

# SPARK SNAPSHOT

A Snapshot of the African American  
& Black Communities in SPARK



UPDATED | Data from December 2015 to March 2022



## **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.

Age 1-4

2,521

Age 5-11

3,835

Age 12-17

1,482

Age 18-24

490

Age 25-34

235

Age 35-44

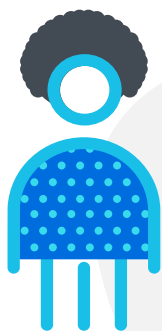
84

Age 45 and older

41

# 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.



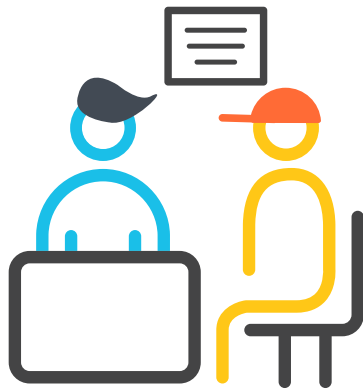
Average age of diagnosis for African American and Black dependent adult **males**

6



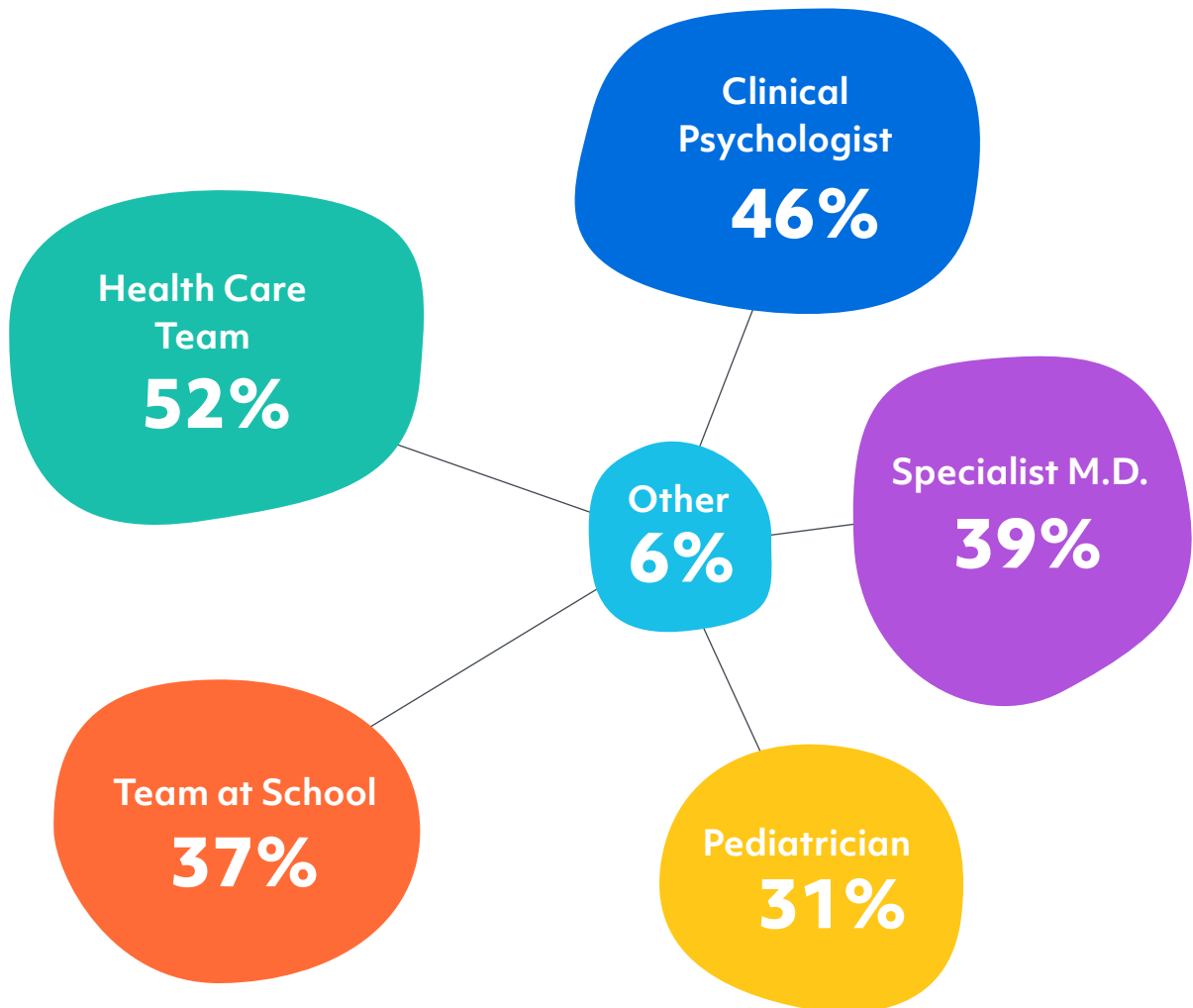
Average age of diagnosis for African American and Black dependent adult **females**

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.

