

Stigma Questionnaire - Taken, with permission, from Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. Journal of Autism and Developmental Disorders, 46(3), 942–953.)

Are you the parent of a child with a confirmed diagnosis of autism spectrum disorder (ASD)?

Yes	
No	

Please indicate your gender:

Male	
Female	
Other (please specify)	

Please indicate your parenting role:

Mother	
Father	
Other (please specify)	

Please indicate your ethnicity:

White	
English / Welsh / Scottish / Northern Irish / British	
Irish	
Gypsy or Irish Traveller	
Any other White background	
Mixed / Multiple ethnic groups	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed / Multiple ethnic background	
Asian / Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	
Any other Asian background	
Black / African / Caribbean / Black British	
African	
Caribbean	

Any other Black / African / Caribbean background	
Other ethnic group	
Arab	
Any other ethnic group	

Please indicate your child's primary diagnosis:

Autism Spectrum Disorder (ASD)	
Asperger Syndrome	
Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)	
Other (please specify)	

Does your child have any other confirmed diagnoses?

Anxiety disorder	
Attention Deficit Hyperactivity Disorder (ADHD)	
Conduct disorder (CD)	
Depression	
Developmental Coordination Disorder	
Dyscalculia	
Dyslexia	
Dyspraxia	
Epilepsy	
Fragile X Syndrome	
Gender dysphoria	
Oppositional Defiance Disorder (ODD)	
Pathological Demand Avoidance (PDA)	
Tourettes	
Other (please specify)	
Don't know	

Please indicate the type of educational provision your child attends:

Mainstream school	
Mainstream nursery	
Unit in mainstream school	
Unit in mainstream nursery	
Specialist day school	
Specialist day nursery	
Specialist residential school	
Home schooled	
Not currently placed	
Other (please specify)	

How often during the past 6 months	Often	Sometimes	Rarely	Never
Head banging				
Threat or aggressive toward others				
Noticeable repetitive behaviors				
Trouble making eye contact				
Trouble with bladder or bowel control				
Serious tantrums or meltdowns				
Became upset with change in routine				

Individuals with autism will never be able to ____. Do you think most people believe that, some people believe that, or only a few people believe that?	Most	Some	A Few
Hold a job			
Live independently			
Marry			

Do most people, some people, or only a few people believe ____?	Most people believe	Some people believe	A few people believe
Individuals with autism cannot be a good friend because of their autism			
Parents can cause their children's autism because of their parenting style			
Individuals with autism are 'mentally ill'			
Individuals with autism are dangerous or a threat to others Individuals with autism have intellectual disabilities			

How often during the past 6 months (child)	Often	Sometimes	Rarely	Never
Teased or called an insulting name				
Left out of activities by other children				
Physically bullied by other children				
Avoided contact by other children				
Heard child called hurtful names or words				
Regarded as weird or odd by other children				
Had difficulty making friends				

How often during the past 6 months (parent)	Often	Sometimes	Rarely	Never
Decided not to spend time with friends and family				
Felt you and your family were excluded				

Impact on parents' work hours	Yes	No
Cut back on work hours because of child's autism		

	Extremely	Very	Somewhat	A little	Not at all
How difficult has the stigma that is often associated with autism been for you and your family?					
How difficult has it been for your family to have a child on the autism spectrum?					

	Definitely yes	Probably yes	Probably no	Definitely no
Individuals with autism are stigmatized				

Please indicate which of the following services you have accessed:

Accommodation

- Residential care

Hospital based health services

- Inpatient
- Outpatient paediatrics
- Outpatient other
- Accident and emergency

Community health, social and voluntary services

- General practitioner (GP)
- Practice nurse
- Health visitor
- Community paediatrician
- Social worker
- Clinical psychologist
- Speech and language therapist (SALT)
- Educational psychologist (EP)
- Special educational needs co-ordinator (SENCo)
- Portage worker
- Play worker
- Art therapist

- Occupational therapists (OT)
- Physiotherapist
- Dietician
- Homeopathy
- Massage
- Osteopath
- Other community services
- Voluntary sector (in person)
- Voluntary sector (phone calls)

Medication

- Prescribed medication
- Complementary medication

Education and childcare

- Mainstream nursery
- Specialist nursery
- Mainstream playgroup
- Specialist playgroup
- Mainstream school
- Specialist school
- Childminder

Parent Courses

- For early years children (e.g Early Bird, Cygnet, Incredible Years)
 - For primary school aged children (e.g Incredible Years)
 - For teenagers (e.g Teen Life)
 - General (e.g Triple P)
-
- Any other service (Please state below)
-

There is an opportunity to take part in an additional part of this research. This will involve an interview with the researcher about your experiences of being the parent of a child with autism. The interview will be approximately 1 hour in length and you will receive a voucher for your time. Please enter your email address or phone number if you are interested in participating.