

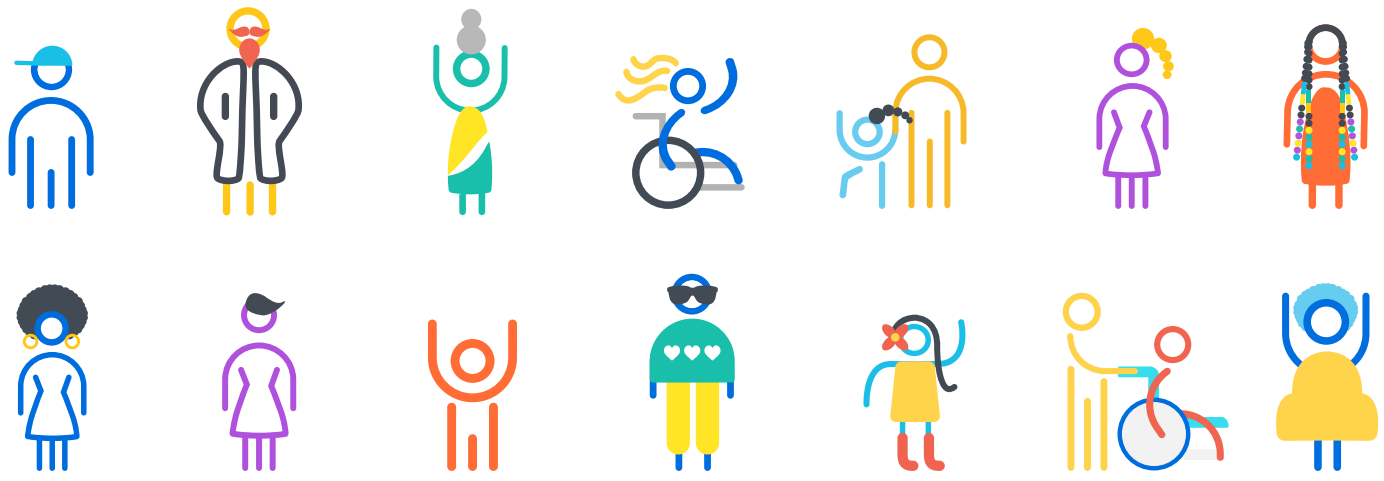


# SPARK

# SNAPSHOT

Report 1: UPDATED | Data from Dec 2015 - Jan 2024





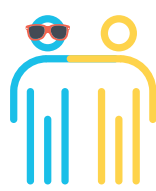
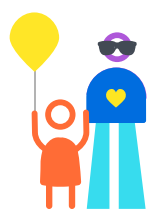
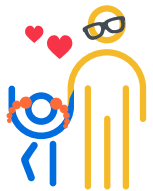
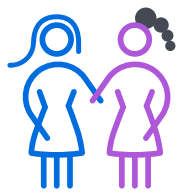
Did you know that

# 139,275 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.

*We recognize a person's gender may be different than their sex assigned at birth. When we say male/female/boy/girl, we are referring to assigned sex at birth.*



# Who Is Participating in SPARK?

## Children

Number of Children  
with Autism\*

**113,267**

## Adults

Number of  
Autistic Adults\*

**25,842**

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.

\*166 participants have no reported age data



**1 to 1**

Ratio of Males to Females  
in Adults Over 18

There has been a significant increase in autistic adult women participating in SPARK over time. This could be due to the rise in awareness of autism in women.



