



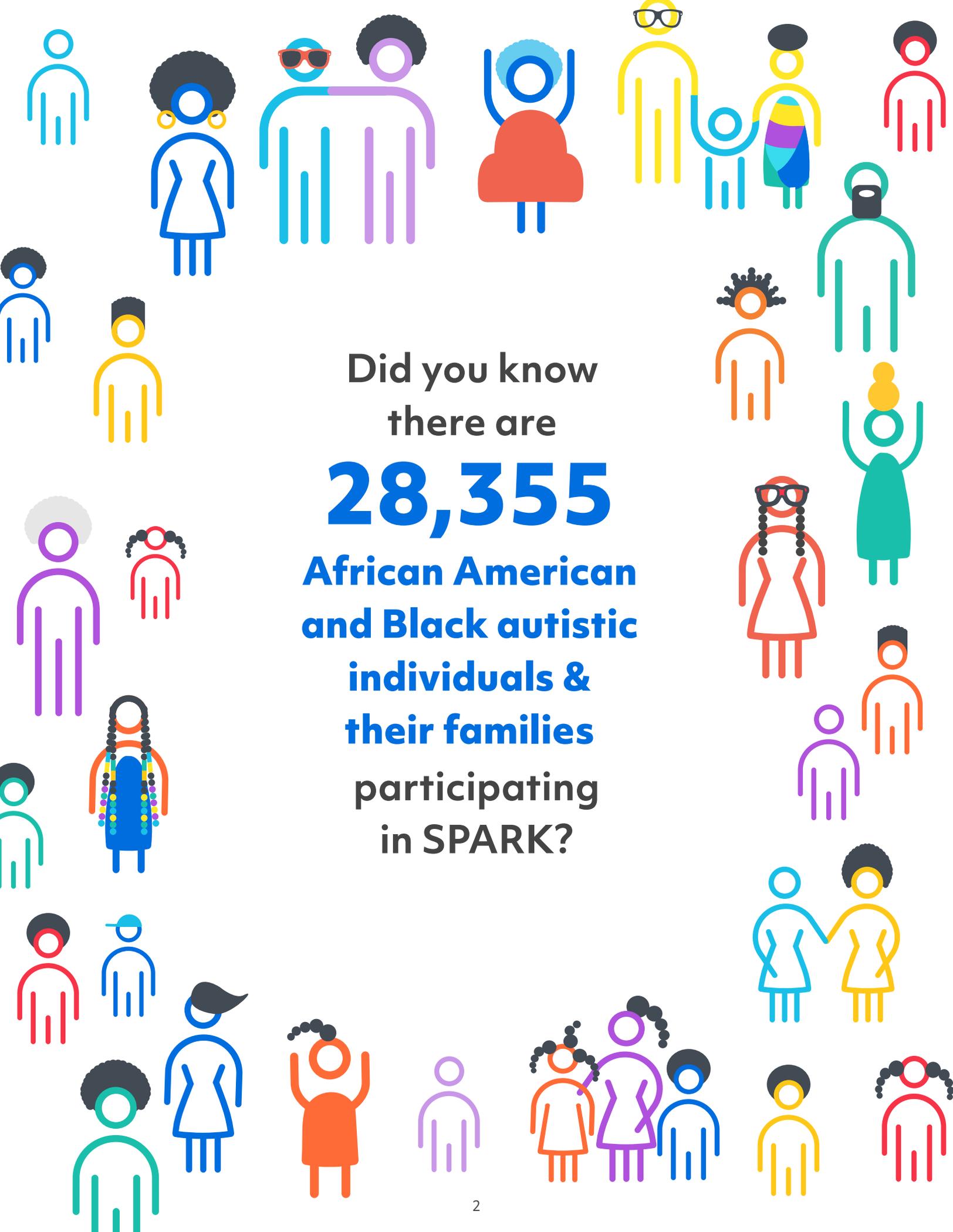
SPARK SNAPSHOT

A Snapshot of the
African American
& Black Communities
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.



Did you know
there are
28,355
**African American
and Black autistic
individuals &
their families**
participating
in SPARK?

Who Is Participating in SPARK?

A look at African American and Black children and dependent adults with autism in SPARK

Children

Number of African American and Black Autistic Children

13,376

Dependent Adults

Number of African American and Black Autistic Dependent Adults

724

Ratio of male to female children



3 to 1

Ratio of male to female dependent adults



1 to 1

Among African American and Black children with autism, boys outnumber girls 3 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.

How Old Are SPARK's African American and Black Participants?