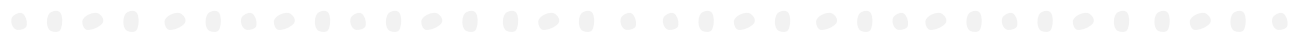
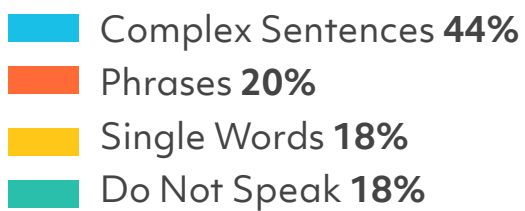




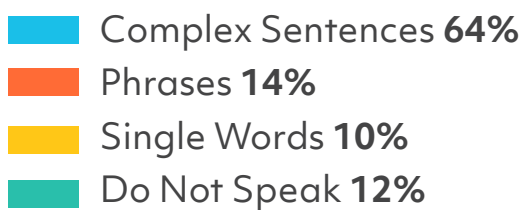
# How Are Participants Using Speech?

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

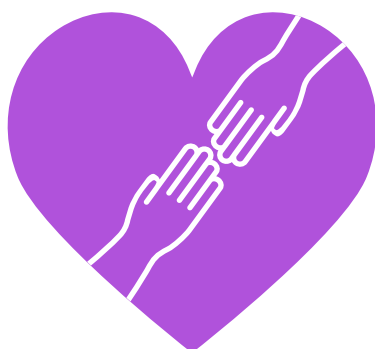
## Children



## Dependent Adults

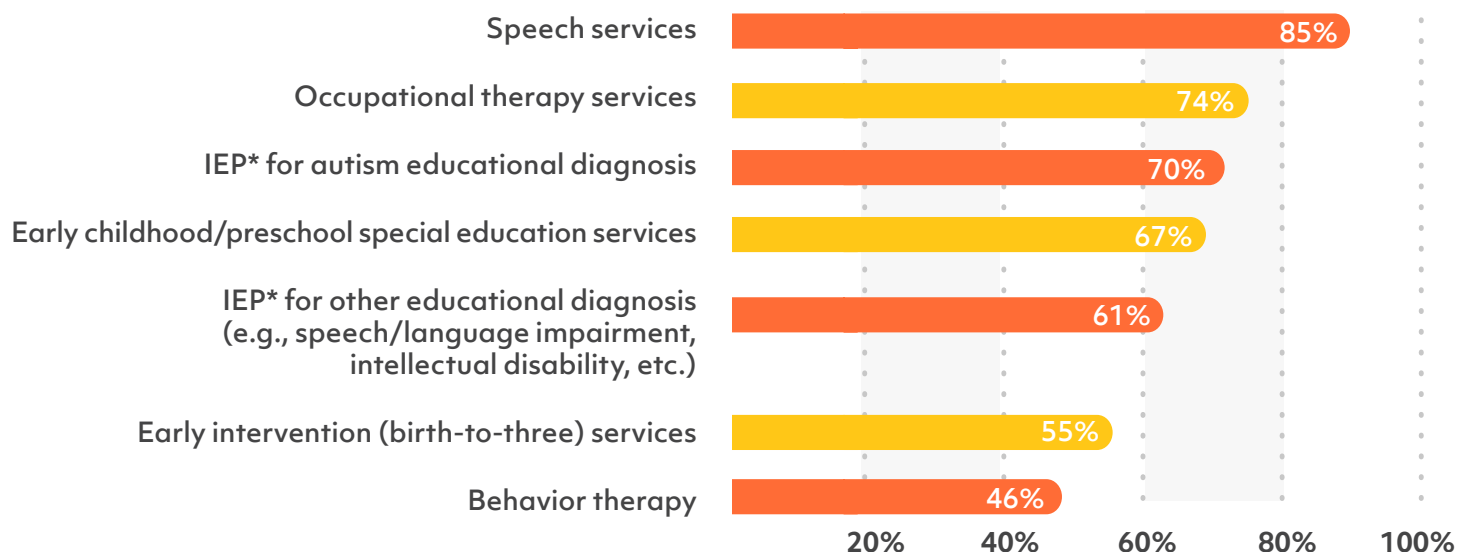




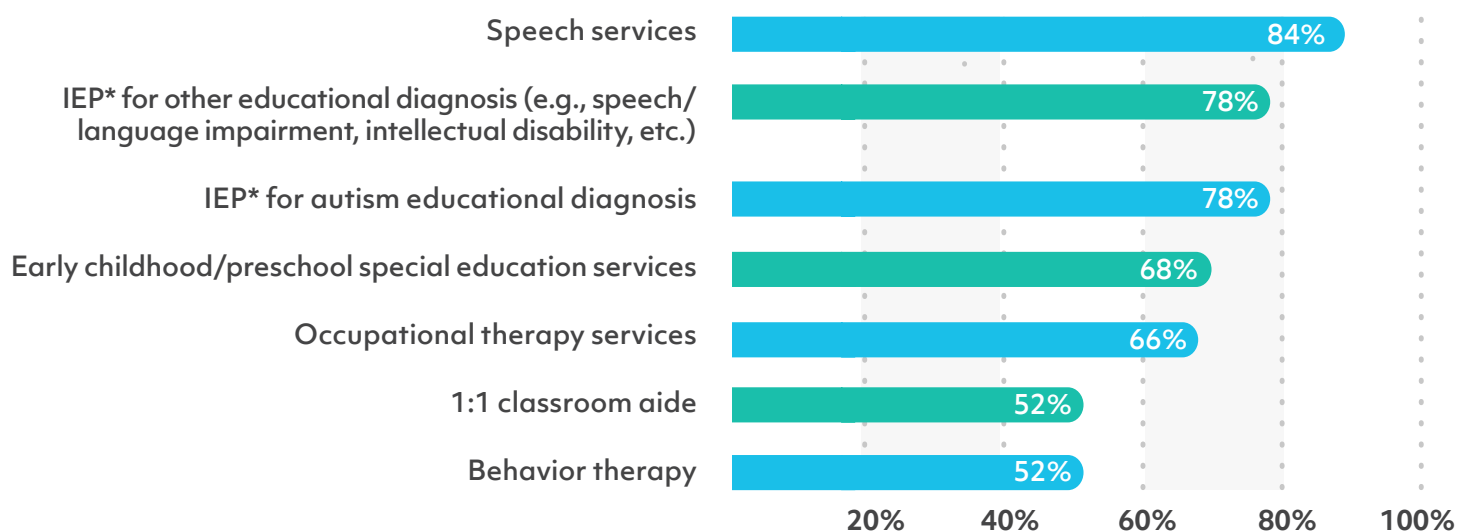


# What Special Education Services Are Used?

## Children



## Dependent Adults



*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.



Percent with Birth Complications

**6%**



Percent Born Prematurely

**11%**



African American and Black participants have shared **lower rates of depression and anxiety disorder.**

Associated Conditions reported in **Children** with ASD

- 40%** Sleep Problems
- 40%** Eating Problems
- 34%** ADHD\*
- 18%** Cognitive Impairment
- 13%** Anxiety Disorder
- 5%** Depression
- 5%** Seizures

Associated Conditions reported in **Dependent Adults** with ASD

- 46%** Cognitive Impairment
- 39%** ADHD\*
- 23%** Anxiety Disorder
- 14%** Depression
- 11%** Seizures

