/group				
Other				
(1)				
(2)				
(3)				
(4)				
(1)			<u> </u>	

ociai skiiis	1						
raining/group							
Other							
1)							
2)							
3)							
4)							
6.4 Has a health professional(s) recommended that your child receives any of the therapies or intervention treatments? $Yes No $							
6.5 If yes, what qualification do they have?							

6.6 Did you see them in the public system e.g. HSE? Yes No Common							
0.7 What therapies of the	er vention treat	illelit(s) ulu	they rece	Jilliichu.			
6.8 How long did they recommend your child should receive the medical care, therapies or intervention treatment for?							
7. Has your child with an	7. Has your child with an ASD received any intervention treatments?						
7.1 If yes, what age were the helpful & who provided it	· · · · · · · · · · · · · · · · · · ·			•			
you feel you would like to	provide more	information	on this y	you can provid	e more		
information in the addition	onal informatio		the end	of the survey.			
		Child 2					
Interventions		Age when started	How long did they receive it	helpful	Who provided it?		
Applied behavioural analysis (A	BA)						
Floortime							
Gluten free/casein free diet							
Occupational therapy							
PECS							
Relationship development interv	vention (RDI)						
The SCERTS model							
Sensory integration therapy							
Speech therapy							
TEACCH approach							
Other (please specify)							
(1)							
(2)							
(3)							
(4)							
(5)							
8. Please specify what medications or supplements your child with an ASD is currently taking.							
Medication	Strength N	No. of times pe	r day Ho	ow long is the chil	ld on this medication		
	<u> </u>						
	<u> </u>						
	<u> </u>						
	<u> </u>						

9. Please specify the services used by your child with an ASD in the past 12 months. Who paid for the service(s) e.g. HSE, voluntary organization, health insurance, paid for it yourself etc. *Please enter '0' if your child had no visit*.

Child 2								
Services	No. of visits	Distance from your home to service (in Km)	Who paid for the service					
Dentist								
GP								
Practice nurse								
Optician								
Dietician								
Speech & language therapist								
Occupational therapist								
Physiotherapist								
Applied Behavioural Analysis								
Sensory integration therapy								
Cognitive behavioural therapy								
Psychiatrist								
Psychologist								
Social worker								
Neurologist								
Gastroenterologist								
Accident & Emergency								
Social skills training/group								
Other (please specify)								
(1)								
(2)								
(3)								
(4)								
(5)								

10. What type of school does your child with an ASD attend? Please tick the box(es) for your child. If you child attends both a mainstream school and a special needs school please write how many days per week they attend each type of school.

Type of schooling	Child 2	Number of days per week that they attend
Pre-school/crèche		
Special pre-school		
Mainstream primary		
Special needs school		
ASD unit		
Mainstream secondary		
Home educated by parents		
Private school		

10.1 Please fill in how many hours per week your child has a special needs assistant in school							
10.2 How many hours has your child being granted under the home tuition grant?							
10.3 Does the teacher in school/home tuition have a qualification in teaching children with an ASD? Yes Don't know Don't know							
If yes, what method do they use e.g. Applied behavioural analysis, TEACCH approach, eclectic approach etc.?							
10.4 Does your child use special transport to school, special equipment or special training devices? Please list them.							
10.5 Does your child receive the July Provision or July Education Programme?] N						
10.6 Please tick whether they receive it in school or at home							
SECTION 2: Child 3 with an Autism Spectrum Disorder							
1. Please fill in what age your child was when first diagnosed with an ASD and the length of time waiting to be referred for a diagnosis. Once referred how long did it take to get a diagnosis?							
PLEASE GIVE THE DETAILS OF YOUR THIRD OLDEST CHILD WITH AN ASD FOR CHILD 3.							
Child Age when diagnosed with an ASD Waiting time to be referred, how long did it take to get a diagnosis diagnosis							
Child 3							
2. What diagnosis did you receive for your child?							
ChildAutism disorderAsperger's disorderChildhood disintegrativePervasive developmentalRetts syndromeNot sure							
disorder disorder							

2.1 It is very important to answer the severity of your child's ASD. Please tick the white box to show whether your <u>child's ASD is severe</u>, <u>moderate or mild</u>. You may find the tables on this page helpful to answer the question.