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 of African American and Black autistic participants enrolled in SPARK*

Age 4 and under



Age 5-11



Age 12-17



Age 18-24



Age 25-34



Age 35-44



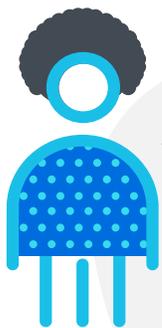
Age 45 and older



* 26 with no age at registration

Age of Diagnosis

Children Under 18



Average age when **boys** were diagnosed

4



Average age when **girls** were diagnosed

4.5

Dependent Adults 18 and Over



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

5

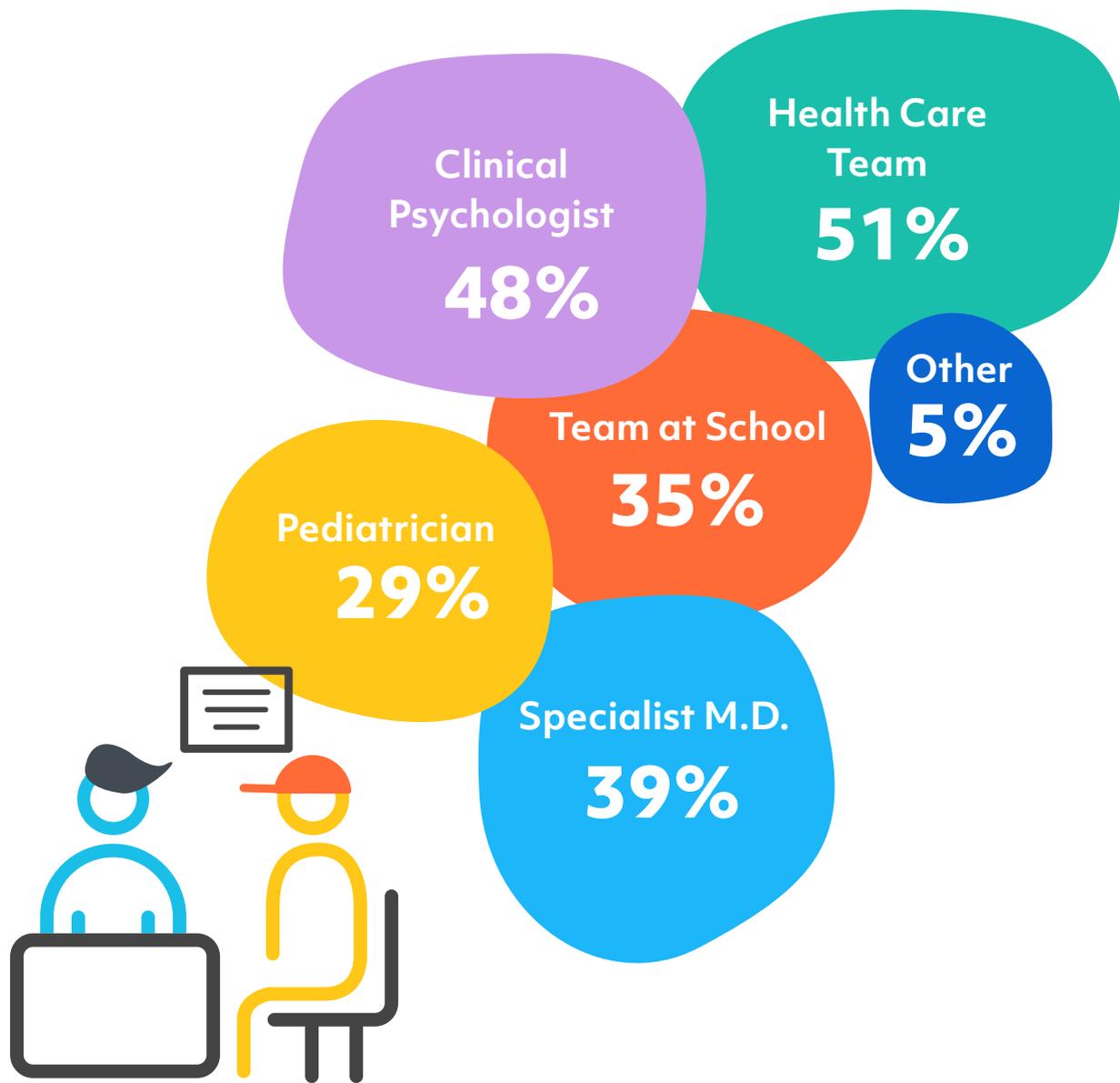


Average age of diagnosis for African American and Black dependent adult **females**

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.



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

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 46%
- Phrases 20%
- Single Words 17%
- Do Not Speak 17%



