Did you know that

90,779 people with autism are participating in SPARK?

Welcome to the SPARK Snapshot — a window into the autism journey of SPARK participants. We’ve compiled these interesting findings from information that families have provided.
Many more children with autism have enrolled in SPARK than adults with autism. We need more adults to participate to better understand autism throughout the lifespan.

Number of Children with Autism
77,017

Number of Adults with Autism
13,762

Ratio of Males to Females in Adults Over 18
2 to 1

Ratio of Males to Females in Children Under 18
4 to 1

The proportion of adult women with autism in SPARK is a little higher than expected, but it is lower than what’s reported in other studies of autism in adults.

Boys with autism outnumber girls 4 to 1 in SPARK — a ratio similar to the one usually reported in other autism studies. This is one clue that SPARK is a good representation of families with autism in the U.S.
Who Is Participating in SPARK?

Age of Participants with Autism Enrolled in SPARK

SPARK represents the whole lifespan, from toddlers who received their diagnosis before 2 to some of the first diagnosed cases, now in their 80s. We also have babies with autism enrolled whom we can watch as they grow and change over time.

Number of participants with autism <18 by age group

<table>
<thead>
<tr>
<th>AGE</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4</td>
<td>38,629</td>
</tr>
<tr>
<td>5-11</td>
<td>19,729</td>
</tr>
<tr>
<td>12-17</td>
<td>18,659</td>
</tr>
</tbody>
</table>

Number of participants with autism >18 by age group

<table>
<thead>
<tr>
<th>AGE</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>7,337</td>
</tr>
<tr>
<td>25-34</td>
<td>3,730</td>
</tr>
<tr>
<td>35-44</td>
<td>1,569</td>
</tr>
<tr>
<td>45-54</td>
<td>719</td>
</tr>
<tr>
<td>over 55</td>
<td>365</td>
</tr>
</tbody>
</table>

There are 22 participants who had missing or unknown ages. They are not included in this chart.
Diagnosis

Children Under 18

Boys and girls were diagnosed on average between ages 4 and 4.5.

<table>
<thead>
<tr>
<th>Average Age When Boys Were Diagnosed</th>
<th>Average Age When Girls Were Diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4.2</strong></td>
<td><strong>4.5</strong></td>
</tr>
</tbody>
</table>

Independent adults with autism were diagnosed later than dependent adults with autism. Some adults were not diagnosed until their 60s or 70s, likely reflecting increased recognition of autism in recent years.

Adults Over 18

<table>
<thead>
<tr>
<th>Average age that DEPENDENT adult males were diagnosed</th>
<th>Average age that DEPENDENT adult females were diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>22</strong></td>
<td>6</td>
</tr>
<tr>
<td>Average age that INDEPENDENT adult males were diagnosed</td>
<td><strong>19</strong></td>
</tr>
<tr>
<td>Average age that INDEPENDENT adult females were diagnosed</td>
<td>7</td>
</tr>
</tbody>
</table>

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Professionals Who Made the Diagnosis

Families are receiving diagnostic evaluations from multiple care providers, most commonly clinical psychologists, medical specialists and entire teams of experts. The school also plays this role for many families.

Language

Most children and dependent adults enrolled in SPARK are able to use full sentences to communicate.

Do not speak

- Children: 14%
- Adults: 10%

Are able to use single words to communicate

- Children: 17%
- Adults: 14%

Use phrases

- Children: 15%
- Adults: 8%

Use longer complex sentences

- Children: 54%
- Adults: 68%
Adults with autism also struggle with depression and anxiety. Independent adults with autism report depression and anxiety at over three times the rate of the general population.

Associated conditions reported by Dependent Adults with ASD
- 21% have a diagnosis of depression
- 34% anxiety disorder
- 40% ADHD

Associated conditions reported by Independent Adults with ASD
- 51% have a diagnosis of depression
- 52% anxiety disorder
- 43% ADHD

Pregnancy, Birth History and Associated Conditions

Percent with Birth Complications
- 8%

Percent Born Prematurely
- 12%

SPARK families reported many concerns about pregnancy and birth for their children, but serious complications causing brain injury are no more likely than they are in the general population.

Premature birth occurs slightly more often in babies who are later found to have autism than it does in other babies. Birth complications such as prematurity are known to increase the risk for developmental disability, and some research says it increases the risk for autism.
Associated Conditions in Children with Autism

- 7% have a diagnosis of depression
- 18% have anxiety
- 39% have sleep problems
- 41% have eating problems
- 36% have ADHD
- 16% have cognitive impairment

The rate of attention deficit (ADHD) in SPARK is over 3 times higher than it is in the general population. Diagnoses of conditions like ADHD and anxiety may rise now that the new diagnostic system used by doctors encourages all other conditions to be documented.