Severity level	Social communication	Restricted, repetitive						
		behaviours						
	Severe deficit in verbal and nonverbal social	Inflexibility of behaviour,						
Level 3	communication skills cause severe	extreme difficulty coping						
	impairments in functioning, very limited	with change, or other						
Requiring	initiation of social interactions, and minimal	restricted/repetitive						
very	response to social overtures from others.	behaviours markedly						
substantial	For example, a person with few words of	interfere with functioning in						
support	intelligible speech who rarely initiates	all spheres. Great						
	interaction and, when he or she does, makes	distress/difficulty changing						
SEVERE	unusual approaches to meet needs only and	focus or action.						
	responds to only very direct social							
	approaches							
	Marked deficits in verbal and nonverbal	Inflexibility of behaviour,						
Level 2	social communication skills; social	difficulty coping with						
Level 2	impairments apparent even with supports in	change, or other						
Requiring	place; limited initiation of social	restricted/repetitive						
substantial	interactions; and reduced or abnormal	behaviours appear						
		frequently enough to be						
support	responses to social overtures from others.	obvious to the casual						
MODEDATE	For example, a person who speaks simple							
MODERATE	sentences, whose interaction is limited to	observer and interfere with						
	narrow special interests, and how has	functioning in a variety of						
	markedly odd nonverbal communication	contexts. Distress and/or						
		difficulty changing focus or						
		action.						
	Without supports in place, deficits in social	Inflexibility of behaviour						
Level 1	communication cause noticeable	causes significant						
	impairments. Difficulty initiating social	interference with functioning						
Requiring	interactions, and clear examples of atypical	in one or more contexts.						
support	or unsuccessful response to social overtures	Difficulty switching between						
	of others. May appear to have decreased	activities. Problems of						
MILD	interest in social interactions. <u>For example,</u>	organization and planning						
	a person who is able to speak in full	hamper independence.						
	sentences and engages in communication							
	but whose to-and-fro conversation with							
	others fails, and whose attempts to make							
	friends are odd and typically unsuccessful.							
2.2 What is you	ır child's IQ?							

No

Yes

2.3 Is your child verbal?

3.	3. If your child also have an intellectual disability please tick how affected your child is											
C	hild	Mild		Moderate	Severe		Pro	found				
C	hild 3											
4.	disorders, sleep disorders, gastrointestinal problems (Please specify)											
5.16.6.1	5. Has your child been hospitalised in the past year? 5.1 How many nights was this for? If none please fill in with "0" 6. Was there any time in the last 12 months when, in your opinion, your child with an ASD needed medical care, therapies or an intervention treatment(s) for their ASD but he/she did not receive it? 6.1 In your opinion, does your child still need medical care, therapies or an intervention treatment(s) for their ASD? 6.2 Why did your child not get the medical care, therapies or intervention treatment for their ASD? Please tick yes or no for each box:											
	(a)	You couldn't afford	to pay			Yes		No				
	(b)	The necessary medic wasn't available to y		/therapy/intervention	treatment	Yes		No				
	(c)	It is too far to travel				Yes		No				
	(d)	You could not take t	time off	work to visit the heal	th professional	Yes		No				
	(e)			if the problem got be		Yes		No				
	(f)			ctor/health profession	nal	Yes		No				
	(g)	Child is on the waiti				Yes		No				
	(h)	Unsure of child's ne				Yes		No				
	(i)		service	es available in our area	a	Yes		No				
	(i)	Other				Yes		No				

6.3 Please fill in which medical care/therapy/intervention treatment you consider your child needed in the past 12 months but did not receive it? If it is not listed below, please add it under "Other". Please enter Yes or No for each treatment listed & the number of sessions needed per month.

Medical care/therapy/intervention treatment	Did your child need it?	Number of sessions needed per month in the last 12 months	Does your child still need it? Yes or No	Number of sessions needed per month for the next 12 months
Applied behavioural analysis (ABA)				
Speech & language therapy				
Occupational therapy				
Physiotherapy				
Cognitive behavioural therapy				
Relationship development intervention (RDI)				
The SCERTS model				
Sensory integration therapy				
Horse riding				
Play therapy				
Respite care				
Neurodevelopmental therapy				
Social skills training/group				
Other				
(1)				
(2)				
(3)				
(4)				

4)							
6.4 Has a health professional(s) recommended that your child receives any of the therapies or intervention treatments?							
(If you received different opinions/advice from health professionals please feel free to write a comment about it in the additional information section at the end of the survey).							
6.5 If yes, what qualificati	ion do they l	nave?					
6.6 Did you see them in th	·		Yes N	о <u></u>			

