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Adult with ASD Questionnaire (Self-report)

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Adult with ASD Questionnaire (Self-report) - 2.0.1 (exported at 1/28/2013 6:55:37 AM)

This is the first of a series of online surveys for adults with Autism Spectrum Disorders (ASD). This survey has five sections:

1. In the first section, we will ask questions about your autism spectrum diagnosis (autism, Asperger's syndrome, etc.).
2. In the second section, we will ask about your strengths, abilities, and special interests.
3. In the third section, we will ask some basic questions about your life.
4. In the fourth section, we will ask you what our next survey for adults with ASD should be about. Which topics are the most important? Our plan is to design future surveys based on your answers.
5. In the fifth section, we will ask you a few question about your participation in research.

Thank you for participating and helping people to learn about the needs and opinions of adults with ASD.

Questionnaire Completion History

Section 1: Autism Spectrum Diagnosis

In this section, we will ask about your autism spectrum diagnosis.

Section 1, Question 1
What was the FIRST autism spectrum disorder (ASD) diagnosis you ever received from a professional? (If it has not changed, this is the ASD diagnosis you have now.)

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)
I never have been diagnosed with an autism spectrum disorder by a professional.

Section 1, Question 2
Approximately how old (in years) were you when you received this **FIRST ASD diagnosis**?

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<thead>
<tr>
<th>Coded Value</th>
<th>Response Value</th>
<th>User Entered Coded Value</th>
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Section 1, Question 3
Please provide the date when you received 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 for day and month.

If you don't know the date at all, click on "I can't answer because..."

Data Type: date has no graph display

Section 1, Question 4
Who gave you this **FIRST 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 5
Is your **CURRENT ASD diagnosis** different than your first?

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

Section 1, Question 6
What is your **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)
- I no longer have an ASD diagnosis (according to a professional).

Section 1, Question 7
Approximately how old *(in years)* were you when you received this **CURRENT ASD diagnosis**?
Section 1, Question 8
Please provide the date when you received 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 for day and month.

If you don’t know the date at all, click on “I can’t answer because...”

Section 1, Question 9
Who gave you 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 2: Strengths, Abilities, and Special Interests

In this section, we will ask about your strengths, abilities, and special interests.

Section 2, Question 1
What particular abilities or strengths do you have because you are a person on the autism spectrum? Check all that apply or “none of the above” if none apply.

Possible Responses
- An ability to think in unusual, creative ways
- An ability to focus intensely on certain topics
- Honesty
Section 2, Question 2
Do you have a special interest or topic?
(Often individuals with an ASD have an unusually intense area of interest or focus. This is what we mean by "special topic.")

Possible Responses
No
Yes

Section 2, Question 3
What type of special interest or topic do you have?
Check all that apply if you have more than one.

Please click on "Explain my answer..." if you would like to tell us more about your special topic.

Possible Responses
Modes of transportation (such as trains, automobiles, aircraft)
History
Science (such as astronomy, geology)
Section 2, Question 4
How does your special topic affect your life? Check all that apply or “none of the above” if none apply.

Possible Responses
My job or career involves my special topic.
My studies in school or college are (or were) related to my special topic.
I have relationships based on my special topic. I make friends or join groups focused on the same interest.
I enjoy activities and hobbies relating to my special topic.
My special topic sometimes gets in the way of success at work, school, or in relationships.
The special topic has gotten me in trouble. (For example, it may have led to addictive behavior or breaking the law.)
Other
None of the above
Section 3: Basic Questions About Education, Work, Living Situation, Financial Support, etc.

In this section, we will ask basic questions about your life.

Section 3, Question 1
What is the **highest** level of education you have completed?

**Possible Responses**
- Less than high school
- High school certificate of completion (special education alternative to diploma)
- High school graduate or equivalent (GED)
- Trade or vocational school (certificate or license but no degree)
- Some college but no degree
- Associate's degree in **vocational or technical** program
- Associate's degree in **academic** program
- Bachelor's degree
- Master's degree
- Ph.D. or Professional degree
- Other

Section 3, Question 2
Are you currently attending school, such as high school, vocational or trade school, or college?

**Possible Responses**
- No
- Yes
Section 3, Question 3
In what type of housing do you currently live?

Possible Responses
- An apartment
- A townhouse, condo, or duplex
- A single family home (a house not attached to other houses)
- A college or other school dormitory
- An intermediate care facility, nursing home, or other institutional setting
- Other

Section 3, Question 4
Do you live with any other people?

Possible Responses
- No
- Yes

Section 3, Question 5
With whom do you live? Check all that apply.

