At SPARK, we believe diversity drives new perspectives and inspires future generations.

SPARK recognizes that we cannot successfully advance discovery and the understanding of autism if we do not include all families. Therefore, we launched a diversity, equity, and inclusion initiative that span all areas of the SPARK study.

We established a DEI Advisory Board in 2021 to engage in important conversations and develop meaningful relationships with subject matter experts, stakeholders, and organizations that serve the African American and Black communities. We are prioritizing this effort and our activities to ensure we remain culturally and ethnically relevant within the African American and Black communities. SPARK is advancing research, the understanding of autism, and the diversity of experiences and genomic data amongst autistic individuals and their families.

We have identified three areas in which we can empower diverse communities, their experiences, perspectives, and cultures. We are committed to acting with purpose and intention to allow all individuals to be represented in our study and meaningfully contribute to our understanding of autism.

- Support the work of diverse researchers. Encourage and create opportunities for SPARK clinical site staff to reflect the community and develop culturally and ethnically relevant engagement.
- Create a transparent and trusted research environment and experience for autistic individuals and their families.
- Amplify the stories of diverse individuals on the spectrum and their families.

The more inclusive we are as a study, the better understanding we will gain, which will accelerate our understanding of autism.
Did you know there are

15,429

African American
and Black autistic
individuals &
their families
participating in SPARK?

Welcome to the SPARK Snapshot
— a window into the autism journey of African American and Black SPARK participants. We’ve compiled these interesting findings from the information that families have provided.
Who Is Participating in SPARK?
A look at African American and Black children and dependent adults within SPARK

Children
Number of African American and Black Autistic Children
7,838

Dependent Adults
Number of African American and Black Autistic Dependent Adults
464

Ratio of female to male children
1 to 4
Among African American and Black children with autism, boys outnumber girls 4 to 1. This is similar to other autism studies and one clue that SPARK is a good representation of families with autism in the U.S.

Ratio of female to male dependent adults
1 to 1.2
The proportion of African American and Black adult women with autism in SPARK is a little higher than expected.
How Old Are SPARK’s African American and Black Participants?

**Age** of African American and Black autistic participants enrolled in SPARK

SPARK represents the whole lifespan, from toddlers who receive their diagnosis before 2 years to people 45 years and older. We can learn more about autism as our participants grow older.

<table>
<thead>
<tr>
<th>Age</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 1-4</td>
<td>2,521</td>
</tr>
<tr>
<td>Age 5-11</td>
<td>3,835</td>
</tr>
<tr>
<td>Age 12-17</td>
<td>1,482</td>
</tr>
<tr>
<td>Age 18-24</td>
<td>490</td>
</tr>
<tr>
<td>Age 25-34</td>
<td>235</td>
</tr>
<tr>
<td>Age 35-44</td>
<td>84</td>
</tr>
<tr>
<td>Age 45 and older</td>
<td>41</td>
</tr>
</tbody>
</table>
Age of Diagnosis

Children Under 18

Average age when boys were diagnosed: 4

Average age when girls were diagnosed: 4

Dependent Adults 18 and Over

Some adults were not diagnosed until later in life. This is likely due to increased recognition of autism in recent years. Also, African American and Black individuals on the spectrum are more likely to receive a misdiagnosis before reaching an autism diagnosis.

Average age of diagnosis for African American and Black dependent adult males: 6

Average age of diagnosis for African American and Black dependent adult females: 8
Who Made the Professional Diagnosis?

African American and Black families in SPARK are receiving diagnostic evaluations from multiple care providers. The school also plays this role for many families.

- Health Care Team: 52%
- Clinical Psychologist: 46%
- Specialist M.D.: 39%
- Team at School: 37%
- Pediatrician: 31%
- Other: 6%
How Are Participants Using Speech?

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

**Children**

- Complex Sentences 44%
- Phrases 20%
- Single Words 18%
- Do Not Speak 18%

**Dependent Adults**

- Complex Sentences 64%
- Phrases 14%
- Single Words 10%
- Do Not Speak 12%
What Special Education Services Are Used?