6.8 How long did they recommend your child should receive the medical care, therapies or intervention treatment for?					
7. Has your child with a	n ASD receiv	ed any interv	ention t	reatments?	☐ Yes ☐ No
7 1 16	ll 4l 4l			. J. J. 41	:4
7.1 If yes, what age were they when they started it, how long did they receive it for, was it helpful & who provided it (e.g. HSE, voluntary organization, paid for it yourself etc.)? If					
you feel you would like to provide more information on this you can provide more					
information in the addition	nal informat	ion section at	the end	of the survey.	
		Child 3			
Interventions		Age when started	How long did they receive it	helpful	Who provided it?
Applied behavioural analysis (A	BA)				
Floortime					
Gluten free/casein free diet					
Occupational therapy					
PECS					
Relationship development interv	vention (RDI)				
The SCERTS model					
Sensory integration therapy Speech therapy					
TEACCH approach					
Other (please specify)					
(1)					
(2)					
(3)					
(4)					
(5)					
8. Please specify what medications or supplements your child with an ASD is currently taking.					
Medication	Strength	No. of times pe	er day H	low long is the chil	d on this medication

6.7 What therapies or intervention treatment(s) did they recommend?

9. Please specify the services used by your child with an ASD in the past 12 months. Who paid for the service(s) e.g. HSE, voluntary organization, health insurance, paid for it yourself etc. *Please enter '0' if your child had no visit*.

Child 3						
Services	No. of visits	Distance from your home to service (in Km)	Who paid for the service			
Dentist						
GP						
Practice nurse						
Optician						
Dietician						
Speech & language therapist						
Occupational therapist						
Physiotherapist						
Applied behavioural analysis						
Sensory integration therapy						
Cognitive behavioural therapy						
Psychiatrist						
Psychologist						
Social worker						
Neurologist						
Gastroenterologist						
Accident & Emergency						
Social skills training/group						
Other (please specify)						
(1)						
(2)						
(3)						
(4)						
(5)						

10. What type of school does your child with an ASD attend? Please tick the box(es) for your child. If you child attends both a mainstream school and a special needs school please write how many days per week they attend each type of school.

Type of schooling	Child 3	Number of days per week that they attend
Pre-school/crèche		
Special pre-school		
Mainstream primary		
Special needs school		
ASD unit		
Mainstream secondary		
Home educated by parents		
Private school		

school						
10.2 How many hours has your child been granted under the home tuition grant?						
10.3 Does the teacher in school/home tuition have a qualification in teaching children with an ASD? Yes No Don't know						
If yes, what method do they use e.g. Applied behavioural analysis, TEACCH approach, eclectic approach etc.?						
10.5 Does your child use special transport to school, special equipment or special training devices? Please list them						
10.6 Does your child receive the July Provision or July Education Programme?						
Please tick whether they receive it in school or at home School Home						

IF YOU HAVE MORE THAN THREE CHILDREN WITH AN ASD PLEASE CONTACT ÁINE AT <u>a.roddy1@nuigalway.ie</u> or 087 7694521 TO REQUEST A SPECIAL SURVEY

SECTION 3: Out-of-Pocket Expenditure

1. Please provide the amount of <u>extra costs</u> you incurred as a direct result of your child/children having an ASD. Each estimate for the different types of expenses can be recorded on a weekly OR monthly OR annual basis depending on how regularly these costs occur for your family. Please report only one for each type of expense.

Type of expenses	Weekly cost	Monthly cost	Cost in the past 12
Type of expenses	Weekly cost	Within Cost	months
Living costs			
Special diet	€	€	€
Special clothing	€	€	€
Continence care e.g. nappies	€	€	€
Replacing/repairing damage	€	€	€
Home adaptations	€	€	€
Extra heat	€	€	€
Extra electricity	€	€	€
Laundry	€	€	€
Telephone	€	€	€
Care and assistance			
Childcare/ carer during the school term	€	€	€
Childcare/carer during the holidays	€	€	€
Respite care	€	€	€
Special activities			
Autism friendly activities	€	€	€
Educational costs			
Specialised education	€	€	€
Therapeutic toys & sensory equipment	€	€	€
Electronic items e.g. ipad	€	€	€
Medical costs			
Out-of-pocket expenses for GP visit	€	€	€
Out-of-pocket expenses for specialists	€	€	€
Out-of-pocket expenses for			
medication/supplements	€	€	€
Out-of-pocket expenses for private			
therapeutic interventions & assessment	€	€	€
Out-of-pocket expenses for hospital			
patient fee	€	€	€
Travel costs			
Fuel/transport/parking costs	€	€	€
Accommodation	€	€	€
Training/ support costs			0
Skills training course(s)/ workshops	€	€	€
Counselling	€	€	€
Autism assistance dog	0		0
Training/veterinary bills/feeding	€	€	€

