CONFIDENTAL QUESTIONNAIRE **No:**

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.

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With Thanks to Our Sponsors

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SECTION 1:	Background Details

1. **Could the person filling the form please fill in their contact details below in BLOCK CAPITAL LETTERS. I would like to assure you all the information provided is strictly confidential and Áine Roddy will have sole ownership of the data. I will need to contact the winners of the five iPads that are being raffled.**

NAME:	
ADDRESS:	
Email address:	
Tel. number	

2. **How many people live in your household in total**? ☐

3. **Could you please provide information on each member of the household in the box below**:

<u>The person filling the form should put their details in the first row</u>
The details of the child or children diagnosed with an ASD should be put in the next row(s) starting from oldest to youngest
The details of anyone else living in the house should be put in the next row(s)
For column B, if date of birth is not available please give the age at last birthday
For column E please tick just one box that describes best the person's current economic status

	(A)	(B)	(C)	(D)	(E)						
No	Sex M F	Date of Birth dd mm yr	Does this person have an ASD Yes No	Relationship of each member of the household to the child e.g. mother, father etc.	Pre-school	School/Education	At Work/ Training	Unemployed	Retired	Home Duties	Other
1	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
2	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
3	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
4	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
5	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
6	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
7	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
8	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐
9	☐ ☐	__ ___ _____	☐ ☐		☐	☐	☐	☐	☐	☐	☐

4. What is your marital status?

☐	Married	☐	Partner	☐	Single	☐	Widow
☐	Separated	☐	Divorced				

5. What County do you live in?

5.1 Please select the type of area that you live in?

☐	Rural	☐	Suburban	☐	Urban

6. Do you or your partner have your own transport?

☐	Yes	☐	No

7. What type of accommodation do you live in?

☐	Owner occupied (with or without mortgage)	☐	Being purchased from a local Authority	☐	Rented privately	☐	Rented from Local Authority	☐	Other

8. Are you or your partner a member of an ASD support group or organisation?

☐	Yes	☐	No

If yes, please list the name(s) of the organisation(s):

SECTION 2:	**Child 1 with an Autism Spectrum Disorder**

This section asks questions about the diagnosis you received for your child and the services he/she uses. It is important to establish what services your child needs, what they found helpful and who parents rely on to provide the services and the costs associated with it.

IF YOU HAVE MORE THAN ONE CHILD WITH AN ASD AGED BETWEEN 2 to 18 YEARS OF AGE PLEASE GIVE THE DETAILS OF YOUR OLDEST CHILD WITH AN ASD FOR CHILD 1. PLEASE FILL IN THE DETAILS FOR CHILD 2 ON PAGE 9.

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 1			

1.1 Was your child diagnosed in the public system e.g. HSE

Yes	☐	No	☐

2. What diagnosis did you receive for your child?

Child	Autism disorder	Asperger's disorder	Childhood disintegrative disorder	Pervasive developmental disorder	Retts syndrome	Not sure
Child 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 child's ASD is SEVERE, MODERATE or MILD. You may find the tables on this page helpful to answer the question. If you are still unsure please contact Áine at a.roddy1@nuigalway.ie 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.**

2.2 What is your child's IQ? ☐

2.3 Is your child verbal? Yes ☐ No ☐

3. If your child also has an intellectual disability please tick how affected your child is

Child	Mild	Moderate	Severe	Profound
Child 1	☐	☐	☐	☐

4. Does your child also have another medical condition(s) e.g. epilepsy, ADHD, anxiety disorders, sleep disorders, gastrointestinal problems Yes ☐ No ☐
(*Please specify*)

5. Has your child been hospitalised in the past year? Yes ☐ No ☐

5.1 How many nights was this for? ***Please enter '0' if none*** |

6. Was there any time in the last 12 months when, in your opinion, your child with an ASD needed medical care, services, therapies or an intervention treatment(s) for their ASD but he/she did not receive it? Yes ☐ No ☐ Don't know ☐

6.1 In your opinion, does your child still need medical care, services, therapies or an intervention treatment(s) for their ASD? Yes ☐ No ☐ Don't know ☐