\*ADHD stands for Attention Deficit Hyperactivity Disorder



## 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**

# Development

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

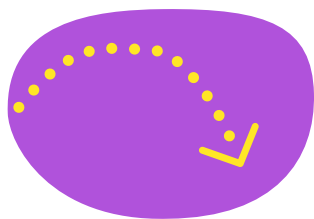
12% Dependent Adults



## Mood

8% Children

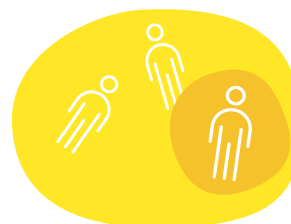
6% Dependent Adults



## A Loss or Change in Ability

10% Children

11% Dependent Adults



## Unusual Habits

7% Children

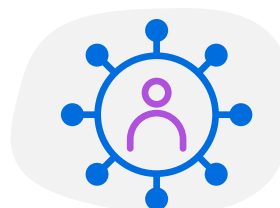
9% Dependent Adults



## Unusual Speech

3% Children

5% Dependent Adults



## Something Else

11% Children

11% Dependent adults

# Development | Regression

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%**

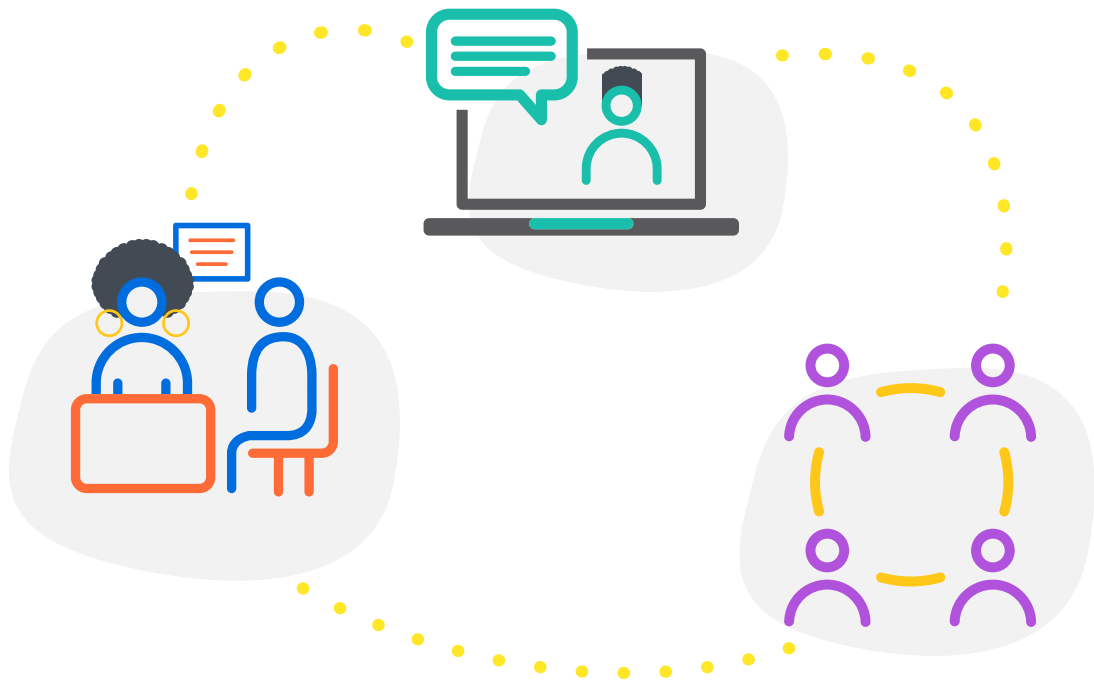
**Development 14%**

**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

# Family Members With Autism



**Simplex**

**84%** of SPARK families only have **one autistic family member**

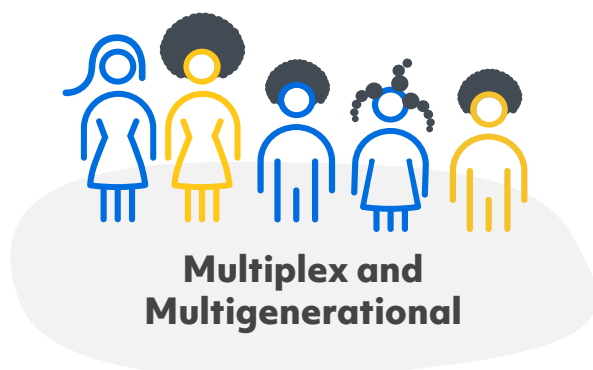
When we say simplex, we mean families with **only one member** who has a professional diagnosis of ASD.



**Multiplex**

**12%** of families have more than **one child with ASD**

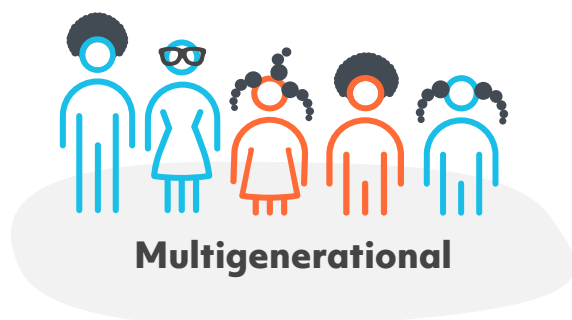
Families where **more than one child** is reported to have an ASD diagnosis and enrolled in SPARK.



