Section 1: AUTISM SPECTRUM DISORDER HISTORY

The following questions are about your experience in receiving a diagnosis for your child with ASD

It may be helpful to have with you any materials regarding your child's diagnosis.

Section 1, Question 1
What was [display_name]'s **FIRST** autism spectrum disorder (ASD) diagnosis?

Possible Responses
- Autism or Autistic disorder
- Asperger's Syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder (PDD) (choose only if none of the above apply)
- Autism Spectrum Disorder (ASD) (choose only if none of the above apply)
Section 1, Question 2
When did |display_name| receive this FIRST ASD diagnosis?

Please indicate the date as accurately as you can. If you do not know the day or month, choose "Don't Know" from the drop down menus.

Data Type: date

Section 1, Question 3
Approximately how old was |display_name| when he/she received this FIRST ASD diagnosis?

Possible Responses
- less than 12 months
- 12 months to 17 months
- 18 months to 23 months
- 2 years old
- 3 years old
- 4 years old
- 5 years old
- 6 years old
- 7 years old
- 8 years old
- 9 years old
- 10 years old
- 11 years old
- 12 years old
- 13 years old
- 14 years old
- 15 years old
- 16 years old
- 17 years old

Section 1, Question 4
Who gave |display_name| this FIRST ASD diagnosis?

Possible Responses
- Pediatrician
- Primary care doctor (other than pediatrician)
- Developmental pediatrician
- Psychiatrist
- Clinical Psychologist
- Neurologist
Section 1, Question 5
Where did [display_name] receive this FIRST ASD diagnosis?

Possible Responses
- Public school system
- Health care system (including a clinic or regional center specializing in ASDs)
- Early intervention program
- Other

Section 1, Question 6
Is [display_name]'s CURRENT ASD diagnosis different than the FIRST?

Possible Responses
- Yes, the CURRENT diagnosis is different
- No, the CURRENT diagnosis is the same

Section 1, Question 7
What is [display_name]'s CURRENT ASD diagnosis?

Possible Responses
- Autism or Autistic disorder
- Asperger's Syndrome
Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
Childhood Disintegrative Disorder (CDD)
Pervasive Developmental Disorder (PDD) (choose only if none of the above apply)
Autism Spectrum Disorder (ASD) (choose only if none of the above apply)

My child has fully recovered and no longer as an ASD (according to a professional)

Section 1, Question 8
When did [display_name] receive this CURRENT ASD diagnosis?

Please indicate the date as accurately as you can. If you do not know the day or month, choose "Don't Know" from the drop down menus

Section 1, Question 9
Approximately how old was [display_name] when he/she received this CURRENT ASD diagnosis?

Possible Responses
less than 12 months
12 months to 17 months
18 months to 23 months
2 years old
3 years old
4 years old
5 years old
6 years old
7 years old
8 years old
9 years old
10 years old
11 years old
12 years old
13 years old
14 years old
15 years old
16 years old
17 years old

Section 1, Question 10
Who gave [display_name] this CURRENT ASD diagnosis?

Possible Responses
Pediatrician
Primary care doctor (other than pediatrician)
Developmental pediatrician
Psychiatrist
Clinical Psychologist
Neurologist
Team of health professionals
Team of professionals in a school system
Speech and Language Pathologist
Other

Section 1, Question 11
Where did |display_name| receive this CURRENT ASD diagnosis?

Possible Responses
Public school system
Health care system (including a clinic or regional center specializing in ASDs)
Early intervention program
Other

Section 1, Question 12
How old was |display_name| when you FIRST became concerned that something was wrong with his/her development?

Possible Responses
Never concerned
At birth
Less than 6 months old
6 months to 11 months old
12 months to 17 months old
18 months to 23 months old
2 years old
3 years old
4 years old
5 years old
6 years old
7 years old
8 years old
9 years old
10 years old
11 years old
Section 1, Question 13, measurement unit in month(s)

If you remember, please give |display_name|’s exact age (in years and months) that you FIRST became concerned that something was wrong with his/her development.

Coded Value  | Response  | Value  | User Entered Coded Value
---|---|---|---

Section 1, Question 14

What was your FIRST concern about |display_name|’s development?

Please try to remember what specific concern first made you think something might be wrong with your child’s development.