6.2 Why did your child not get the medical care, service, 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 medical care/therapy/intervention treatment wasn't available to you	Yes	☐	No	☐
(c)	It is too far to travel to	Yes	☐	No	☐
(d)	You could not take time off work to visit the health professional	Yes	☐	No	☐
(e)	You wanted to wait and see if the problem got better	Yes	☐	No	☐
(f)	The child refused/fear of doctor/health professional	Yes	☐	No	☐
(g)	Child is on the waiting list	Yes	☐	No	☐
(h)	Unsure of child's needs	Yes	☐	No	☐
(i)	There are no private services available in our area	Yes	☐	No	☐
(j)	Other	Yes	☐	No	☐

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? Yes or No**	**<u>Number of sessions needed per month in the last 12 months</u>**	**Does your child still need it? Yes or No**	**<u>Number of sessions needed per month for the next 12 months</u>**
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)				

6.4 Has a health professional(s) recommended that your child receives any of the therapies or intervention treatments? Yes ☐ No ☐

(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 qualification do they have?

6.6 Did you see them in the public system e.g. HSE? Yes ☐ No ☐

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

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 ASD received any intervention treatments? ☐ Yes ☐ No

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 additional information section at the end of the survey.

Child 1				
Interventions	**Age when started**	**How long did they receive it**	**Was it helpful Yes/No/Not sure**	**Who provided it?**
Applied behavioural analysis (ABA)				
Floortime				
Gluten free/casein free diet				
Occupational therapy				
PECS				
Relationship development intervention (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 per day	How long is the child on this medication

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 schooling	Child 1	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 ☐ 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 child receive the July Provision or July Education Programme? ☐ Yes ☐ No

10.7 Please tick whether they receive it in school 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 ASD FOR CHILD 2. If you 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	Autism disorder	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 child's ASD is SEVERE, MODERATE or MILD. You may find the tables on this page helpful to answer the question.

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.**

2.2 What is your child's IQ? ☐

2.3 Is your child verbal? Yes ☐ No ☐

3. If your child also has an intellectual disability please tick how affected your child is

Child	Mild	Moderate	Severe	Profound
Child 2	☐	☐	☐	☐

4. Does your child also have another medical condition(s) e.g. epilepsy, ADHD, anxiety disorders, sleep disorders, gastrointestinal problems (*Please specify*)

Yes ☐ No ☐

5. Has your child been hospitalised in the past year? Yes ☐ No ☐

5.1 How many nights was this for? *Please enter '0' if none*

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? Yes ☐ No ☐ Don't know ☐

6.1 In your opinion, does your child still need medical care, therapies or an intervention treatment(s) for their ASD? Yes ☐ No ☐ Don't know ☐

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 medical care/therapy/intervention treatment wasn't available to you	Yes	☐	No	☐
(c)	It is too far to travel to	Yes	☐	No	☐
(d)	You could not take time off work to visit the health professional	Yes	☐	No	☐
(e)	You wanted to wait and see if the problem got better	Yes	☐	No	☐
(f)	The child refused/fear of doctor/health professional	Yes	☐	No	☐
(g)	Child is on the waiting list	Yes	☐	No	☐
(h)	Unsure of child's needs	Yes	☐	No	☐
(i)	There are no private services available in our area	Yes	☐	No	☐
(j)	Other	Yes	☐	No	☐

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 last 12 months?** **Yes or No**	**<u>Number of sessions needed per month in the last 12 months</u>**	**Does your child still need it?** **Yes or No**	**<u>Number of sessions needed per month for the next 12 months</u>**
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)				

6.4 Has a health professional(s) recommended that your child receives any of the therapies or intervention treatments? Yes ☐ No ☐

(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 qualification do they have?

6.6 Did you see them in the public system e.g. HSE? Yes ☐ No ☐

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

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 ASD received any intervention treatments? ☐ Yes ☐ No

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 additional information section at the end of the survey.

Child 2				
Interventions	**Age when started**	**How long did they receive it**	**Was it helpful Yes/No/Not sure**	**Who provided it?**
Applied behavioural analysis (ABA)				
Floortime				
Gluten free/casein free diet				
Occupational therapy				
PECS				
Relationship development intervention (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 per day	How long is the child on this medication

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	☐	No	☐	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?