Children

- Speech services: 85%
- Occupational therapy services: 74%
- IEP* for autism educational diagnosis: 70%
- Early childhood/preschool special education services: 67%
- IEP* for other educational diagnosis (e.g., speech/language impairment, intellectual disability, etc.): 61%
- Early intervention (birth-to-three) services: 55%
- Behavior therapy: 46%

Dependent Adults

- Speech services: 84%
- IEP* for other educational diagnosis (e.g., speech/language impairment, intellectual disability, etc.): 78%
- IEP* for autism educational diagnosis: 78%
- Early childhood/preschool special education services: 68%
- Occupational therapy services: 66%
- 1:1 classroom aide: 52%
- Behavior therapy: 52%

These graphs show the most common school supports used by children and dependent adults. SPARK participants tend to be younger. As participants age, school supports may change as the children’s needs change.

* IEP stands for Individualised Education Program
Pregnancy, Birth History and Associated Conditions

African American and Black families in SPARK reported concerns about the pregnancy and birth of their children. Infants born prematurely are at higher risk for breathing, heart, and brain challenges, among other complications.

<table>
<thead>
<tr>
<th>Associated Conditions reported in Children with ASD</th>
<th>Associated Conditions reported in Dependent Adults with ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>40% Sleep Problems</td>
<td>46% Cognitive Impairment</td>
</tr>
<tr>
<td>40% Eating Problems</td>
<td>39% ADHD*</td>
</tr>
<tr>
<td>34% ADHD*</td>
<td>23% Anxiety Disorder</td>
</tr>
<tr>
<td>18% Cognitive Impairment</td>
<td>14% Depression</td>
</tr>
<tr>
<td>13% Anxiety Disorder</td>
<td>11% Seizures</td>
</tr>
<tr>
<td>5% Depression</td>
<td>*ADHD stands for Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>5% Seizures</td>
<td></td>
</tr>
</tbody>
</table>

African American and Black participants have shared lower rates of depression and anxiety disorder.
Development | Age of milestones

First Words
- Children: 1 year and 9 months
- Dependent Adults: 1 year and 9 months

First Steps
- Children: 1 year and 2 months
- Dependent Adults: 1 year and 2 months

Average age of the child when parents had their first concern
- Children: 1 year and 10 months
- Dependent Adults: 2 years
First things that caused parents’ concern about their child’s development

- **Late Speech**
  - 32% Children
  - 22% Dependent Adults

- **Social Interactions**
  - 18% Children
  - 24% Dependent Adults

- **Late Walking**
  - 11% Children
  - 12% Dependent Adults

- **Mood**
  - 8% Children
  - 6% Dependent Adults

- **A Loss or Change in Ability**
  - 10% Children
  - 11% Dependent Adults

- **Unusual Habits**
  - 7% Children
  - 9% Dependent Adults

- **Unusual Speech**
  - 3% Children
  - 5% Dependent Adults

- **Something Else**
  - 11% Children
  - 11% Dependent adults
Children develop in waves, and sometimes a skill is temporarily lost. When we say “regression,” we mean a change or loss of skills or abilities for six or more months. African American and Black families report a higher rate of regression and fewer experiences of resolution of the regression in comparison to dependent adults in the entire SPARK cohort.

**Children**

- **Language regression** 36%
- **Average age of language regression** 1.8 years
- **Language returned** 59%
- **Other regressions:**
  - **Social skills** 17%
  - **Play** 11%
  - **Development** 15%
- **Average age of other regression** 2.8 years
- Of the above regressions, 45% had their language return.

**Dependent Adults**

- **Language regression** 36%
- **Average age of language regression** 2.5 years
- **Language returned** 51%
- **Other regressions:**
  - **Social skills** 22%
  - **Play** 12%
  - **Development** 14%
- **Average age of other regression** 3.6 years
- Of the above regressions, 43% experienced a return of skills.
Development | Support

Children
More than 2 out of 3 children need some support in their daily lives.