Possible Responses

- More focused on objects or self (minimal interest in other people)
- Did not initiate or rarely initiated social interaction
- Poor eye contact
- Delayed or absent response to his/her own name (appeared not to hear)
- Delayed or abnormal babbling or speaking
- Repetitive behaviors (such as hand flapping or rocking)
- Self-injurious behaviors (head-banging)
- Unusually intense interests in certain topics, toys, or activities (such as lining up objects)
- Unusual responses to touch, taste, smell, or sounds
- Did not point, gesture or imitate others
- Started losing skills
- Did not need as much sleep as other children of the same age
- Abnormal motor development or muscle tone (unusually stiff or floppy)
- Other people told me something was wrong
- Other
Section 1, Question 15
Did [display_name] lose words, daily living skills, motor abilities, or social skills that he/she previously had?

Possible Responses
No
Yes

Section 1, Question 16
How significant was [display_name]'s loss of skills?

Possible Responses
Severe
Moderate
Mild

Section 1, Question 17
Which type of skill was affected the most?

Possible Responses
Speech and language
Motor abilities (like walking, jumping, and playing with small toys)
Social skills (like eye contact and playing with other children)
Section 1, Question 18, measurement unit in month(s)
What age was [display_name] when you FIRST noticed this loss of skills?

Please give the exact age in years and months as best as you can remember.

Coded Value | Response
--- | ---
Value | User Entered Coded Value

Section 1, Question 19
Did your child's development plateau or halt such that he/she stopped gaining new skills but retained previously acquired skills?

Possible Responses
No
Yes

Section 1, Question 20, measurement unit in month(s)
What age was your child when you FIRST noticed this plateau or halt in his/her development?

Please give the exact age in years and months as best as you can remember.
Section 1, Question 21
Has |display_name| ever been given an IQ test or intelligence test?

Possible Responses
No
Yes

Section 1, Question 22
What was |display_name|’s most recent IQ test score?

Possible Responses
40 or below
41 - 55
56 - 70
71 - 85
86 - 115
116 - 130
Above 130
Section 1, Question 23
Has |display_name| ever been given the ADOS (Autism Diagnostic Observation Schedule)?

This is a "test" commonly used to determine if a child has an autism spectrum disorder. An examiner observes the child's communication and social interaction looking for behaviors that are common in autism spectrum disorders. It usually takes 1-2 hours.

Possible Responses
No
Yes

Section 1, Question 24
Did the ADOS show that |display_name| had an autism spectrum disorder?

Possible Responses
No
Yes

Section 1, Question 25
Have you ever completed the ADI (Autism Diagnostic Interview) for |display_name|?

This "test" involves interviewing the parent(s) or other primary caregiver. The interviewer asks a lot of questions about the child's communication, social interactions and development. The child does not have to be in the room. The interview usually lasts 1-2 hours.

Possible Responses
No
Yes
Did the ADI (Autism Diagnostic Interview) show that |display_name| had an autism spectrum disorder?

Possible Responses
- Yes
- No
- Results were not given

Section 1, Question 27
Has |display_name| had an MRI (magnetic resonance imaging) of his/her brain?

An MRI looks at the structure of the brain. It requires the child to be very still and usually medicine is given to make the child sleepy. The test usually takes one HOUR and requires all metal objects to be removed.

Possible Responses
- No
- Yes

Section 1, Question 28
Were the results from the MRI (magnetic resonance imaging) normal for |display_name|?

Possible Responses
- Yes, results were normal
- No, results were not normal

Section 1, Question 29
Has |display_name| had a CT Scan of his/her brain?

A CT looks at the structure of the brain (but in less detail than the MRI). It also requires the child to be very still and sometimes medicine is given to make the child sleepy. This test only...
Section 1, Question 30
Were the results from the CT Scan normal?

Possible Responses
Yes, results were normal
No, results were not normal

Section 1, Question 31
Has [display_name] had an (EEG) electroencephalogram of his/her brain?

An EEG is a test to detect abnormalities in the electrical activity of the brain. Many small electrodes (metal discs) are placed on the scalp. The test is used to study seizure disorders and sleep disorders.

Possible Responses
No
Yes

Section 1, Question 32
Were the results of the (EEG) electroencephalogram normal for [display_name]?

Possible Responses
Yes, results were normal
Section 2: DEVELOPMENTAL HISTORY

The following questions are about your child’s developmental milestones.

You should not need any special materials or records to answer these questions.

Section 2, Question 1
How old was |display_name| when he/she first walked?