**Multiplex and  
Multigenerational**

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

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



**Multigenerational**

**3%** of families have at least one **parent and only one child with ASD**

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



# SPARK SNAPSHOT



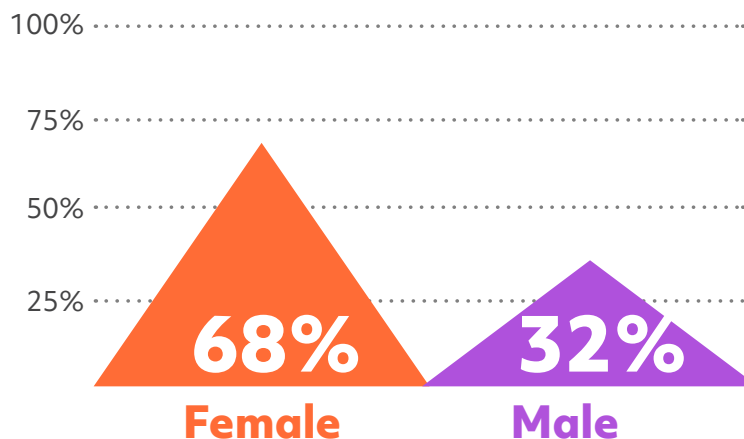
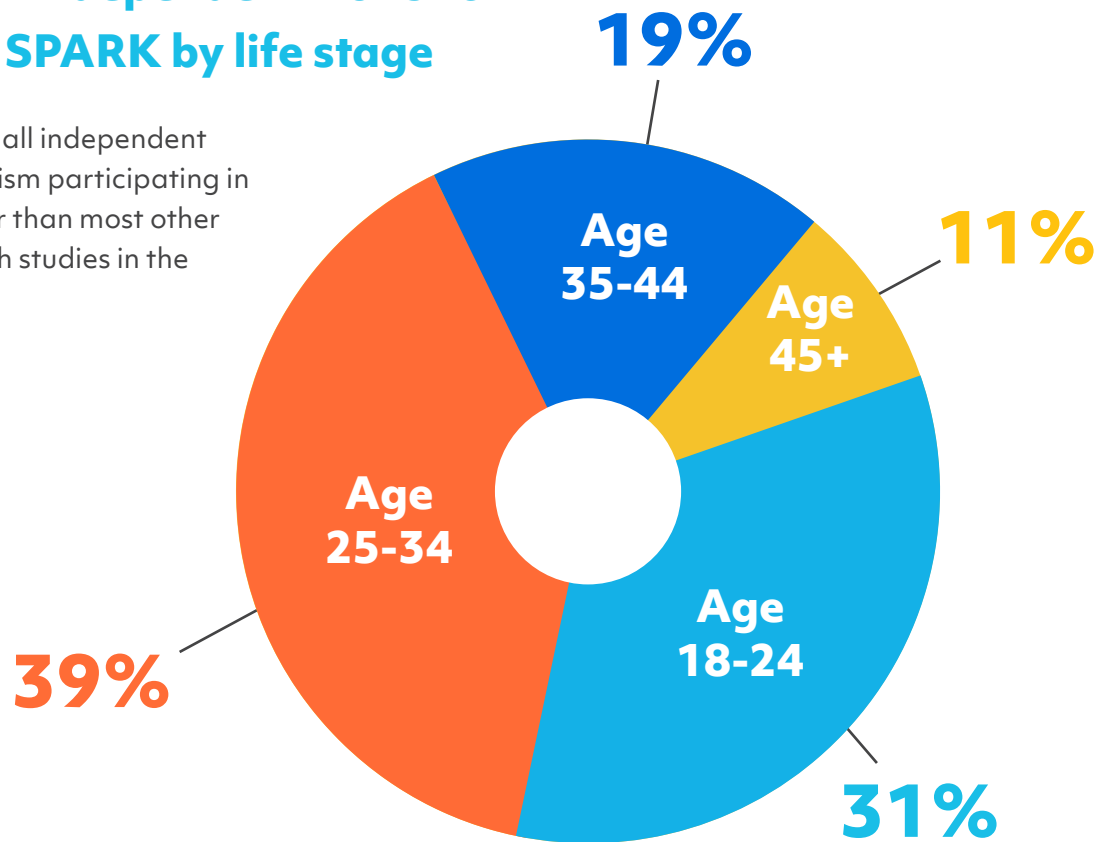
African American & Black  
**Independent Adults**

**386** African American and  
Black independent adults  
are in **SPARK**



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

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



### Sex at Birth



## Diagnosis



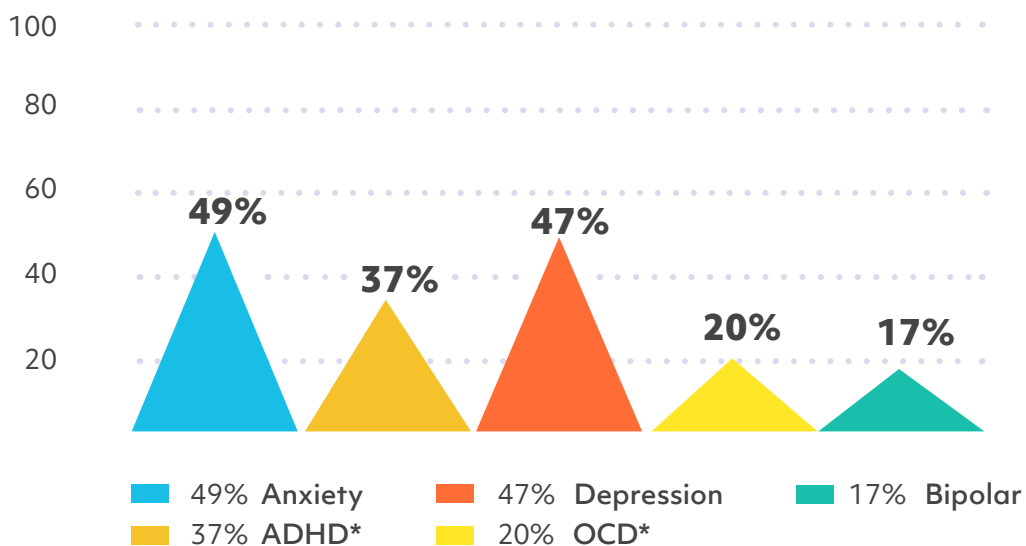
Average Age of African American  
and Black Independent Adult  
**Males** Diagnosis



Average Age of African American  
and Black Independent Adult  
**Females** Diagnosis