1.1 If there are any other expenses not listed in question 1 please enter them below

Type of expenses	Weekly cost	Monthly cost	Cost in the past 12 months
Other (Please specify)			
(1)	€	€	€
(2)	€	€	€
(3)	€	€	€
(4)	€	€	€
(5)	€	€	€
(6)	€	€	€
(7)	€	€	€
(8)	€	€	€
(9)	€	€	€

2. Is there any type of expense which you cannot afford or that you need to spend more on to meet your child's needs but cannot afford to? (Please specify below the type of expense(s) and whether you cannot afford it or need to spend more. How much (or additional) would you need to spend to meet your child's particular need(s))

	Type of expenses	If you cannot afford it at all how much would it cost to meet your child's/children's needs?	How much more would you need to spend to meet your child's/children's needs
(1)		€	€
(2)		€	€
(3)		€	€
(4)		€	€
(5)		€	€
(6)		€	€
(7)		€	€
(8)		€	€

3.	Has your family go	tten into del	ot in th	ie pa	st 12	mont	hs specifically due to your
	child's/children's co	ondition?	Yes		No		
3.1	If yes; how much de	ebt do you ha	ave as	a res	sult of	f your	child's condition?
	€						

	Have need	•		ortgage your l	house l	because (of your c	child's/ch	ildren	's special
4. Have you experienced a reduction in some expenditure as a direct result of your child having an ASD e.g. less entertainment, less holidays, not buying branded clothing for the child/children with an ASD due to increased staining etc? If yes: please specify the type of expense(s) and estimates of the reduction in expenditure on a weekly, monthly or annual basis depending on how regularly these reductions in expenditure occur for your family.										
		Тур	e of ex	penses	,	Weekly c	eost N	Monthly (cost	Cost in the past 12 months
	(1)				€		€		ŧ	€
	(2)				€		€		;	€
	(3)				€		€			€
	(4)				€		€			€
	(5)				€		€			€
	(6)				€		€			€
(Thi	SECTION 4: Families use of healthcare services (This information is needed to calculate the societal cost of an ASD. If a family member(s) have to attend a doctor, specialist, counsellor or need treatment because of caring for their child, this cost is included when calculating the societal cost.) 1. Please specify what members of the household have a medical card/ GP visit card									
		cal card								
(GP vi	sit card								
2	2. D	oes the fan	nily ha	ve private me	dical i	nsurance	e?			
		Yes, in full	1 🗆	Yes, partially		No 🗆	Don't l	know		

□ No

☐ Don't know

2.1 Does that insurance include the cost of GP visits?

Yes, partially

Yes, in full

3. Please specify any healthcare or services used by the other members of the household in the past year as a result of your child/children having an ASD. Examples: counselling, additional visits to GP, psychiatric services etc. Who paid for the service(s) e.g. HSE, voluntary organization, health insurance, paid for it yourself etc. Please enter '0' in the no. of visits box if a member of the household hasn't used any healthcare or service as a result of your child/children having an ASD.

No. of person given in household background details box	Services	No. of visits	Average time of each visit (approx in minutes)	Who paid for the service?

4. Please specify what medications other members of the household are currently taking as a result of your child/children having an ASD

Medication	Strength	No. of times per day	How long is the person on this medication