☐	Yes	☐	No

10.6 Please tick whether they receive it in school or at home

☐	School	☐	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 for a diagnosis	Once referred, how long did it take to get a diagnosis
Child 3			

2. **What diagnosis did you receive for your child?**

Child	Autism disorder	Asperger's disorder	Childhood disintegrative disorder	Pervasive developmental disorder	Retts syndrome	Not sure
Child 3	☐	☐	☐	☐	☐	☐

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

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 how 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.**

2.2 What is your child's IQ? ☐

2.3 Is your child verbal? Yes ☐ No ☐

3. If your child also have an intellectual disability please tick how affected your child is

Child	Mild	Moderate	Severe	Profound
Child 3	☐	☐	☐	☐

4. Does your child also have another medical condition(s) e.g. epilepsy, ADHD, anxiety disorders, sleep disorders, gastrointestinal problems (*Please specify*)

Yes ☐ No ☐

5. Has your child been hospitalised in the past year?

Yes ☐ No ☐

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?

Yes ☐ No ☐ Don't know ☐

6.1 In your opinion, does your child still need medical care, therapies or an intervention treatment(s) for their ASD?

Yes ☐ No ☐ Don't know ☐

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 medical care/therapy/intervention treatment wasn't available to you	Yes	☐	No	☐
(c)	It is too far to travel to	Yes	☐	No	☐
(d)	You could not take time off work to visit the health professional	Yes	☐	No	☐
(e)	You wanted to wait and see if the problem got better	Yes	☐	No	☐
(f)	The child refused/fear of doctor/health professional	Yes	☐	No	☐
(g)	Child is on the waiting list	Yes	☐	No	☐
(h)	Unsure of child's needs	Yes	☐	No	☐
(i)	There are no private services available in our area	Yes	☐	No	☐
(i)	Other	Yes	☐	No	☐

6.3 Please fill in which medical care/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?** **Yes or No**	**<u>Number of sessions needed per month in the last 12 months</u>**	**Does your child still need it?** **Yes or No**	**<u>Number of sessions needed per month for the next 12 months</u>**
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)				

6.4 Has a health professional(s) recommended that your child receives any of the therapies or intervention treatments? Yes ☐ No ☐

(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 qualification do they have?

6.6 Did you see them in the public system e.g. HSE? Yes ☐ No ☐

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

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 ASD received any intervention treatments? ☐ Yes ☐ No

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 additional information section at the end of the survey.

Child 3				
Interventions	**Age when started**	**How long did they receive it**	**Was it helpful Yes/No/Not sure**	**Who provided it?**
Applied behavioural analysis (ABA)				
Floortime				
Gluten free/casein free diet				
Occupational therapy				
PECS				
Relationship development intervention (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 per day	How long is the child on this medication

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	☐	

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 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?

☐	Yes	☐	No

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 a.roddy1@nuigalway.ie 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 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			
Skills training course(s)/ workshops	€	€	€
Counselling	€	€	€
Autism assistance dog			
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 <u>cannot afford it at all</u> how much would it cost to meet your child's/children's needs?	How <u>much more</u> 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 gotten into debt in the past 12 months specifically due to your child's/children's condition? Yes ☐ No ☐

3.1 If yes; how much debt do you have as a result of your child's condition?

€

3.2 Have you had to re-mortgage your house because of your child's/children's special needs?

Yes	☐	No	☐

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.

	Type of expenses	Weekly cost	Monthly cost	Cost in the past 12 months
(1)		€	€	€
(2)		€	€	€
(3)		€	€	€
(4)		€	€	€
(5)		€	€	€
(6)		€	€	€

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

Medical card	
GP visit card	

2. Does the family have private medical insurance?

Yes, in full	☐	Yes, partially	☐	No	☐	Don't know	☐

2.1 Does that insurance include the cost of GP visits?

Yes, in full	☐	Yes, partially	☐	No	☐	Don't know	☐

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

SECTION 5:	Mother's/Stepmother's Employment

(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. I would like to assure you all the 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. Please tick the box which shows the highest level of education you have completed