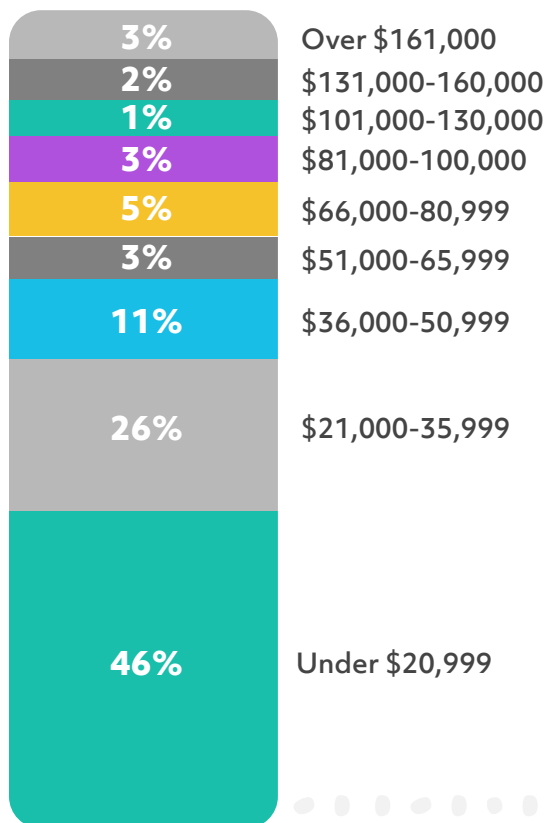
## Mental Health in Independent Adults

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

# SNAPSHOT African American & Black Independent Adults



## Household Income

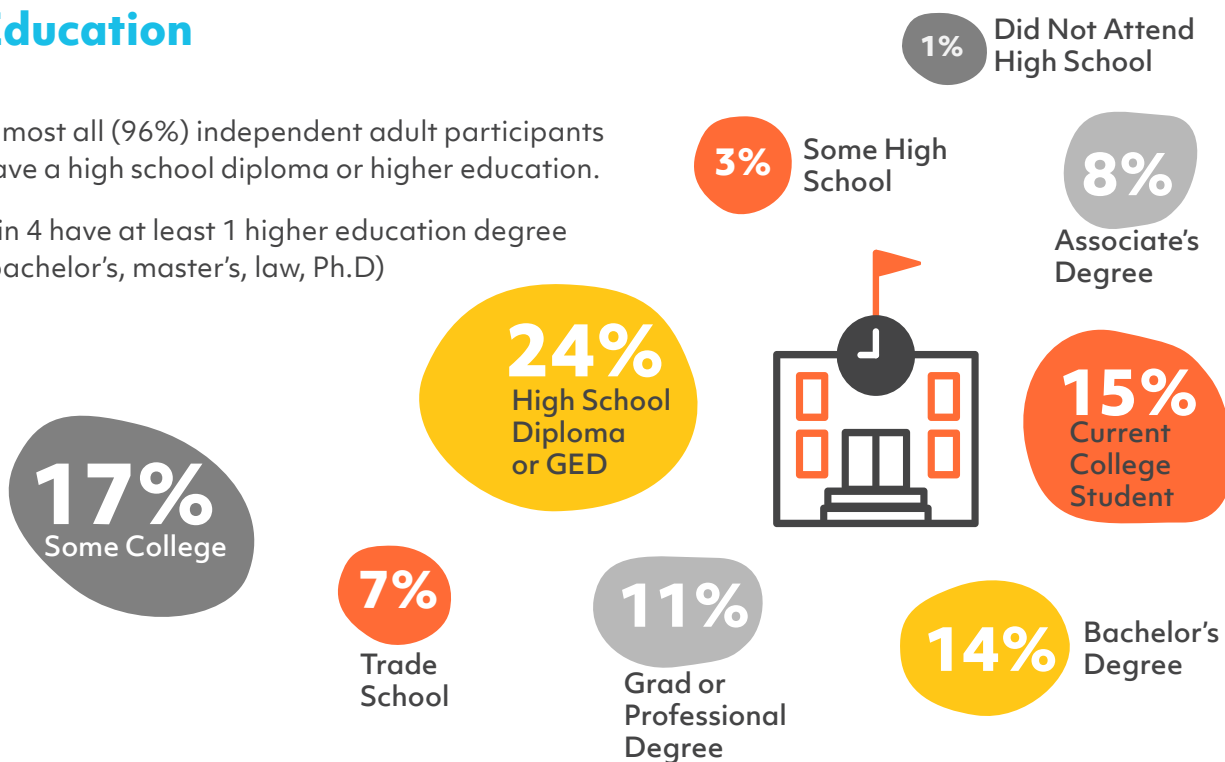
Out of the 216 African American and Black independent adults who responded, household income (e.g., salaries, wages, etc.) reported is lower than the national average for employed people.

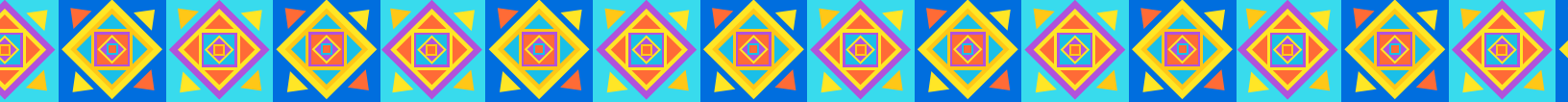
Only a little over half of independent adults make over \$20,000.