**3 to 1**

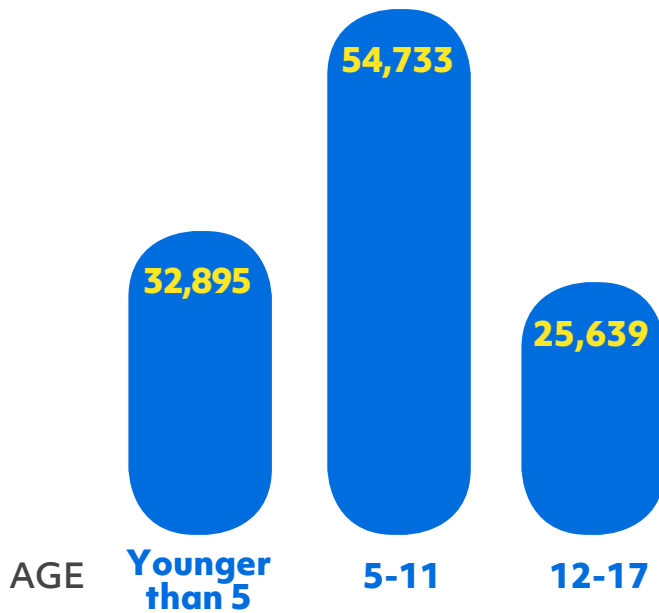
Ratio of Males to Females  
in Children Under 18

Boys with autism outnumber girls 3 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.

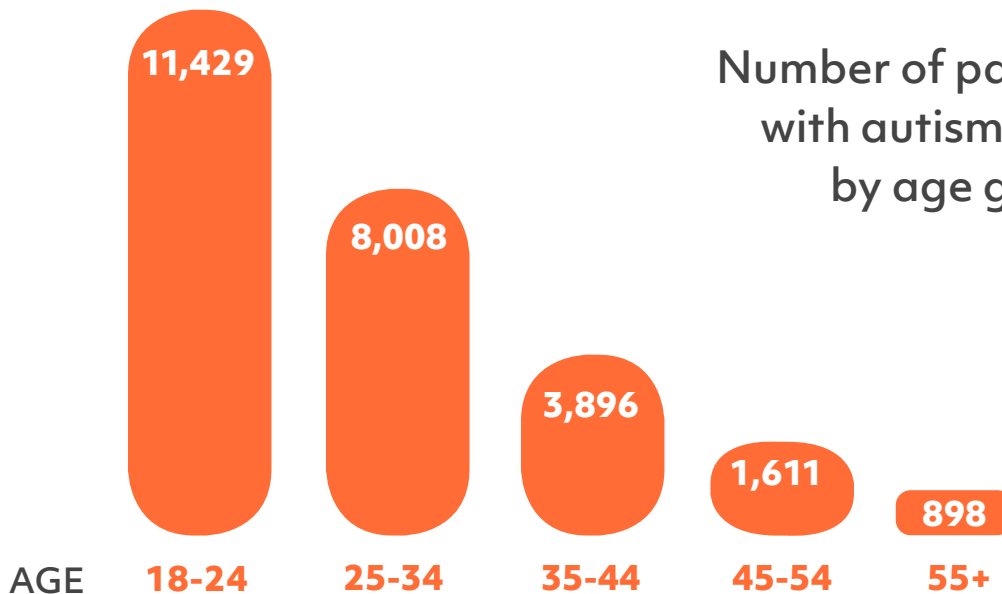
# Who Is Participating in SPARK?

