Did you know that

106,582 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 autistic adults. We need more adults to participate to better understand autism throughout the lifespan.

*About 50% of the adults in the study are dependent adults

**Ratio of Males to Females in Adults Over 18**

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

**Ratio of Males to Females in Children Under 18**

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 under 18 by age group

<table>
<thead>
<tr>
<th>AGE</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4</td>
<td>24,081</td>
</tr>
<tr>
<td>5-11</td>
<td>44,317</td>
</tr>
<tr>
<td>12-17</td>
<td>21,548</td>
</tr>
</tbody>
</table>

### Number of participants with autism over 18 by age group

<table>
<thead>
<tr>
<th>AGE</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>8,471</td>
</tr>
<tr>
<td>25-34</td>
<td>4,626</td>
</tr>
<tr>
<td>35-44</td>
<td>2,090</td>
</tr>
<tr>
<td>45-54</td>
<td>915</td>
</tr>
<tr>
<td>over 55</td>
<td>534</td>
</tr>
</tbody>
</table>
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>4.3</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Adults Over 18

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

<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>22.5</td>
<td>6</td>
</tr>
<tr>
<td>20.3</td>
<td>7.4</td>
</tr>
</tbody>
</table>

Average age that INDEPENDENT adult males were diagnosed

Average age that INDEPENDENT adult females were diagnosed
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.

Diagnosis

Do not speak

Are able to use single words to communicate

Use phrases

Use longer complex sentences
Autistic adults also struggle with depression and anxiety. Independent adults with autism report depression and anxiety at over three times the rate of the general population.

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 reported by Dependent Autistic Adults
21% have a diagnosis of depression
35% have anxiety disorder
40% have ADHD

Associated conditions reported by Independent Autistic Adults
53% have a diagnosis of depression
55% have anxiety disorder
45% have ADHD
### Associated Conditions in Children with Autism

- **7%** have a diagnosis of depression
- **19%** 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.

- **6%** of all SPARK participants with a seizure disorder
Multiplex Families Enrolled in SPARK

When we say *multiplex*, we mean families with more than one member who has a professional diagnosis of ASD.

16% of SPARK families have more than 1 autistic family member enrolled in the study.

12% of families have *more than 1 child* with ASD enrolled in SPARK.

1% of families have *more than 1 child and at least 1 parent* with ASD enrolled in SPARK.

3% of families have *at least 1 parent and only 1 child* - with ASD enrolled in SPARK.
Development
Milestones

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

Average age of first steps
Children 1.2 years
Dependent Adults 1.3 years

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

- **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%

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

- **Something else**
  - Children: 12%
  - Dependent Adults: 14%
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, 63% regained their skills, whereas only 33% 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.
The percentages shown are from the caregivers who responded to SPARK’s Background History Survey. Of the children, 16% 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  35%
Very substantial support  24%
Thank you
to all of the participating families!

Together, we can learn so much more.