Possible Responses
Never or not yet
Less than 12 months
12 months to 17 months
18 months to 23 months
2 years
3 years
4 to 6 years
7 years or older

Section 2, Question 2, measurement unit in month(s)
If you remember, please give the exact age (in years and months) that |display_name| first walked.

Coded Value  Response
Value      User Entered Coded Value
Section 2, Question 3

How old was |display_name| when he/she said his/her first words?

Possible Responses

- Never or not yet
- Less than 12 months
- 12 months to 17 months
- 18 months to 23 months
- 2 years
- 3 years
- 4 years
- 5 years
- 6 years
- 7 years
- 8 years
- 9 years
- 10 years
- 11 years
- 12 years
- 13 years
- 14 years
- 15 years
- 16 years
- 17 years

Section 2, Question 4, measurement unit in month(s)

If you remember, please give the exact age (in years and months) that |display_name| said his/her first words.

Coded Value  |  Response
Value |  User Entered Coded Value
Section 2, Question 5
How old was |display_name| when he/she was able to use two to three words together for meaningful speech?

Possible Responses
Never or not yet
Less than 12 months
12 months to 17 months
18 months to 23 months
2 years
3 years
4 years
5 years
6 years
7 years
8 years
9 years
10 years
11 years
12 years
13 years
14 years
15 years
16 years
17 years

Section 2, Question 6
How old was |display_name| when he/she was toilet trained?

Toilet trained means urinating and moving bowels in toilet most of the time

Possible Responses
Never or not yet
Less than 12 months
12 months to 17 months
18 months to 23 months
2 years
Section 3: BIRTH HISTORY

The following questions are about your child’s birth. You may want to have on-hand birth records, including birth weight.

Section 3, Question 1
What was the length of the pregnancy with |display_name|?

Possible Responses
- Very premature or very early (fewer than 34 weeks)
- Premature or early (34 weeks through 36 weeks)
- On or near due date (37 weeks through 41 weeks)
- More than 2 weeks late (42 weeks or more)

Section 3, Question 2
Which one of these describes |display_name|’s birth?

Possible Responses
- Single birth
- Twins
- Triplets
- Quadruplets (4 babies at one time)
- Other (5 or more babies at one time)
Section 3, Question 3
What was [display_name]'s BIRTH ORDER?

Do not include miscarriages. Count twins as two births.

Possible Responses
1st
2nd
3rd
4th
5th
6th
7th
8th or higher

Section 3, Question 4, measurement unit in oz
How much did [display_name] weigh at birth?

Please provide in pounds and ounces.

Coded Value | Response
--- | ---
Value | User Entered Coded Value
Section 4: ADDITIONAL MEDICAL HISTORY

The following questions are about other medical conditions your child might have.

*Please report only conditions that have been diagnosed by a qualified health professional.*

**Section 4, Question 1**
Has |display_name| ever been diagnosed with **Fragile X**?

Possible Responses
No
Yes

**Section 4, Question 2**
Has |display_name| ever been diagnosed with **Tuberous Sclerosis**?

Possible Responses
No
Yes

**Section 4, Question 3**
Has |display_name| ever been diagnosed with a **Seizure Disorder** or **Epilepsy**?

*Febrile seizures during childhood are not considered a seizure disorder.*

Possible Responses
No
Yes
Section 4, Question 4
Has \{\text{display_name}\} ever been diagnosed with \textit{Mental Retardation}?  

Possible Responses

No
Yes

Section 4, Question 5
Has \{\text{display_name}\} ever been diagnosed with a \textit{Motor Delay}?  

Possible Responses

No
Yes

Section 4, Question 6
Has your child ever been diagnosed with \textit{Cerebral Palsy (CP)}?  

Possible Responses

No
Yes
Section 4, Question 7
Has |display_name| ever been diagnosed with or received treatment for Depression?

Possible Responses
No
Yes

Section 4, Question 8
Has |display_name| ever been diagnosed with or received treatment for Bipolar Disorder (Manic/Depressive Disorder)?

Possible Responses
No
Yes

Section 4, Question 9
Has |display_name| ever been diagnosed with or received treatment for Attention Deficit/Hyperactivity Disorder (AD/HD) or Attention Deficit Disorder (ADD)?

Possible Responses
No
Yes
Section 4, Question 10
Has [display_name] ever been diagnosed with or received treatment for an Anxiety Disorder?