## 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



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

# Diagnosis



Average Age  
When Boys  
Were Diagnosed

**4.3**



Average Age  
When Girls  
Were Diagnosed

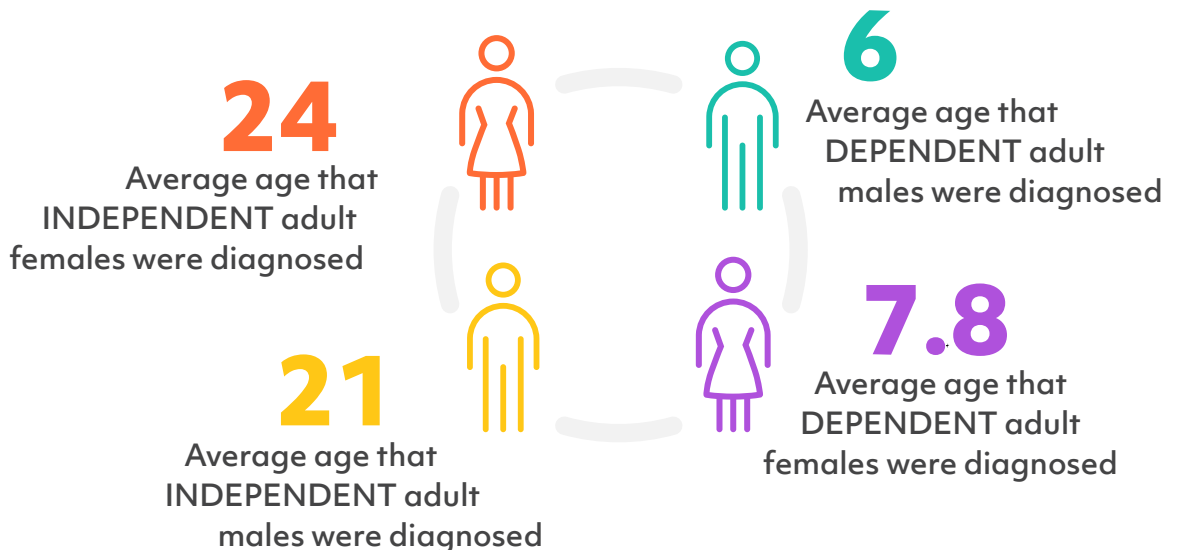
**4.8**

## Children Under 18

Boys and girls were diagnosed on average between ages 4 and 5.

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.

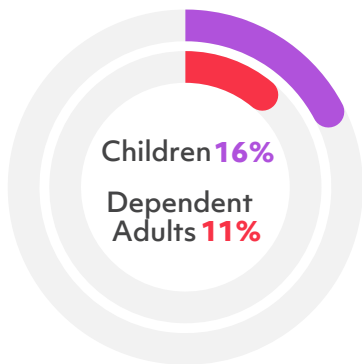
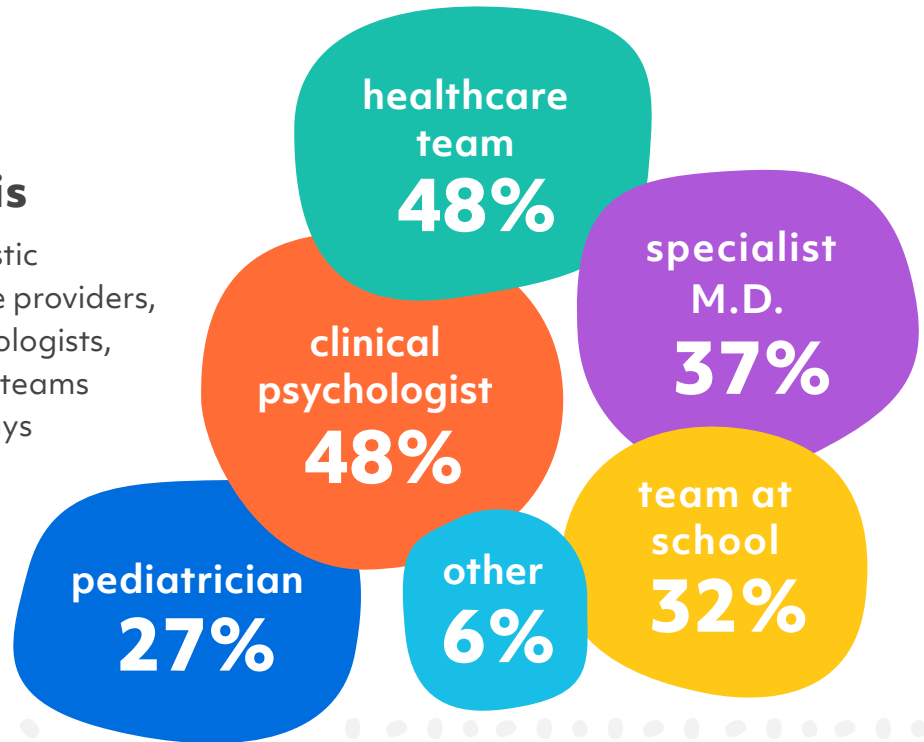
## Adults Over 18