Possible Responses
- With a spouse or other life partner
- With my children
- With housemates or friends that I got to choose
- With housemates I didn't get to choose
- With my parents
Section 3, Question 6
Do you currently have paid employment?

Possible Responses
No
Yes

Section 3, Question 7
On average, how many hours per week do you work?

Possible Responses
1 - 9 hours
10 - 19 hours
20 - 29 hours
30 - 39 hours
40 or more hours
Section 3, Question 8
Would you like to work more hours than you currently are able to get?

Possible Responses
No
Yes

Section 3, Question 9
What is your current work situation? Check yes or no for each response.

Possible Responses
Regular employment (with no help or support)
Supported employment (you may have a job coach or other special help at work)
Sheltered workshop
Enclave employment (you may work in a business with a group of other people with special needs, all under supervision of an agency serving people with disabilities)
Day program that includes work or vocational activities
Internship or work study program
Other

Section 3, Question 10
You have told us you are not working. Please help us understand your situation. Check yes or no for each response.

Possible Responses
Unemployed - want to work but can't find work
Have tried to work but faced discrimination or other difficulties with employers because of ASD
Do not wish to work at present (maybe in school, a stay-at-home parent, etc.)
Not able to work because it would interfere with federal or state benefits (such as disability payments)
Not able to work because the workplace would be too challenging (because of ASD or other health or mental health issues)
Other
Section 3, Question 11
How much, if any, do you rely on your extended family (such as parents and siblings) for financial support?

Possible Responses
- My family does not provide any financial support for me at all.
- My family provides less than half of my financial support. They help me financially sometimes.
- My family provides about half of my financial support.
- My family provides more than half (but not all) of my financial support.
- My family provides all of my financial support.

Section 3, Question 12
Do you currently receive any federal or state benefits, such as Social Security Disability Insurance (SSDI) or Medicaid?

Possible Responses
- Yes
- No
- Not sure

Section 3, Question 13
What federal or state benefits do you currently receive? Check all that apply or "none" if none apply.

Possible Responses
- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- State disability programs that use only state and/or local funds
- Medicaid (for health insurance)
- Medicare
Section 3, Question 14
Do you suffer from any of the following? Check yes or no for each response.

Possible Responses
- Gastrointestinal issues (such as chronic diarrhea, constipation, nausea, vomiting, acid reflux, etc.)
- Allergies
- Sleep issues (such as problems going to sleep or staying asleep)
- Skin conditions (such as psoriasis or eczema)

Section 3, Question 15
Have you been diagnosed with any of the following conditions by a professional? Check yes or no for each response.

Possible Responses
- A seizure disorder or epilepsy
- Asthma
- Diabetes
- Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)
- Oppositional Defiant Disorder (ODD)
- Obsessive Compulsive Disorder (OCD)
- Anxiety (such as social phobia, generalized anxiety disorder, panic disorder, or some other kind of anxiety)
- Depression (such as major depressive disorder, seasonal affective disorder, postpartum depression, or some other kind of depression)
- Bipolar Disorder
- Schizophrenia
- Other
What treatments or interventions are you currently using to help with ASD or other conditions you might have, such as attention deficit hyperactivity disorder (ADHD) or anxiety? Check all that apply or "none" if none apply.

Possible Responses
- Medication
- Alternative Medicine (herbs, homeopathic remedies, acupuncture, vitamins, etc.)
- Individual Therapy or Counseling (for example, talk therapy or cognitive behavioral therapy)
- Group Therapy
- Marital or Family Therapy
- Support Group, in person
- Support Group, online
- Spiritual practice (such as prayer or meditation)
- Speaking with a pastor, rabbi, etc.
- Self-help books
- Applied Behavior Analysis (ABA)
- Physical Therapy
- Occupational Therapy
- Speech and Language Therapy
- Social Skills Training or a Social Skills Group
- Life-Skills or Self-Care Training
- Other
- None
Section 4: What Do We Need to Learn About Adults with ASD?

We are developing a series of surveys for adults with ASD so that people will better understand the challenges faced by adults on the autism spectrum. To help us decide which topics to study first, we are asking you to rate the importance of 15 general topics that are common to daily life.

Section 4, Question 1
Understanding and Accepting Adults with ASD
How important is this kind of research?

(This research will answer questions about how to teach other people, like educators and employers, how adults with ASD experience the world, how they feel, why they behave the way they do, and what they need.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

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Section 4, Question 2
Employment and Adults with ASD
How important is this kind of research?

(This research will answer questions about whether adults with ASD are succeeding in the workplace, what kind of help they need at work, and whether they have faced discrimination at work.)