Dependent Adults

- Complex Sentences 61%
- Phrases 16%
- Single Words 12%
- Do Not Speak 11%

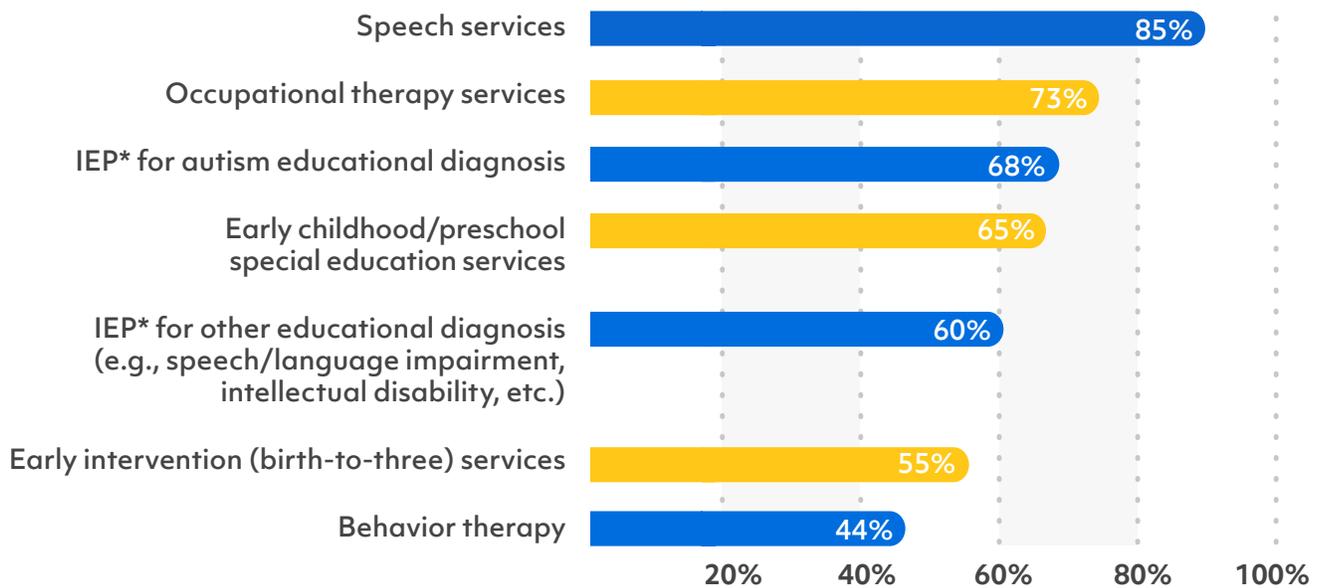


What Special Education Services Are Used?

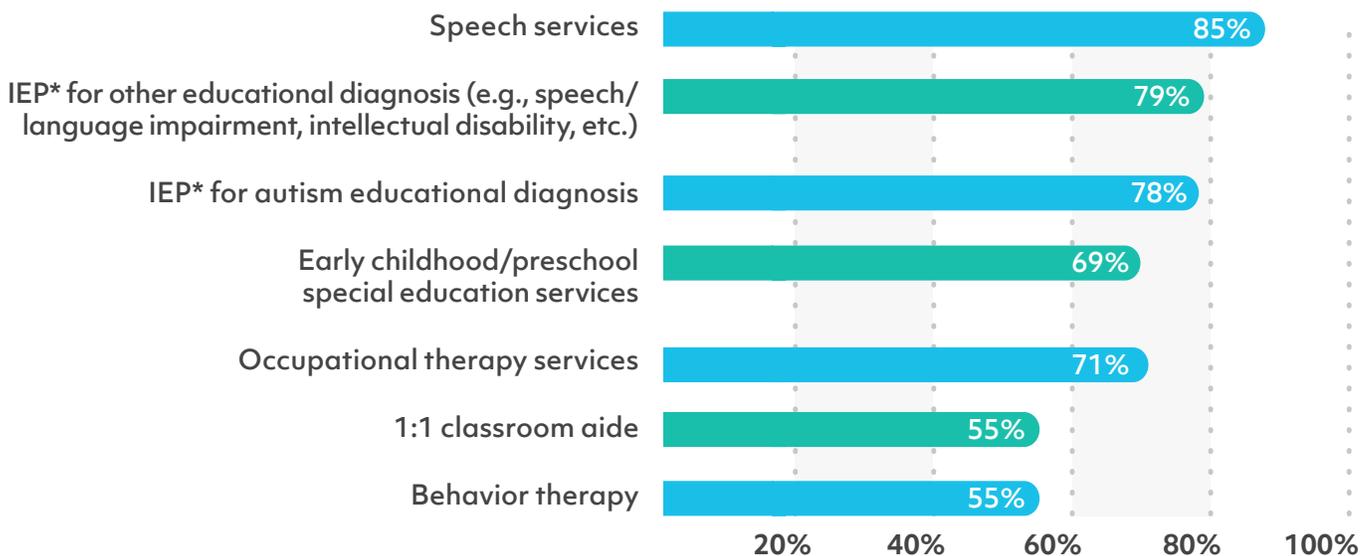
Information on special education services is available for 4,763 children with autism and 280 dependent autistic adults in SPARK.

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.