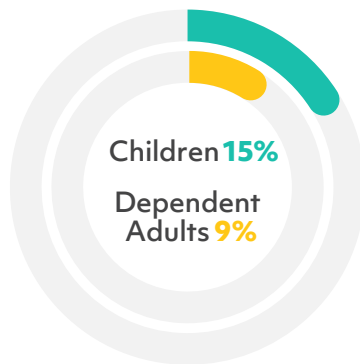
# Diagnosis

## Professionals Who Made the Diagnosis

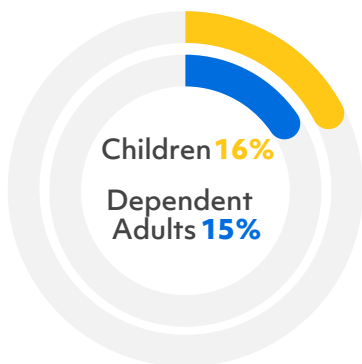
Families are receiving diagnostic evaluations from multiple care providers, most commonly clinical psychologists, medical specialists and entire teams of experts. The school also plays this role for many families.



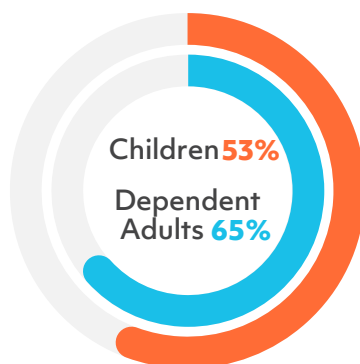
Do not speak



Are able to use single words to communicate



Use phrases



Use longer complex sentences

## Language

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

# Pregnancy, Birth History and Associated Conditions

Percent with Serious Pregnancy and Birth Complications

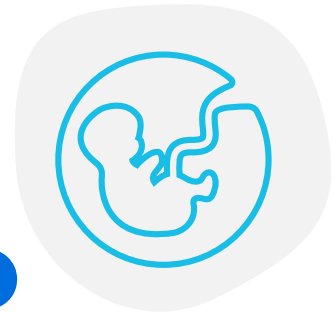
8%



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.

Percent Born Prematurely

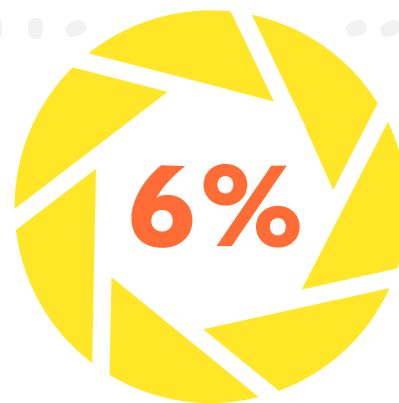
12%



Preterm birth has been associated with autism. Birth complications such as prematurity are known to increase the risk for developmental disability, and some research says it increases the risk for autism.

## 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.



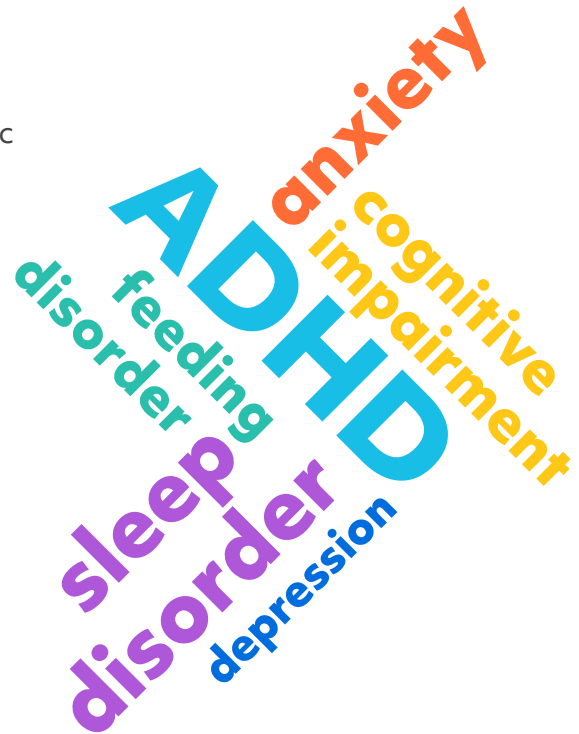
Percent of all SPARK participants with a seizure disorder

# Pregnancy, Birth History and Associated Conditions

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.