<u>-</u>	SECTION 5: Mother's/Stepmother's Employment								
_							child/children with a	 n	
	(This section asks questions about the impact of caring for your child/children with an ASD on the parent's ability to work and earn money. <u>I would like to assure you all the</u>								
	information provided is strictly confidential. The only reason you are asked about								
	your income is to calculate the proportion of your income you have to spend on your								
•	child's /children's special needs. No one else will have access to this information.)								
1.	1. Please tick the box which shows the highest level of education you have completed								
		Primary school			☐ Third level				
		Junior Cert or equi	valent]]	Postgraduate			
		Leaving Cert or eq	uivalent			Other (please)	specify)		
2.	Wl	nat is your ethnic o	r cultural backgro	ound	?			_	
		Irish			Ar	y other Black	background		
		Irish Traveller			Ch	inese			
		Any other white ba	nckground		A	Any other Asian background			
		African					ked background		
					(sp	ecify)			
3.	Ho	w would you defin	e vour current wo	rk st	atus	?			
		Working full-time					1.1		
-						Long-term s	ickness or disability		
_		Working part-time				Full-time stu	ıdent		
		Unemployed				*Full-time c	arer to child/children		
						with an ASE)		
		Home duties/ looki	ng after home or			Full-time car	rer to someone other		
		family	8		_	than your child with an ASD			
	П	Other (Please speci	fy)					_	
L		ull-time carer canno	t he engaged in emi	nlovr	nent	self-employr	nent training or		
			0 0			•	. During your absence,		
		uate care for the per							
		and the per							
4.	Н	ow many children v	with an ASD are v	ou a	full	-time carer fo	or?		
5.		d you leave paid er	· · · · · · · · · · · · · · · · · · ·				ition?	T -	
		•			V		Yes 1	No 🗆	
6.	Ple	ease tick what finar		rece	ive a	and the amou	T T T T T T T T T T T T T T T T T T T		
		Domiciliary Care		Paym	nent	per month	€		
		Carer's Allowance	e l	Paym	nent	per week	€		
		Carer's Benefit		Paym	nent	per week	€		
		Disability Allowa	ince	Paym	nent	per week	€		
		Respite Care Gran	nt 1	Early	pay	ment	€		
	П	Other (please specify & state the amount received)							

7.	How many paid hours work do you u overtime?	nder	take per week including any regular				
	over time:						
8.	If you left your job to become a full-						
	hours you used work per week including any regular overtime						
0							
9.	When were you last in paid employm	ent?	Month Year				
10.	Which of the following best describes	the	type of paid employment you work at? If				
	you are a full-time carer please tick w						
	worked at please.						
	Professional Managers		Skilled manual				
E	Managerial & Technical		Semi-skilled				
	Non-manual		Unskilled				
	Skilled manual						
	11. Have you had to take time off wor	rk of	change reduce your work hours because				
	of your child's condition? Yes	N	•				
	i es						
10			1 00 0				
12.	If yes; how many days have you had 12 months?	to ta	ake off from work in the past				
	12 months.						
13.	If you have had to take time off work	s or 1	reduce your work hours due to your				
		te th	e loss in your take home pay for the last				
	year as a result €						
14.	Have you ever had to turn down wor	k opi	portunities or a promotion because				
	of your child/children having an ASI		Yes No				
		•					
		7/7					
15.	What impact has caring for your chil	d/ch	ildren with an ASD had on your pension				
16.	_ · · · · · · · · · · · · · · · · · · ·	rn in	the past year, after deductions for tax				
	and PRSI contributions?						
17	For full-time _carers how much take	hom	e pay did you earn in the last year you				
17.	were in paid employment	110111	pay the you carn in the last year you				

SEC	CTION 5:	Father's/Stepfather's/Partner's Employment						
. Please tick the box which shows the highest level of education you have completed								
	Primary sch	ool	[Third level			
	Junior Cert	or equivalent	[Postgraduate			
	Leaving Ce	rt or equivalent		7	Other (please s	specij	fy)	
2. What is your ethnic or cultural background?								
	Irish				ny other Black	back	ground	
	Irish Travel				hinese			
		white background		_	any other Asian		<u> </u>	
	African				ther – incl. Mix	ked ba	ackground	
				(S	pecify)			
. н	ow would you	ı define your current wo	rk s	tatu	s?			
	Working ful	l-time			Long-term si	Long-term sickness or disability		
	Working par	rt-time			Full-time stu	Full-time student		
	Unemployed	l				*Full-time carer to child/children with an ASD		
	Home duties family	s/ looking after home or			Full-time carer to someone other than your child with an ASD			
П	Other (Pleas	se specify)						
*A	full-time carer	cannot be engaged in em	ploy	men	t, self-employn	nent.	training or	
		outside the home for mor	- •		- •			
ade	quate care for	the person requiring full-t	ime	care	and attention r	nust	be arranged.	
4. How many children with an ASD are you a full-time carer for? 5. Did you leave paid employment because of your child's								
co	ondition?						Yes No	
n	loogo tielr wh	at financial gunnantg van			and the amou	t		
$-\frac{\mathbf{P}}{\Box}$		at financial supports you ry Care Allowance			per month			
H	Carer's Al	•	<u> </u>		per week	€		
片	Carer's Be				per week	€		
片	Disability				per week			
片	Respite Ca				yment	€_		
〒	-	ase specify & state the am						