Children



Dependent Adults



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

*IEP stands for Individualized Education Plan

Pregnancy and Birth History

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 serious birth complications

6%



Percent born prematurely

9%

Associated conditions

Associated conditions reported in **Children** with autism

- 40%** Sleep Problems
- 41%** Eating Problems
- 32%** ADHD*
- 23%** Cognitive Impairment
- 12%** Anxiety Disorder
- 5%** Depression
- 5%** Seizures

Associated conditions reported in **Dependent Adults** with autism

- 46%** Cognitive Impairment
- 40%** ADHD*
- 26%** Anxiety Disorder
- 17%** Depression
- 11%** Seizures

*ADHD stands for Attention Deficit Hyperactivity Disorder

Development

Age of milestones



First Words

Children **1 year and 10 months**

Dependent Adults **1 year and 10 months**

First Steps

Children **1 year and 2 months**

Dependent Adults **1 year and 3 months**



Average age of the child when parents had their first concern

Children **1 year and 9 months**

Dependent Adults **2 years**

Development

First things that caused parents' concern about their child's development



Late Speech
31% Children
20% Dependent Adults



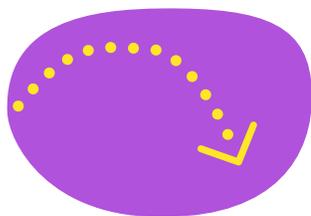
Social Interactions
19% Children
26% Dependent Adults



Late Walking
11% Children
11% Dependent Adults



Mood
8% Children
6% Dependent Adults



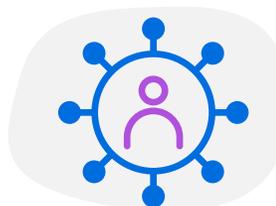
A Loss or Change in Ability
10% Children
10% Dependent Adults



Unusual Habits
7% Children
8% Dependent Adults



Unusual Speech
3% Children
4% Dependent Adults



Something Else
11% Children
15% Dependent adults

Development | Regression

Children develop in waves, and sometimes a skill is temporarily lost. When we say regression, we mean a total loss of skills or abilities for a period of time. **African American and Black families report a higher rate of language regression**, and fewer experiences of regaining the lost language, in comparison to children and dependent adults in the entire SPARK cohort.

Children

Language regression **36%**

Average age of language regression **1 year and 11 months**

Language returned **57%**

Other regressions:

Social skills **17%**

Play **11%**

Development **15%**

Average age of other regression **2 years and 11 months**

Of the above regressions,
47% had their language return.

Dependent Adults

Language regression **38%**

Average age of language regression **2 years and 5 months**

Language returned **45%**

Other regressions:

Social skills **23%**

Play **15%**

Development **15%**

Average age of other regression **3 years and 9 months**

Of the above regressions,
37% experienced a return of skills.

Development | Support



Children

- Minimal to none **10%**
- Some **36%**
- Substantial **36%**
- Very Substantial **18%**

Dependent Adults

- Minimal to none **9%**
- Some **33%**
- Substantial **37%**
- Very Substantial **21%**

Family Members With Autism



84%

of SPARK families only have one autistic family member

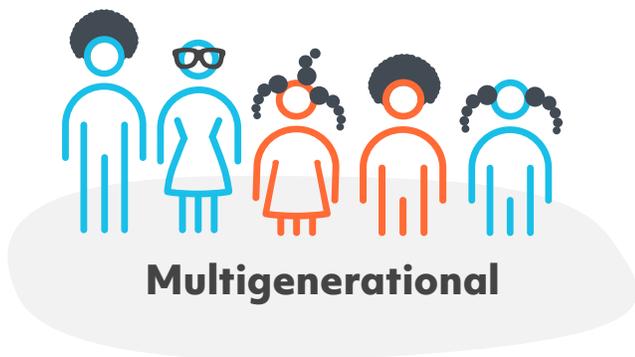
When we say simplex, we mean families with **only one member** who has a professional diagnosis of ASD.



12%

of families are multiplex-sibling

Multiplex-sibling refers to families where **more than one child** is reported to have an autism diagnosis and is enrolled in SPARK.



4%

of families are multiplex multigenerational

Multiplex multigenerational refers to families where **at least one parent and only one child** reported having an autism diagnosis and are enrolled in SPARK.



SPARK

SNAPSHOT

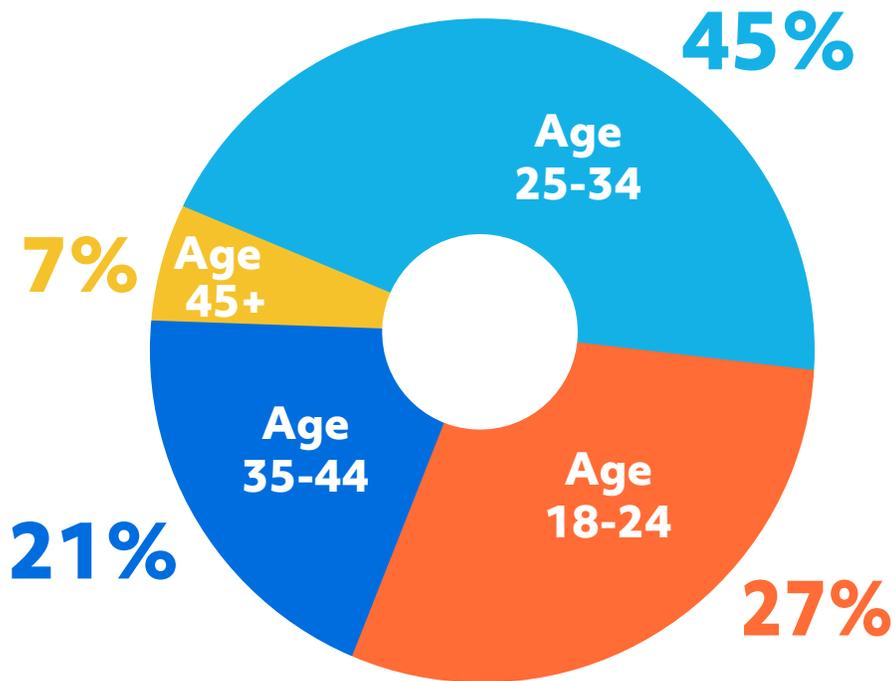
PART 2 African American & Black Independent Autistic Adults