☐	Primary school	☐	Third level
☐	Junior Cert or equivalent	☐	Postgraduate
☐	Leaving Cert or equivalent	☐	Other (*please specify*) _____

2. What is your ethnic or cultural background?

☐	Irish	☐	Any other Black background
☐	Irish Traveller	☐	Chinese
☐	Any other white background	☐	Any other Asian background
☐	African	☐	Other – incl. Mixed background (specify)_____

3. How would you define your current work status?

☐	Working full-time	☐	Long-term sickness or disability
☐	Working part-time	☐	Full-time student
☐	Unemployed	☐	*Full-time carer to child/children with an ASD
☐	Home duties/ looking after home or family	☐	Full-time carer to someone other than your child with an ASD
☐	Other (Please specify)		

*A full-time carer cannot be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours a week. During your absence, adequate care for the person requiring full-time care and attention must 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 condition?

Yes	☐	No	☐

6. Please tick what financial supports you receive and the amount

☐	Domiciliary Care Allowance	Payment per month	€ _____
☐	Carer's Allowance	Payment per week	€ _____
☐	Carer's Benefit	Payment per week	€ _____
☐	Disability Allowance	Payment per week	€ _____
☐	Respite Care Grant	Early payment	€ _____
☐	Other (*please specify & state the amount received*) _____		

7. **How many paid hours work do you undertake per week including any regular overtime?** ☐

8. **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** ☐

9. **When were you last in paid employment?** ☐ / ☐
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 which best describes the last paid job you worked at please.**

☐	Professional Managers	☐	Skilled manual
☐	Managerial & Technical	☐	Semi-skilled
☐	Non-manual	☐	Unskilled
☐	Skilled manual		

11. **Have you had to take time off work of change reduce your work hours because of your child's condition?** Yes ☐ No ☐

12. **If yes; how many days have you had to take off from work in the past 12 months?** ☐

13. **If you have had to take time off work or reduce your work hours due to your child's/children's ASD please estimate the loss in your take home pay for the last year as a result €**_____

14. **Have you ever had to turn down work opportunities or a promotion because of your child/children having an ASD?** Yes ☐ No ☐

_____

15. **What impact has caring for your child/children with an ASD had on your pension?**

_____

_____

_____

16. **How much take home pay did you earn in the past year, after deductions for tax and PRSI contributions?** ☐

17. **For full-time –carers how much take home pay did you earn in the last year you were in paid employment** ☐

SECTION 5:	Father's/Stepfather's/Partner's Employment

1. Please tick the box which shows the highest level of education you have completed

☐	Primary school	☐	Third level
☐	Junior Cert or equivalent	☐	Postgraduate
☐	Leaving Cert or equivalent	☐	Other (*please specify*) _____

2. What is your ethnic or cultural background?

☐	Irish	☐	Any other Black background
☐	Irish Traveller	☐	Chinese
☐	Any other white background	☐	Any other Asian background
☐	African	☐	Other – incl. Mixed background (specify)_____

3. How would you define your current work status?

☐	Working full-time	☐	Long-term sickness or disability
☐	Working part-time	☐	Full-time student
☐	Unemployed	☐	*Full-time carer to child/children with an ASD
☐	Home duties/ looking after home or family	☐	Full-time carer to someone other than your child with an ASD
☐	Other (Please specify)		

*A full-time carer cannot be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours a week. During your absence, adequate care for the person requiring full-time care and attention must 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 condition?

Yes	☐	No	☐

6. Please tick what financial supports you receive and the amount

☐	Domiciliary Care Allowance	Payment per month	€ _____
☐	Carer's Allowance	Payment per week	€ _____
☐	Carer's Benefit	Payment per week	€ _____
☐	Disability Allowance	Payment per week	€ _____
☐	Respite Care Grant	Early payment	€ _____
☐	Other (*please specify & state the amount received*) _____		

7. **How many paid hours work do you undertake per week including any regular overtime?** ☐

8. **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** ☐

9. **When were you last in paid employment?** ☐ / ☐
   Month Year

10. **Which of the following best describes the type of paid employment you work? If you are a full-time carer please tick which best describes the last paid job you worked at please.**