## Education

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)



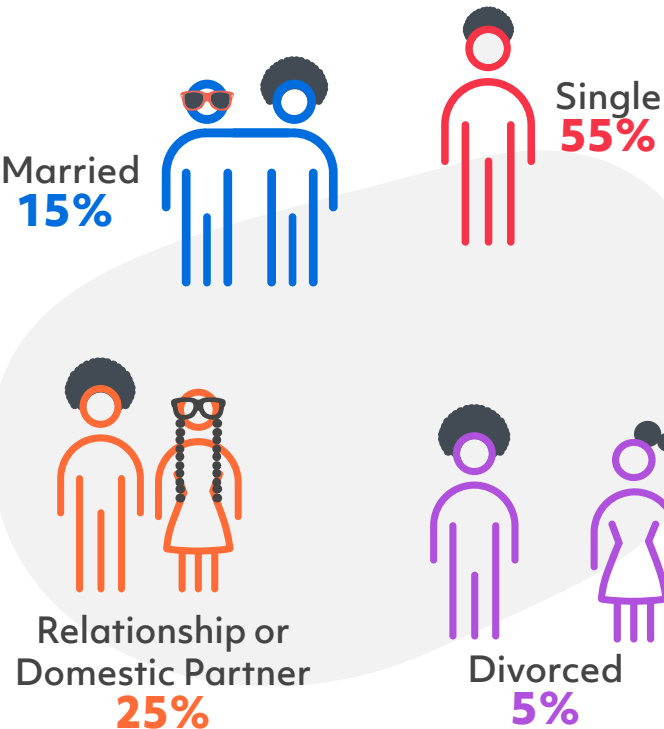
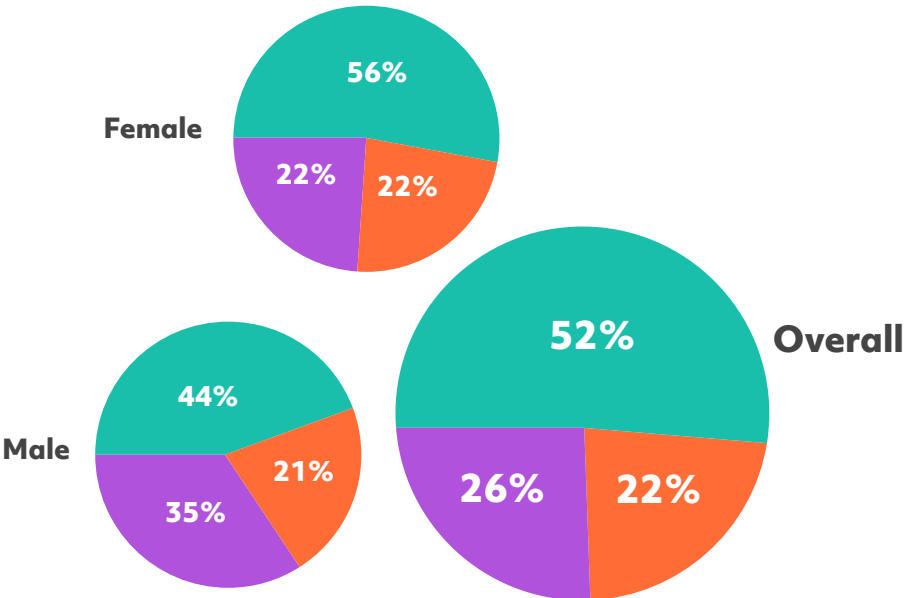


# SNAPSHOT

African American & Black  
Independent Adults

## Employment

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



## Marital Status

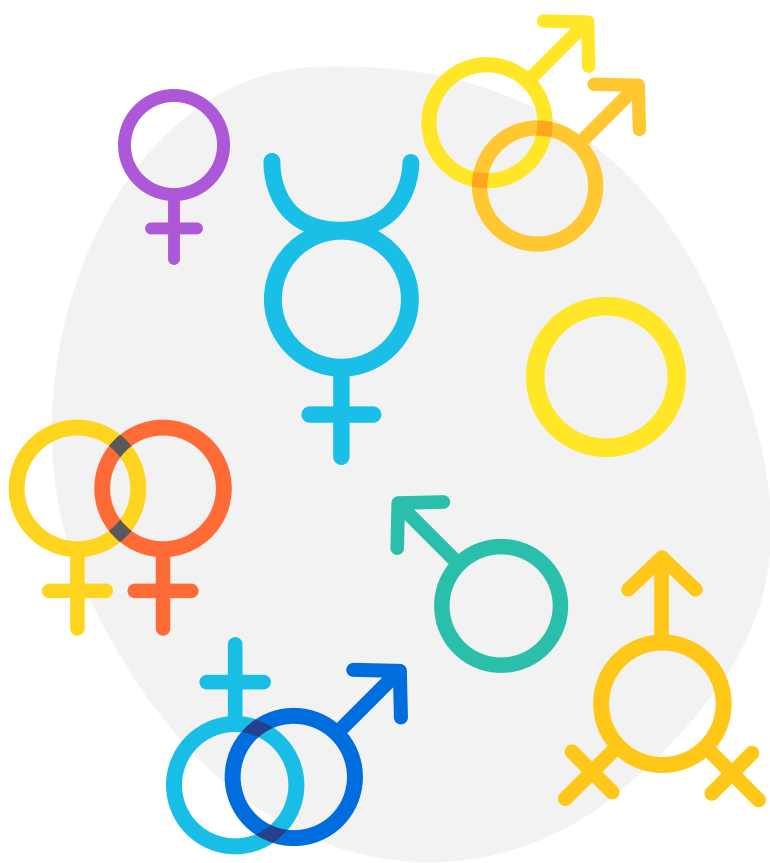
Just over half the African American and Black independent adults with autism enrolled in SPARK are single. Many are married or in a relationship. Only 5% are divorced.