1,029 African American and Black independent autistic adults are in **SPARK**

SPARK uses both person-first and identity-first language. This means that we alternate between the use of the phrase “person with autism” and “autistic person.” SPARK’s language choices are determined by our community’s preferences.

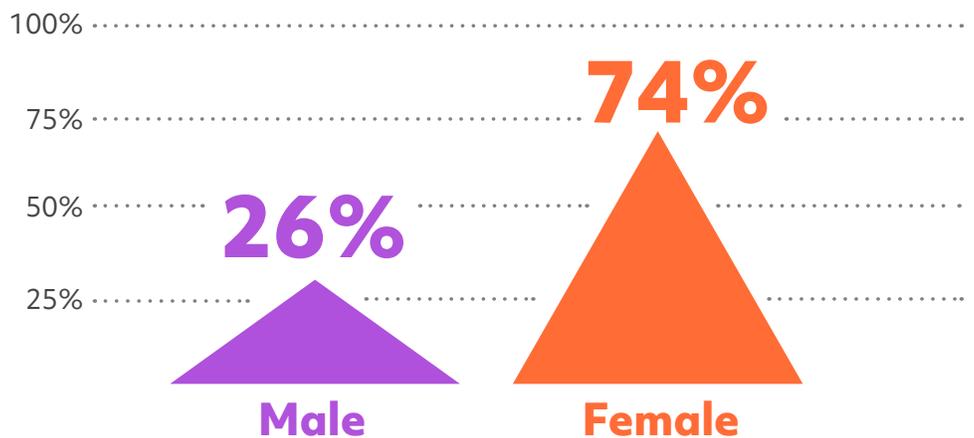
Percent of African American and Black Independent Autistic Adults in SPARK by life stage