☐	Professional Managers	☐	Skilled manual
☐	Managerial & Technical	☐	Semi-skilled
☐	Non-manual	☐	Unskilled
☐	Skilled manual		

11. **Have you had to take time off work or reduce your work hours because of your child's condition?** Yes ☐ No ☐

11.1 If yes; how many days have you had to take off from work in the past 12 months? ☐

12. **If you have had to take time off work or reduce your hours due to your child's/children's ASD please estimate the loss in your take home pay for the last year as a result €**_____

13. **Have you ever had to turn down work opportunities or a promotion because of your child/children having an ASD?**

_____

14. **What impact has caring for your child/children with an ASD had on your pension?**

_____

_____

_____

15. **How much take home pay (after deductions for tax and PRSI contributions) did you earn in the past year?** ☐

16. **For full-time –carers how much take home pay did you earn in the last year you were in paid employment?** ☐

SECTION 5.1:	Support Payments

1. **Does your child receive a disability allowance payment?** Yes ☐ No ☐
2. **Does your household receive any other social welfare payments that are not directly related to your child's/children's condition?** (*e.g. Jobseekers benefit, One-Parent Family Benefit, Child Benefit (used to be called children's Allowance), Pension, Disability Payment for adults, Family Income Supplement*) Yes ☐ No ☐
3. **If yes; please specify the title of the payments and the amount you receive per week/month depending on how regularly you receive the payment(s)**

Type of payment	Weekly/monthly	Amount
		€
		€
		€
		€

4. **What is the total amount of social welfare payments received by your household in the past 12 months including those related to your child's/children's full-time care mentioned in question 2.1** €_____

<u>Again I would like to reassure you all the information provided is strictly confidential</u>. 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.

5. **What is your total household take-home pay for the past year including social welfare payments, incapacitated child tax credit or any other source of income?** (*e.g. rental income, pensions, interest, dividends*). €_____
6. **If you were given a choice between receiving better services provided by the State or increased allowances/ benefits, which would you prefer and why** ?

7. **Could you explain what the better services would be please and where would you like them located?**

SECTION 6:	Time Spent Caring for your Child/Children with an ASD

1. **Do you have a paid carer who comes into your home to help you care for your child/ allows you to take a break?**

Yes	☐	No	☐

2. **Please specify how much time in hours and minutes a carer(s) paid by you or someone else spends at the following caring activities on a <u>typical 24 hour day/night. If one of the parents receives a carer's payment for the child/children please fill this in</u>.**

Caregiver activity	Hours	Minutes
Personal Care		
Feeding		
Dressing		
Personal hygiene		
Administrating medication		
Attend to your child/children with an ASD 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 an ASD are safe		
Keeping company		
Appointments		
Bringing your child to appointments		
Bringing your child to ASD friendly activities		
Transportation		
The amount of time spent bringing your child to a particular service		
Other (please specify)		
(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. How many people provide paid care to your child/ children with an ASD?

4.1 Apart from the child's/ children's parents how many people provide unpaid care to your child/children with an ASD?

5. **Please estimate how many hours you spend on a <u>typical 24 hour day & night</u> caring for your child/children with & without an ASD**

Family members	**Child/Children with an ASD** **Age of child**	**Hours**	**Child/Children without an ASD** **Age of child**	**Hours**
Mother				
Father				

5. Imagine your child/ children did not have special needs. How much time would you and your partner and each unpaid carer (<u>includes the child's brothers, sisters, grandparents etc. caring for your child/children with an ASD</u>) would spend at the following per week:

Parents & other Unpaid carer(s) **(Please specify No. of person given in household background details box or how the person is associated with the child/children)**	**Paid work** **Hours**	**Unpaid work** **Hours**	**Leisure activities** **Hours**

6. Have you had a respite break in the past year? ☐ Yes ☐ No

6.1 If yes, for how many nights in the past year?

6.2 What agency provided the respite care?

7. Do you or your partner or any of the unpaid carers have a disability or chronic illness? (If so, please specify which carer(s), the disability or chronic illness they have and its impact**)**

SECTION 7:	Additional Information

If you have any additional 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 section and included in the evidence based report which will be made available publicly. Please be assured that all 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.