## Conditions Diagnosed in Children with Autism

- 36%** have ADHD
- 20%** have a sleep disorder
- 19%** have anxiety
- 17%** have cognitive impairment
- 16%** have a feeding disorder
- 7%** have depression



Autistic adults also struggle with depression and anxiety. Independent adults with autism report anxiety and depression at rates 2 and 3 times higher than the general population, respectively.



## Conditions Diagnosed in Dependent Autistic Adults

- 21%** have depression
- 35%** have anxiety disorder
- 40%** have ADHD

## Conditions Diagnosed in Independent Autistic Adults

- 59%** have depression
- 62%** have anxiety disorder
- 50%** have ADHD



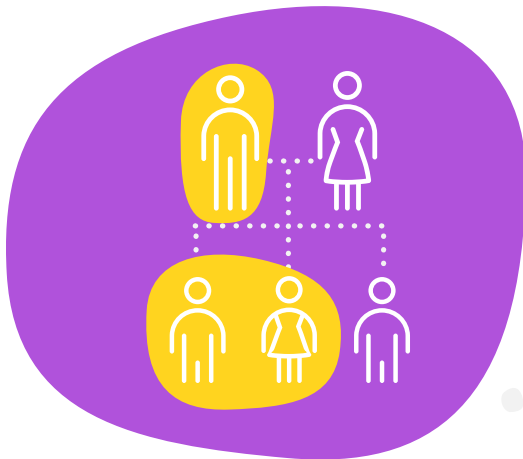
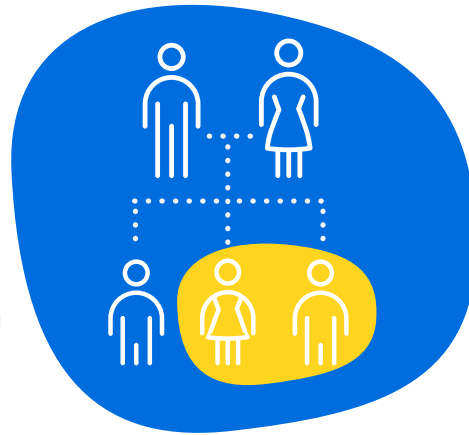
# Multiplex Families Enrolled in SPARK



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

18% 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



2% of families have **more than 1 child and at least 1 parent** with ASD enrolled in SPARK

4% 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 **1.8 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 **10%**  
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 **2%**



Late walking or other  
motor milestones

Children **12%**  
Dependent Adults **13%**



Something else

Children **12%**  
Dependent Adults **14%**



# Development

## Regression

- Dependent Adults



Percent who experienced a **regression in language abilities 32%**

Percent of those whose **language returned** after the regression **62%**

**Average age** of language regression **2.3 years**

## Other types of regression

- Dependent Adults



- Average age of non-language regression **3.7 years**
- Skills returned **32%**

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, 62% regained their skills, whereas only 32% 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

## Regression

- Children



Percent who experienced a regression in language abilities **32%**

Percent of those whose language returned after the regression **65%**

Average age of language regression **1.8 years**

## Other types of regression

- Children

Social skills  
**16%**

Play  
**11%**

Development  
**15%**

- Average age of non-language regression **2.9 years**
- Skills returned **33%**

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 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.

# Development

## Support Required for Dependent Adults

Minimal to no support **8%**

Some support **31%**

Substantial support **37%**

Very substantial support **24%**