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

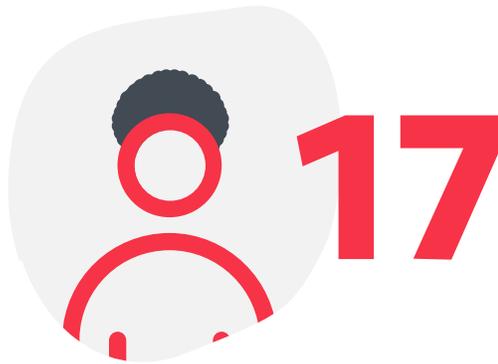


Sex at Birth

n = 412



Diagnosis

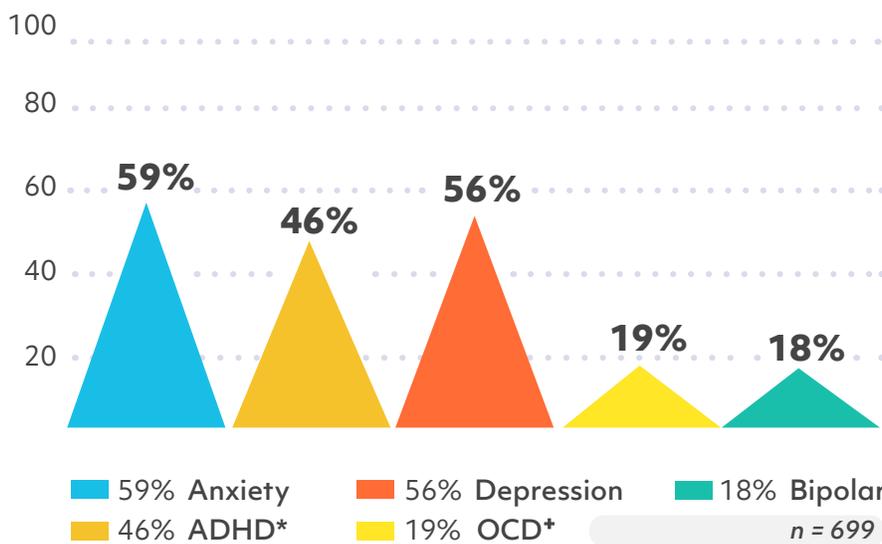


Average Age of African American and Black Independent Adult **Males** Diagnosis



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

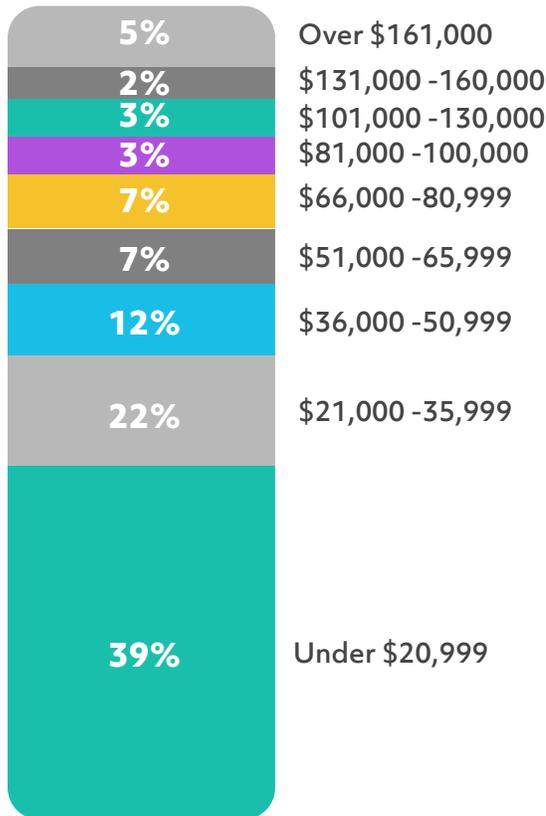
Mental Health in Independent Adults



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. (93% of respondents are younger than 45 years old).

*ADHD stands for Attention Deficit Hyperactivity Disorder

*OCD stands for Obsessive Compulsive Disorder



Household Income

Out of the 412 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.

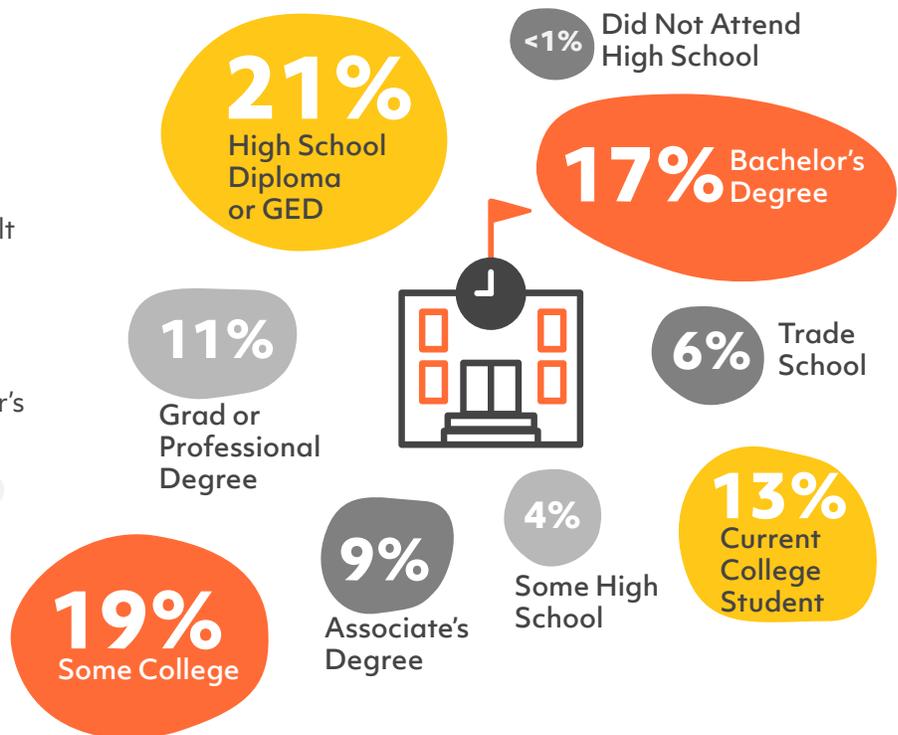
n = 412

Education

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

More than 1 in 4 have at least 1 higher education degree (bachelor's graduate, or professional degree).

n = 412

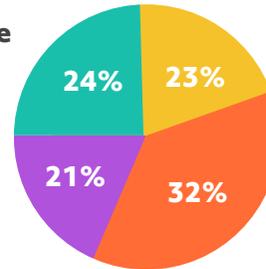


Employment

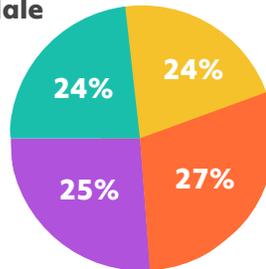
- Unable to work
- Employed Part-Time
- Employed Full-Time
- Unemployed (incl. retirees and unpaid student interns)