11% Minimal to none
37% Some
36% Substantial
16% Very Substantial

Dependent Adults
More than 2 out of 3 dependent adults need some support in their daily lives.

10% Minimal to none
35% Some
35% Substantial
20% Very Substantial
When we say simplex, we mean families with only one member who has a professional diagnosis of ASD.

Families where at least one parent and only one child are reported as having an ASD diagnosis and enrolled in SPARK.

84% of SPARK families only have one autistic family member

Families where at least one parent and more than one child are reported to have an ASD diagnosis and enrolled in SPARK.

12% of families have more than one child with ASD

Families where at least one parent and more than one child are reported to have an ASD diagnosis and enrolled in SPARK.

1% of families have more than one child and at least one parent with ASD

Families where at least one parent and only one child are reported as having an ASD diagnosis and enrolled in SPARK.

3% of families have at least one parent and only one child with ASD
African American & Black Independent Adults

386 African American and Black independent adults are in SPARK
The number of all independent adults with autism participating in SPARK is larger than most other autism research studies in the United States.

**Percent of African American and Black Independent Autistic Adults in SPARK by life stage**

- **Age 18-24**: 31%
- **Age 25-34**: 39%
- **Age 35-44**: 19%
- **Age 45+**: 11%

**Sex at Birth**

- Female: 68%
- Male: 32%
Most of the African American and Black independent adults in SPARK represent young and middle-aged adults. This may not be representative of what older adults are experiencing. (80% of respondents are 40 years old or below)

*ADHD stands for Attention Deficit Hyperactivity Disorder | OCD stands for Obsessive Compulsive Disorder
Out of the 216 African American and Black independent adults who responded, household income (e.g., salaries, wages, etc.) reported is lower than the national average for employed people.

Only a little over half of independent adults make over $20,000.

Almost all (96%) independent adult participants have a high school diploma or higher education.

1 in 4 have at least 1 higher education degree (bachelor’s, master’s, law, Ph.D)
Employment

- Unable to work
- Employed Part-Time
- Employed Full-Time

Female
- 56% Unable to work
- 22% Employed Part-Time
- 22% Employed Full-Time

Male
- 44% Unable to work
- 35% Employed Part-Time
- 21% Employed Full-Time

Overall
- 52% Unable to work
- 26% Employed Part-Time
- 22% Employed Full-Time

Marital Status

- Single: 55%
- Married: 15%
- Relationship or Domestic Partner: 25%
- Divorced: 5%

Just over half the African American and Black independent adults with autism enrolled in SPARK are single. Many are married or in a relationship. Only 5% are divorced.
**Gender & Sexuality**

Many African American and Black independent adults reported they are LGBTQ+ and 5% identify as a gender other than their sex at birth. Other research among adults with autism has reported this as well. “Pansexual” is defined as attraction to individuals of any sex or gender.

Almost 1 in 2 independent adults in SPARK identify as not being heterosexual.

- 9% Pansexual
- 3% No Response
- 10% Asexual
- 51% Heterosexual
- 9% Homosexual
- 3% Don’t Know
- 3% Queer
- 12% Bisexual
- <1% Other
Most African American and Black independent adults participating in SPARK live with a partner or spouse or a family member. A smaller number live alone, with roommates or in a group home.

- **Living with Parents or Relatives**: 35%
- **Living with Partner or Spouse**: 29%
- **Living Alone**: 26%
- **Living with Roommates**: 9%
- **Living in Group Home**: 1%
Leisure Time

Most African American and Black independent adults participating in SPARK enjoy spending their free time engaging in their favorite hobbies or with their families. Many also enjoy spending their free time in online communities, with friends, and their special talents.

- **82%** Hobbies
- **25%** Talents
- **38%** Time with Friends
- **57%** Time with Family
- **37%** Time with Online Communities
- **14%** Autism Specific Groups
- **18%** Volunteering
- **21%** Classes