Welcome to the second SPARK Snapshot
—a window into the autism journey of SPARK participants

The findings in this report were gathered from information provided by independent adults with autism participating in SPARK. This information is self-reported.

In this report, an “independent adult with autism” is defined as an individual with autism who is at least 18 years old and who does not have a legal guardian. The data in this report are preliminary.

SPARK uses person-first language. This means that we use the phrase “person with autism”, however, we ask individuals with autism how they prefer to be identified if they are being featured in any of our content. We believe that this celebrates and champions the distinct individual in all of us. We feel that this phrase is inclusive of all members of our community—families, children, and adults. We also appreciate that there are different perspectives on this topic and respect that each individual has the right to refer to themselves as they choose.
Number of independent adults with autism

The number of independent adults with autism participating in SPARK is larger than most other autism research studies in the United States.

Age of independent adults

The majority of independent adults with autism enrolled in SPARK are between the ages of 18 and 34. This is similar to the composition of other large studies of independent adults with autism.
Race and ethnicity

- 80% White
- 4% African-American
- 2% Asian
- 11% Hispanic
- 1% Native American

Nine percent of independent adults with autism enrolled in SPARK reported more than one race.

Sex (at birth)

The male to female ratio of independent adults with autism enrolled in SPARK is about one to one.

- 1,030 (53%) Female
- 911 (47%) Male
**Age at diagnosis**

Of the independent adults with autism enrolled in SPARK, 61% of males were diagnosed as children, as were 46% of females. The median age at diagnosis was 16.5 years — that is, half the people enrolled were diagnosed prior to 16.5 years, and half were diagnosed after 16.5 years.

<table>
<thead>
<tr>
<th>Age at diagnosis in years</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>18+</td>
<td>54% (560)</td>
<td></td>
</tr>
<tr>
<td>6 - 17</td>
<td>39% (359)</td>
<td></td>
</tr>
<tr>
<td>0 - 5</td>
<td>25% (254)</td>
<td>33% (298)</td>
</tr>
</tbody>
</table>

**Who made the diagnosis?**

- 55% Clinical psychologist
- 28% Medical specialist
- 14% Pediatrician
- 16% School team
- 11% Others
- 33% Health care team

These percentages do not add up to 100 because participants were able to select more than one.

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**Relatives with autism**

Over half the independent adults with autism enrolled in SPARK reported that they have one or more relatives who also have a diagnosis of autism.
Anxiety and depression were the most common concerns reported by independent adults with autism enrolled in SPARK. Other studies also report high levels of anxiety and depression in adults with autism.

**Age 18 - 24 (n=331)**
- ADHD: 43% (142)
- Anxiety: 41% (135)
- Bipolar disorder: 40% (131)
- Depression: 21% (68)
- OCD: 11% (36)

**Age 25 - 34 (n=505)**
- ADHD: 50% (251)
- Anxiety: 49% (249)
- Bipolar disorder: 41% (209)
- Depression: 23% (116)
- OCD: 16% (79)

**Age 35 - 54 (n=465)**
- ADHD: 49% (227)
- Anxiety: 45% (207)
- Bipolar disorder: 33% (153)
- Depression: 21% (98)
- OCD: 12% (56)

**Age 55+ (n=114)**
- ADHD: 54% (61)
- Anxiety: 36% (41)
- Bipolar disorder: 30% (34)
- Depression: 17% (19)
- OCD: 12% (14)

These percentages do not add up to 100 because participants were able to select more than one of these conditions.
**Lifestyle**

### Household income

Employment income (e.g., salaries, wages, etc.) reported by independent adults with autism enrolled in SPARK is lower than the national average for employed people. Other autism studies have found this as well.

- **13%** Over $101,000
- **20%** $51,000–$100,999
- **11%** $36,000–$50,999
- **17%** $21,000–$35,999
- **39%** Under $20,999

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### Education

More than three-quarters of independent adults with autism enrolled in SPARK have a degree or training beyond high school, including the 10% of participants who are currently enrolled in college.

- **<1%** Did not attend high school
- **4%** High school diploma or GED
- **17%** Associate’s degree
- **9%** Trade school
- **10%** Some college
- **16%** Current college student
- **23%** Bachelor’s degree
- **15%** Graduate or professional degree
Employment

Nearly half of the independent adults with autism enrolled in SPARK are employed either full time or part time. The unemployment rate among independent adults with autism enrolled in SPARK — that is, the proportion who are seeking but have not found paid work — is 22%. More female than male participants report being full-time caretakers.

Marital status

Just over half the independent adults with autism enrolled in SPARK are single. Many are married or in a relationship. Only 6% are divorced.
Gender & sexuality

**Gender identity**

When asked about gender, 3% of independent adults with autism enrolled in SPARK reported a gender other than male or female, and 1% reported being transgender. Other studies have indicated that gender dysphoria — defined as a conflict between the physical or assigned gender and the gender with which the person identifies — is higher among individuals with autism than it is in the population at large.

**Sexual orientation**

Many independent adults with autism enrolled in SPARK do not identify as heterosexual. Other research among adults with autism has reported this as well. “Pansexual” is defined as attraction to individuals of any sex or gender.
Most independent adults with autism enrolled in SPARK live with a partner or spouse or a family member. A smaller number live alone, with roommates or in a group home.
Did you know that as of April 2018, 34,214 people with autism have participated in SPARK?

- 2,997 dependent adults with autism
- 1,941 independent adults with autism
- 29,276 children with autism
Thank you to all participating individuals and families!
Special thanks to the adults with autism on our Community Advisory Council who helped to determine what kind of data to show in this report.

Together we will learn so much more.

SPARKforAutism.org/UNC
Join UNC SPARK today
www.SPARKforAutism.org/UNC

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