n = 410

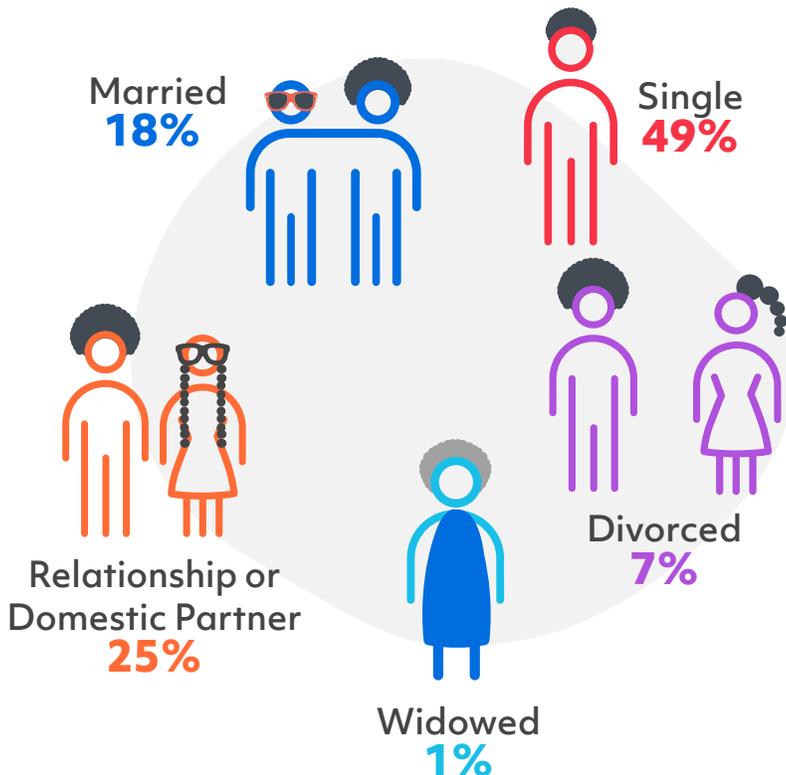
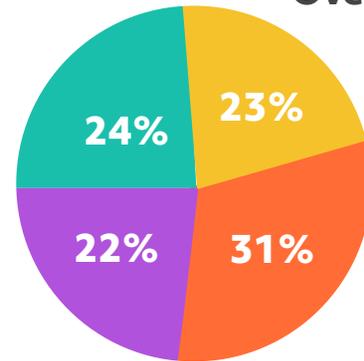
Female



Male



Overall



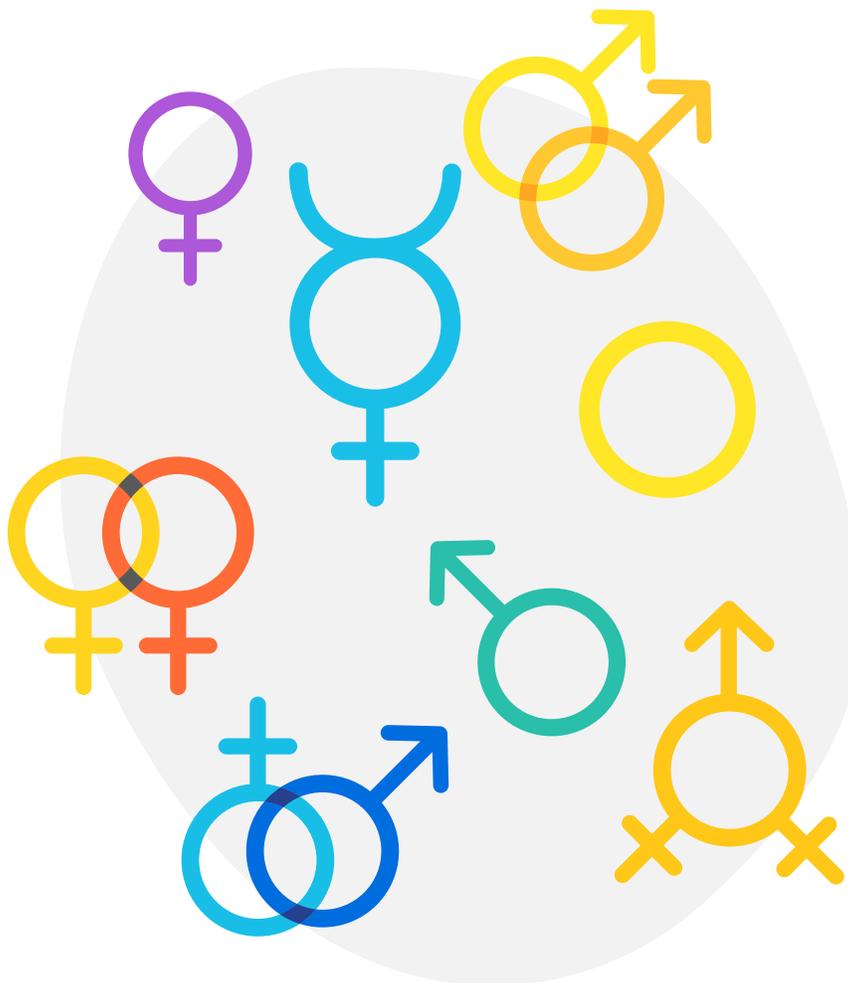
Marital Status

Nearly half of the African American and Black independent adults with autism enrolled in SPARK are single. Many are married or in a relationship. A significant number - 43% - are either married or in a relationship and/or domestic partnership.

n = 412

Gender & Sexuality

About 7% of African American and Black independent autistic adults in SPARK identify as a different gender than their sex at birth. Other research among adults with autism has reported this as well. Many participants also reported that they are LGBTQ+.