Anxiety disorders include panic disorder/panic attacks, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), social anxiety disorder (social phobia), specific phobias, and generalized anxiety disorder (GAD).

Possible Responses
No
Yes

Section 4, Question 11
Has [display_name] ever been diagnosed with or received treatment for Schizophrenia?

Possible Responses
No
Yes

Section 5: EDUCATIONAL HISTORY

The following questions are about the type and extent of schooling your child is receiving.

You should not need any special materials or records to answer these questions.

Section 5, Question 1
What type of school (or preschool) does [display_name] attend?
Section 5, Question 2
What is [display_name]'s current grade or level of school?

If in between grades or levels of school, please select the higher grade. For example, if your child just completed 6th grade and will be going into 7th grade, then choose 7th grade.

Possible Responses
- No grade assigned
- Preschool
- Kindergarten
- Grade 1
- Grade 2
- Grade 3
- Grade 4
- Grade 5
- Grade 6
- Grade 7
- Grade 8
- Grade 9
- Grade 10
- Grade 11
- Grade 12
- College undergraduate (freshmen to senior)
Section 5, Question 4
What is [display_name]'s CURRENT special education code?

If your child is receiving special education services, he/she will have one of these special education codes. It may be different than what you consider to be your child's diagnosis.

Possible Responses
- Autism
- Speech or Language Impairment
- Other Health Impairment
- Specific Learning Disability
- Emotional Impairment
- Young Child with Developmental Delay
- Multiple Handicaps including Autism
- None
- Other

Section 5, Question 5
How would you best describe [display_name]'s classroom setting?

This question is about the classroom setting only and does not try to address opportunities for inclusion. Special education classrooms may include typically developing peers, which is also known as "reverse inclusion."

Possible Responses
- Regular education classroom for ALL of child's school day
- More time in REGULAR EDUCATION classroom than special education classroom
- Same amount of time in regular education and special education classrooms
- More time in SPECIAL EDUCATION classroom than regular education classroom
- Special education classroom for ALL of child's school day
Section 5, Question 6
Does [display_name] have a personal aide or one-on-one assistant in the classroom?

Possible Responses
Yes, my child has a FULL-TIME aide or assistant
Yes, my child has a PART-TIME aide or assistant
No

Section 5, Question 7
Does your child have classroom opportunities for inclusion with typically developing peers?

Possible Responses
No
Yes

Section 6: FAMILY HISTORY

The following questions are about your child’s extended family.
You should not need any special materials or records to answer these questions. Please include family members who are no longer living.

Section 6, Question 1
Does [display_name] have any second-degree relatives (that is aunts and uncles by blood, and grandparents) who have been diagnosed with the following?
Section 6, Question 2
Does [display_name] have any first cousins who have been diagnosed with the following?

Possible Responses
- Autism Spectrum Disorder (ASD)
- Fragile X
- Seizure Disorder or Epilepsy
- Mental Retardation
- Schizophrenia
- Attention Deficit/Hyperactivity Disorder (AD/HD) or Attention Deficit Disorder (ADD)
- Language delays or speech problems

Section 7: PRIOR PARTICIPATION IN AUTISM RESEARCH

The following questions are about your child's prior participation in any ASD-related research studies.

You should not need any special materials or records to answer these questions.

Section 7, Question 1
Has [display_name] ever been in a RESEARCH STUDY about autism spectrum disorders (prior to this one)?

Possible Responses
- No
- Yes
Section 7, Question 2
Has |display_name| ever been in a RESEARCH STUDY about the **GENETICS** of autism spectrum disorders?

*Genetics studies will often take a blood test to look at a child's genes or ask questions about the health history of the parents.*

**Possible Responses**
- No
- Yes

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Section 7, Question 3
Has |display_name| ever been in a RESEARCH STUDY about **DRUGS/MEDICATIONS** for treating autism spectrum disorder?

**Possible Responses**
- No
- Yes

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Section 8: Summary

Section 8, Question 1
What do you think about the length of this form?

**Possible Responses**
- It was too short and did not ask all of the questions I would have expected.
- It was too long.
- It was just right.
Child with ASD Questionnaire, Section B, Question 1.
Based on data from Jun-10-2014 (total responses = 9930)
What do you think about the length of this form?
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- 1,226 It was too short and did not ask all of the questions I would have expected.
- 767 It was too long.
- 7,937 It was just right.