7.	How many paid hours work do you undertake per week including any regular												
O	overtime?												
ð.	. If you left your job to become a full-time carer please answer how many paid hours you used work per week including any regular overtime												
	1100	uis y	ou us	ocu v	OI K	per	***************************************	12 111	iciu	ing (illy IX	8	unar overtime
							_	_				Г	
9.	Wi	hen v	vere y	you I	ast i	n pa	id e	mpl	oym	ent?		L	Manth Year
10	Wł	hich (of the	foll	owii	ıσ he	et d	ASCI	rihe	s the	tyne (Month Year paid employment you work? If
10.						_					~ -		escribes the last paid job you
	•	rked											1 3
			Prof	essic	nal	Mana	ager	S					Skilled manual
			Mar	nager	ial &	z Tec	hnic	cal					Semi-skilled
			Non	-mar	nual								Unskilled
			Skil	led n	nanu	al							
11	Н	ave v	zou h	ad to	n tak	ce tin	ne o	ff w	ork	or re	-duce	v	our work hours because of your
11.		ild's				10 1111	_					<i>у</i> П	our work nours because or your
							L	Zes	Ш	No	Ш		
			· í	how	mai	ny da	ays l	have	e yo	u had	l to ta	k	e off from work in the past 12
	mo	nths	?										
12.	•											•	your hours due to your
						D pl	leas	e est	tima	ite th	e loss	i	n your take home pay for the last
	yea	ar as	a res	uit €					_				
13.	Ha	ve vo	on ev	er ha	ad to) turi	n do	wn	wor	k on	oortu	ni	ities or a promotion because
		your									, , ,		or a promotion security
	OI	your	CIIII	u/CIII	luic	ii iiu	V 1116	5 411		•			
													-
14.	Wł	hat ir	npac	t has	car	ing f	or y	our	chi	ld/ch	ildren	۱ ۱	with an ASD had on your pension?
15.	Ho	w m	uch t	ake l	om	e nav	v (af	fter	ded	nctio	ns for	۰	ax and PRSI contributions) did
10.		u ear							ucu	uctio	115 101	j	as and I ker contributions, and
				1									
16.	Fo	r full	-time	e –ca	rers	how	mu	ich t	take	hom	e pay	d	lid you earn in the last year you
	we	re in	paid	emp	loyi	nent	?						

	CECTION 5.1.		C					
	SECTION 5.1: Support Payments							
		d receive a disability allowance payment?						
2.		s your household receive any other social welfare payments that are not						
	· · · · · · · · · · · · · · · · · · ·	to your child's/children's condition? (e.g. Jobseekers benefit, One- enefit, Child Benefit (used to be called children's Allowance), ity Payment for adults, Family Income Supplement) Yes No						
3.		cify the title of the payments and the amount you receive per ending on how regularly you receive the payment(s)						
	Type of payment	ing on now regulari	Weekly/monthly	Amount				
				€				
				€		+		
				€		\dashv		
				€		+		
Ag con pr	welfare payments, incapacitated child tax credit or any other source of income? (e.g. rental income, pensions, interest, dividends). €							
7.	Could you explain w	what the better servi	ces would be please a	and where	e would	you		
						$-\ $		