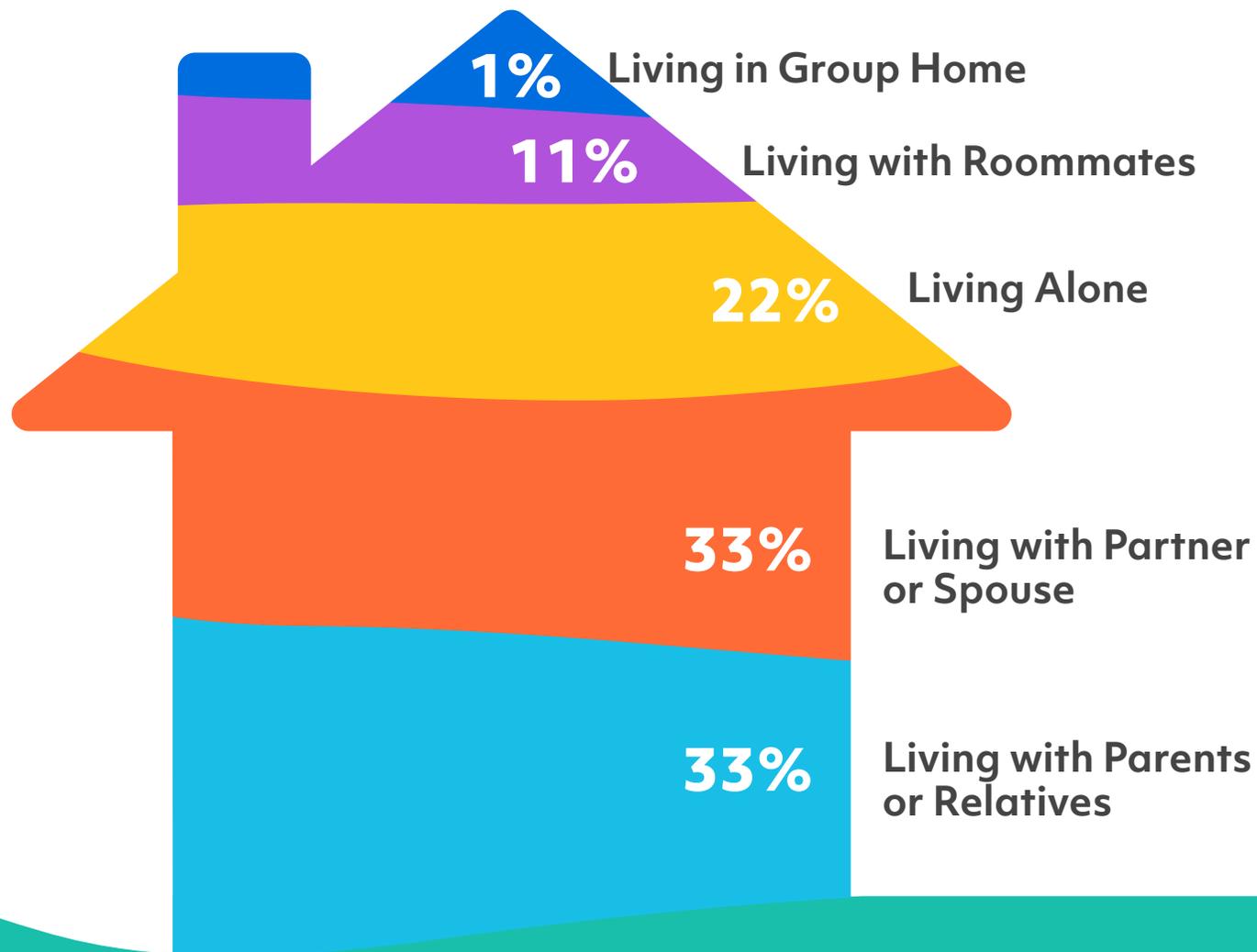
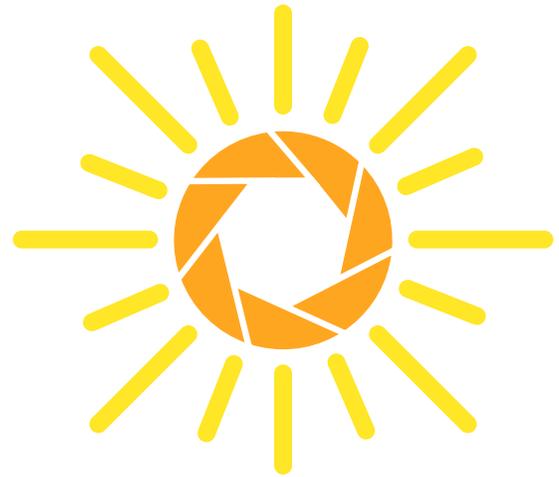
- 10% Pansexual**
- 3% No Response**
- 8% Asexual**
- 44% Heterosexual**
- 7% Homosexual**
- 6% Don't Know**
- 5% Queer**
- 16% Bisexual**
- 1% Other**

n = 410

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.

n = 409



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.

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





Thank you

to all of the participating
individuals and families!

Together, we can learn
so much more.