# SNAPSHOT **African American & Black Independent Adults**

## 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.

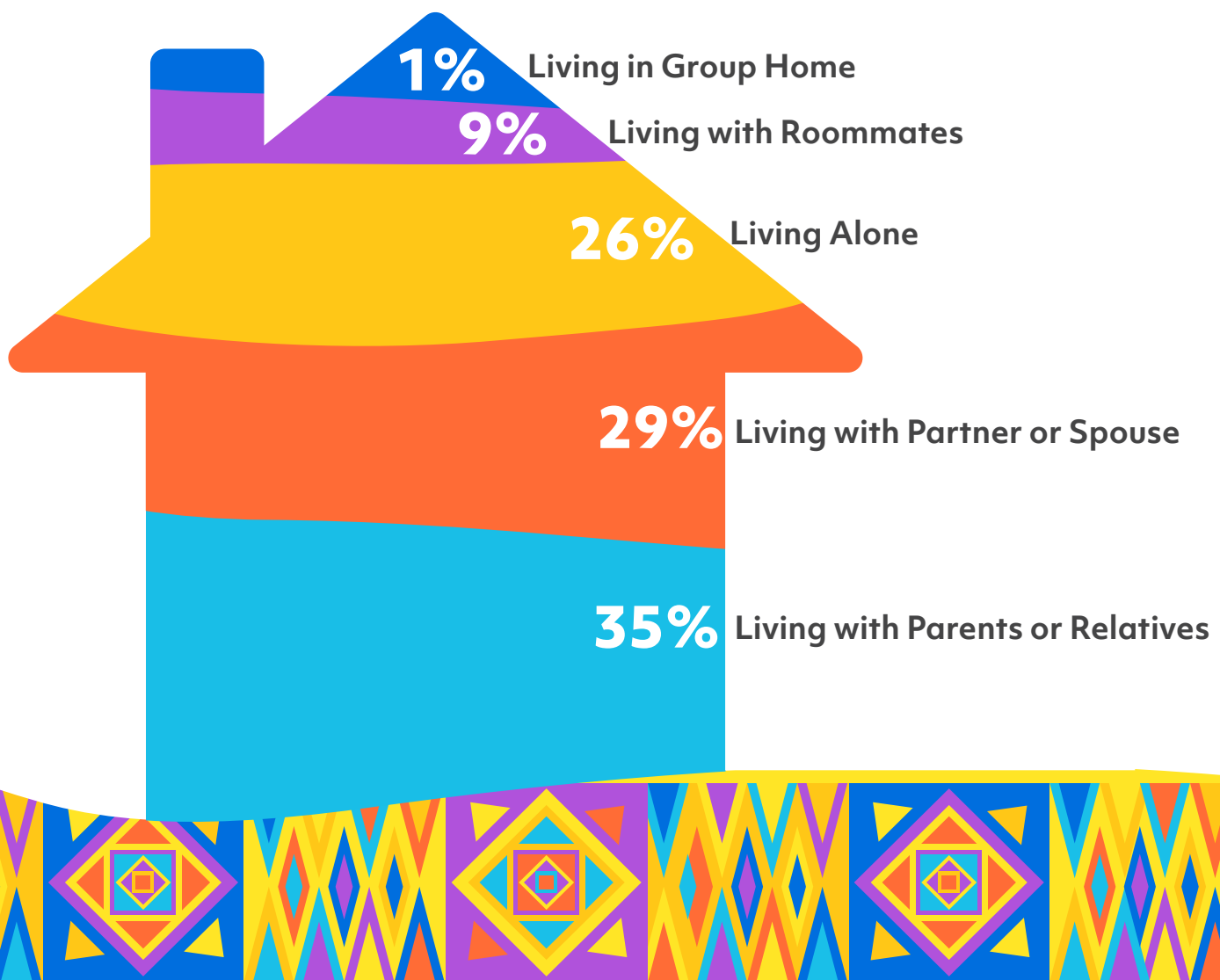
Almost 1 in 2 independent adults in SPARK identify as not being heterosexual.



- 9% Pansexual**
- 3% No Response**
- 10% Asexual**
- 51% Heterosexual**
- 9% Homosexual**
- 3% Don't Know**
- 3% Queer**
- 12% Bisexual**
- <1% Other**

### Housing

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.





### 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.