	SECTION 6:	Time Spent Ca	ring for	your Child/C	Childr	en with an ASD
1	. Do you have a paid ca		nto your	home to hel	p you	care for your
	,	L	105	110		
2	. Please specify how m	uch time in hour	s and mi	nutes a care	r(s) ne	aid by you or
_	someone else spends a					· · · · · · · · · · · · · · · · · · ·
	day/night. If one of th			·		
		ie pareius receiv	es a care	i s payment	101 (1)	ie cimu/cimuren
	please fill this in.					
	Caregiver	activity		Hours		Minutes
Pe	rsonal Care	activity		Hours		Millutes
	eding					
	essing					
	rsonal hygiene					
	Iministrating medication					
	tend to your child/children	n with an ASD at	night			
	actical help		<u> </u>			
	ommunicating /Therapie	S				
	cial & life skills e.g. helpi		get used			
	new situations.					
Sp	eech and occupational the	erapy				
iPa	ad interaction					
Pla	ny therapy					
	plied behavioural analysi	s techniques				
	usic therapy					
	elping with homework					
	havioural management					
	aling with meltdowns					
	ixiety issues					
	pervision					
	aking sure your child/child	dren with an ASD	are			
saf						
	eping company					
	pointments					
	inging your child to appoi					
	inging your child to ASD	friendly activities	8			
	ansportation					
	e amount of time spent br	inging your child	to a			
	rticular service					
	her (please specify)					
(1)				1		

(2) (3)

(4) (5)

Time Spent Caring For Your Child/Children with an ASD

3. Please specify how much time in hours and minutes an unpaid carer(s) spend at the
following caring activities on a typical 24 hour day/night. If the parents don't receive a
carers payment please fill in for parent(s) & any other unpaid carer(s) & say whether the
carer is a parent, sibling, friend, relative or other:

Caregiver activity	Hours	Minutes
Personal Care		
Feeding		
Dressing		
Personal hygiene		
Administrating medication		
Attend to your child/children with autism at night		
Practical help		
Communicating /Therapies		
Social & life skills e.g. helping your child to get used of new situations.		
Speech and occupational therapy		
iPad interaction		
Play therapy		
Applied behavioural analysis techniques		
Music therapy		
Helping with homework		
Behavioural management		
Dealing with meltdowns		
Anxiety issues		
Supervision		
Making sure your child/children with autism are safe		
Keeping company		
Appointments		
Bringing your child to appointments		
Bringing your child to autism friendly activities		
Transportation		
The amount of time spent bringing your child to a		
particular service		
Other (please specify)		
(1)		
(2)		
(3)		
(4)		
(5)		

	(-)			
	(4)			
	(5)			
4. H	ow many people provide paid care t	o your child/ chil	dren with an AS	D?
1.1	Apart from the child's/ children's pa	rents how many	people provide u	npaid care to
	your child/children with an ASD?			
		32		

Family nembers	Child/Child	lren with an ASD Hours		Child/Children without an ASD			
Mother			Age of chil	d Hours			
viouier							
utilci							
5. Imagii	ne your child/	children did not	have special nee	eds. How much time w			
			tara di Paranta di Par	es the child's brothers.			
			<u>ild/children with</u>	n an ASD) would spend			
	owing per we						
Parents & Unpaid ca		Paid work	Unpaid work	Leisure activities			
Onpaid ca (Please speci							
	in household						
background	details box or						
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w	details box or son is ith the	Hours	Hours	Hours			
background how the pers associated w child/childre	details box or son is ith the en)						
background how the pers associated w child/childre	details box or son is ith the en)	Hours pite break in the		Hours Yes No			
background how the pers associated w child/childre	details box or son is ith the en)	pite break in the	past year?				
background how the pers associated w child/childre	details box or son is ith the en)		past year?				
background how the pers associated w child/childre	details box or son is ith the en) you had a response, for how man	pite break in the	past year?				
background how the persassociated we child/childred 6. Have y 6.1 If yes 6.2 What	details box or son is ith the en) you had a respondence of the son is ith the en ith the entire enti	pite break in the p ny nights in the p ided the respite c	past year? ast year? are?	Yes No			
6. Have y 6.1 If yes 6.2 What 7. Do you	details box or son is ith the en) you had a response, for how many tagency proves a or your particular to the end of the	pite break in the prided the respite contact t	past year? ast year? are? unpaid carers l	Yes No			
6. Have y 6.1 If yes 6.2 What 7. Do you illness?	details box or son is ith the en) you had a response, for how many tagency proves a or your particular to the end of the	pite break in the prided the respite contact t	past year? ast year? are? unpaid carers l	Yes No			

5.

SECTION 7:	Additional Information					
If you have any additional	l information or comments you would like to provide or wish to					
tell about the impact your child's condition has on your family life and other children						
please use this section to do so. Some quotes about your experiences may be taken from this						
	e evidence based report which will be made available publicly.					
	quotes will be fully anonymized and there will be no way anyone					
can be identified.						

Thank you very much for your time and patience in completing this survey.