Seizures

The rate of seizure disorders in SPARK is higher than it is in the general population. But SPARK’s reported rate is much lower than the rates reported by other autism studies. We need everyone in SPARK to finish their basic medical screening survey to give us a complete picture.
Past Genetic Testing for Autism

People Who Have Had Genetic Testing Related to Autism in the Past

Even though it is known that autism is strongly influenced by genetics, most families have not received genetic testing before.

Most Common Genetic Findings Reported by Families in SPARK

A small number of families report they received a genetic diagnosis in the past that could explain their autism. The most common known genetic cause of autism, and the most common reported in SPARK, is Fragile X syndrome.

We still have much to learn about genetic causes, and SPARK offers the chance to increase our understanding.

<table>
<thead>
<tr>
<th>Number of People</th>
<th>Genetic Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>344</td>
<td>Fragile X</td>
</tr>
<tr>
<td>123</td>
<td>15q duplication</td>
</tr>
<tr>
<td>88</td>
<td>PTEN</td>
</tr>
<tr>
<td>66</td>
<td>22q11 deletion</td>
</tr>
<tr>
<td>65</td>
<td>7q11.23 deletion</td>
</tr>
<tr>
<td>62</td>
<td>22q13 deletion</td>
</tr>
<tr>
<td>57</td>
<td>Rett syndrome (MECP2)</td>
</tr>
<tr>
<td>44</td>
<td>NF1</td>
</tr>
<tr>
<td>41</td>
<td>Angelman syndrome</td>
</tr>
<tr>
<td>39</td>
<td>15q deletion</td>
</tr>
<tr>
<td>26</td>
<td>Noonan syndrome</td>
</tr>
<tr>
<td>24</td>
<td>16p11.2 deletion</td>
</tr>
<tr>
<td>20</td>
<td>ADNP</td>
</tr>
<tr>
<td>20</td>
<td>16p11.2 duplication</td>
</tr>
<tr>
<td>17</td>
<td>1q21.1 duplication</td>
</tr>
<tr>
<td>14</td>
<td>2p16.3 deletion</td>
</tr>
<tr>
<td>13</td>
<td>22q11 duplication</td>
</tr>
<tr>
<td>12</td>
<td>SCN2A</td>
</tr>
</tbody>
</table>
Development
Milestones

Average age of first words
Children 1.7 years
Dependent Adults 4.3 years

Average age of first steps
Children 1.2 years
Dependent Adults 1.4 years

Average age of the child when parents had their first concern
Children 1.8 years
Dependent Adults 2.1 years

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Development

First thing that caused parents concern about their child’s development

- Late speech
  - Children: 28%
  - Dependent Adults: 22%

- Interaction with others (such as poor eye contact, no response, or not joining in)
  - Children: 19%
  - Dependent Adults: 22%

- Something else
  - Children: 12%
  - Dependent Adults: 14%

- Late walking or other motor milestones
  - Children: 11%
  - Dependent Adults: 12%

- Mood or temperament
  - Children: 9%
  - Dependent Adults: 8%

- A change or loss in abilities
  - Children: 9%
  - Dependent Adults: 11%

- Unusual habits (such as getting stuck on doing things over and over)
  - Children: 9%
  - Dependent Adults: 8%

- Unusual speech (such as saying things over and over)
  - Children: 3%
  - Dependent Adults: 3%
Development

Regression

- Dependent Adults

Percent who experienced a regression in language abilities 30%

Percent of those whose language returned after the regression 62%

Average age of language regression 2.3 years

Other types of regression

- Dependent Adults

Social skills 20%

Play 12%

Development 16%

Average age of non-language regression 3.6 years

Skills returned 32%

The percentages shown are from the caregivers who responded to SPARK’s Background History Survey. Of the dependent adults, 20% experienced a regression in their social skills. On average, some types of changes that cause parents concern, such as potty training, might happen later than regression in language. Of those who experienced a regression in language, 62% regained their skills, whereas only 32% of those experiencing another type of regression regained their lost skills. This is likely because decreased social engagement is a common feature of autism throughout the lifespan.
Development

Regression

- Children

Percent who experienced a regression in language abilities **32%**

Percent of those whose language returned after the regression **65%**

Average age of language regression **1.9 years**

Other types of regression

- Children

  - Social skills **17%**
  - Play **11%**
  - Development **15%**

- Average age of non-language regression **2.9 years**
- Skills returned **34%**

The percentages shown are from the caregivers who responded to SPARK’s Background History Survey. Of the children, 17% experienced a regression in their social skills. On average, some types of changes that cause parents concern, such as potty training, might happen later than regression in language. Of those who experienced a regression in language, 65% regained their skills, whereas only 34% of those experiencing another type of regression regained their lost skills. This is likely because decreased social engagement is a common feature of autism throughout the lifespan.
Development

Support Required for Dependent Adults

Minimal to no support  9%
Some support  32%
Substantial support  34%
Very substantial support  25%
Thank you to all of the participating families!

Together, we can learn so much more.