Possible Responses
Extremely high priority
High priority
Medium priority
Low priority
Not a priority

Section 4, Question 3
Education and Adults with ASD
How important is this kind of research?

(This research will answer questions about whether adults with ASD are succeeding at college or in other educational programs, what kind of help they need, and whether or not they are getting the help they need.)

Possible Responses
Extremely high priority
High priority
Medium priority
Low priority
Not a priority

Section 4, Question 4
Federal and State Assistance for Adults with ASD
How important is this kind of research?

(This research will answer questions about whether adults with ASD need and are receiving things government help such as supplemental security income (SSI), social security disability insurance (SSDI), or Medicaid.)

Possible Responses
Extremely high priority
High priority
Medium priority
Low priority
Not a priority
Section 4, Question 5
Financial Issues and Adults with ASD
How important is this kind of research?

(This research will answer questions about how adults with ASD pay for food, housing, and health care, and if they can afford what they need.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

Section 4, Question 6
Living Situation and Adults with ASD
How important is this kind of research?

(This research will answer questions about where adults with ASD are living, who they are living with, and if they are happy with their living situation.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority
Section 4, Question 7
Transportation and Adults with ASD
How important is this kind of research?

(This research will answer questions about whether adults with ASD have a way to travel to school, work, or other activities, and if problems with transportation are preventing them from living the life they want.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

Section 4, Question 8
Health Conditions and Adults with ASD
How important is this kind of research?

(This research will answer questions about how many adults with ASD are coping with medical conditions or mental health issues.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority
Section 4, Question 9
Health Care Access and Adults with ASD
How important is this kind of research?

(This research will answer questions about how many adults with ASD have health insurance and can get the medical care, dental care, or mental health care they need.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

Section 4, Question 10
Current Treatments and Adults with ASD
How important is this kind of research?

(This research will answer questions about what treatments adults with ASD are using to help them with any medical or mental health issues, and what treatments are the most helpful.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

Section 4, Question 11
Daily Life and Adults with ASD
How important is this kind of research?

(This research will answer questions about how adults with ASD spend their time, and whether they are satisfied with their lives.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority
Section 4, Question 12
Friendship and Adults with ASD
How important is this kind of research?
(This research will answer questions about adults with ASD and their social relationships, including whether they are satisfied with their ability to make friends and with the friendships they have.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

Section 4, Question 13
Romantic Relationships and Adults with ASD
How important is this kind of research?
(This research will answer questions about adults with ASD and their romantic relationships, including whether they are satisfied with their ability to find a romantic partner, and with the romantic relationships they have.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority
Section 4, Question 14
Sexuality and Sexual Health and Adults with ASD
How important is this kind of research?

(This research will answer questions about adults with ASDs, their knowledge about sex, their sexual experiences, and their sexual health and safety.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

Section 4, Question 15
The Criminal Justice System and Adults with ASD
How important is this kind of research?

(This research will answer questions about what happens when adults with ASD become involved with the criminal justice system whether they have been the victims of a crime or accused of committing a crime.)

Possible Responses
- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority
Section 5: Participation in ASD Research

The following few questions are about your prior participation in ASD Research.

Section 5, Question 1
Have you ever participated in a RESEARCH STUDY about autism spectrum disorders (prior to this one)?

Possible Responses
No
Yes

Section 5, Question 2
Have you participated in a RESEARCH STUDY about autism spectrum disorders after you became an adult (18 years of age and older) prior to this one?

Possible Responses
No
Yes

Section 5, Question 3
Have you ever participated in a RESEARCH STUDY about the GENETICS of autism spectrum disorders?

Possible Responses
No
Yes
Section 5, Question 4
Have you ever participated in a RESEARCH STUDY about DRUGS/MEDICATIONS for treating autism spectrum disorders?

Possible Responses
- No
- Yes

Section 5, Question 5
What did you think about the length of this questionnaire?

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.

Section 5, Question 6
In what ways did you hear about IAN prior to deciding to join? Check all that apply.

Possible Responses
- Invited by family member already in IAN
- Received a "mass" e-mail
- Television
- Radio
- Print media (including newspapers, magazines, etc.)
- Internet search
- IAN Community website
- Website/online (not IAN Community)
IAN Research ad or link from other website (not IAN Community)
Autism fundraising event, such as walk or bike ride
Conference
Health care provider
School
"Word of mouth" from friend or family
Participated in IAN as a child, but now adult.
Other

![Bar chart showing various ways participants heard about IAN](chart.png)

Adult with ASD Questionnaire (Scif-report), Section 5. Question 6
In what ways did you hear about IAN prior to deciding to join? Check all that apply.
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