

# SPARK SNAPSHOT

Report 1  
Data from December 2015 - May 2017



Did you know that

18,089  
people  
with  
autism

are participating in SPARK?

## Welcome to the first **SPARK Snapshot**

— a window into the autism journey of SPARK participants. We've compiled these interesting findings from information that families have provided when SPARK began recruiting in December of 2015.



# Who Is Participating in SPARK?

## Children

Number of Children  
with Autism

**15,302**

## Adults

Number of Adults  
with Autism

**2,787**

Many more children with autism have enrolled in SPARK than adults with autism. We need more adults to participate to better understand autism throughout the lifespan.



### Ratio of Males to Females in Adults Over 18

The proportion of adult women with autism in SPARK is a little higher than expected given the usual male to female ratio, but it is lower than what's reported in other studies of autism in adults.



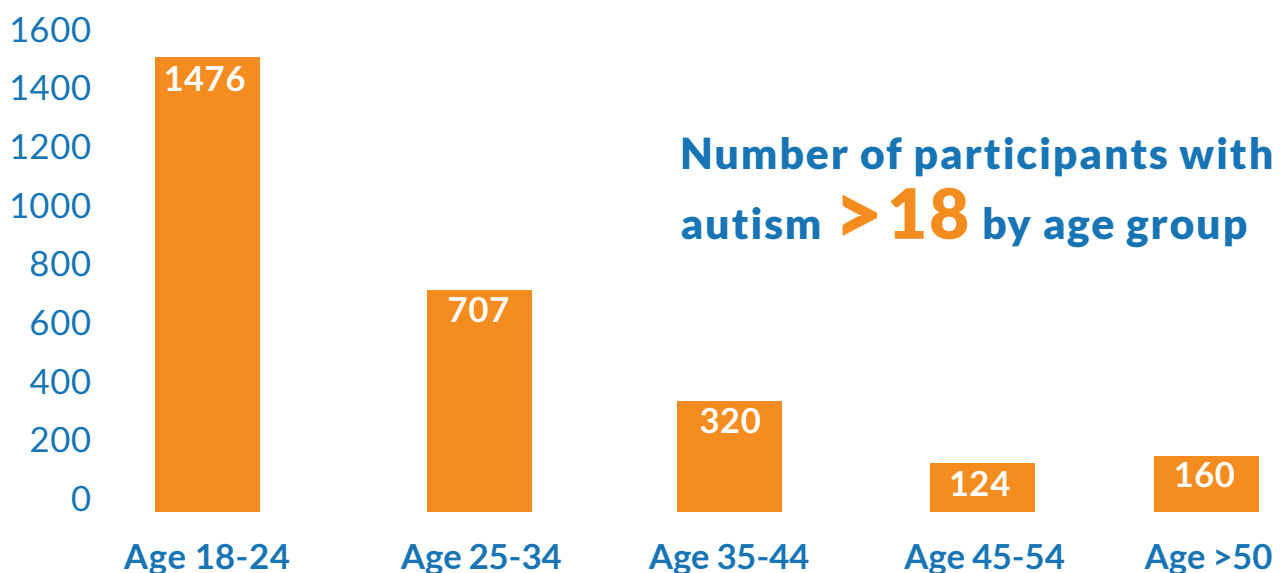
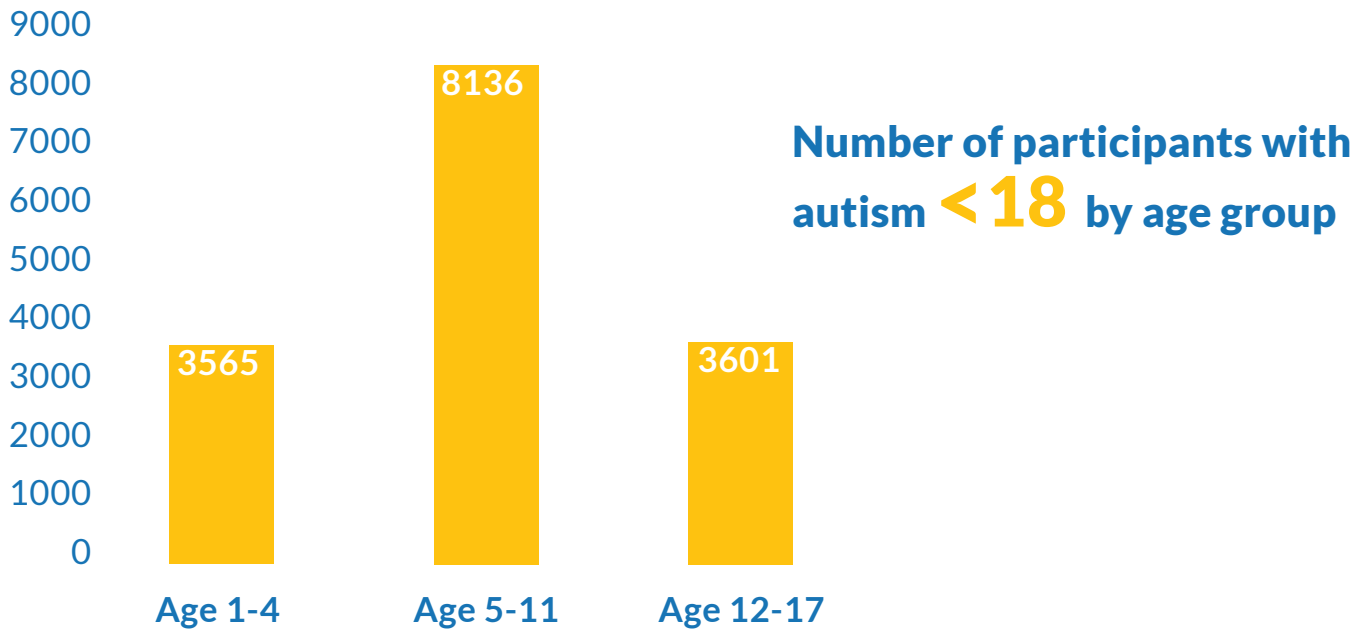
### Ratio of Males to Females in Children Under 18

Boys with autism outnumber girls 4 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.

# 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 70s. We also have babies with autism enrolled whom we can watch as they grow and change over time.





# Diagnosis

4.1

Average Age When  
Boys Were Diagnosed



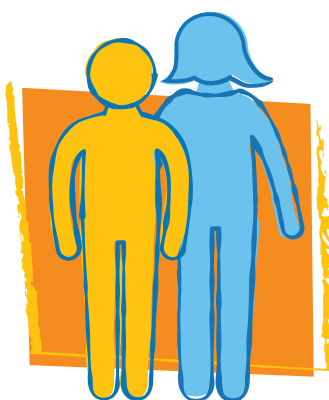
4.4

Average Age When  
Girls Were Diagnosed

Boys and girls were diagnosed on average between ages 4 and 4.5. On average, children enrolled in SPARK seem to have been diagnosed a little later than those in other autism studies. This may be because they are from a larger sample of the U.S.

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Average Age When  
Adult Males Were  
Diagnosed



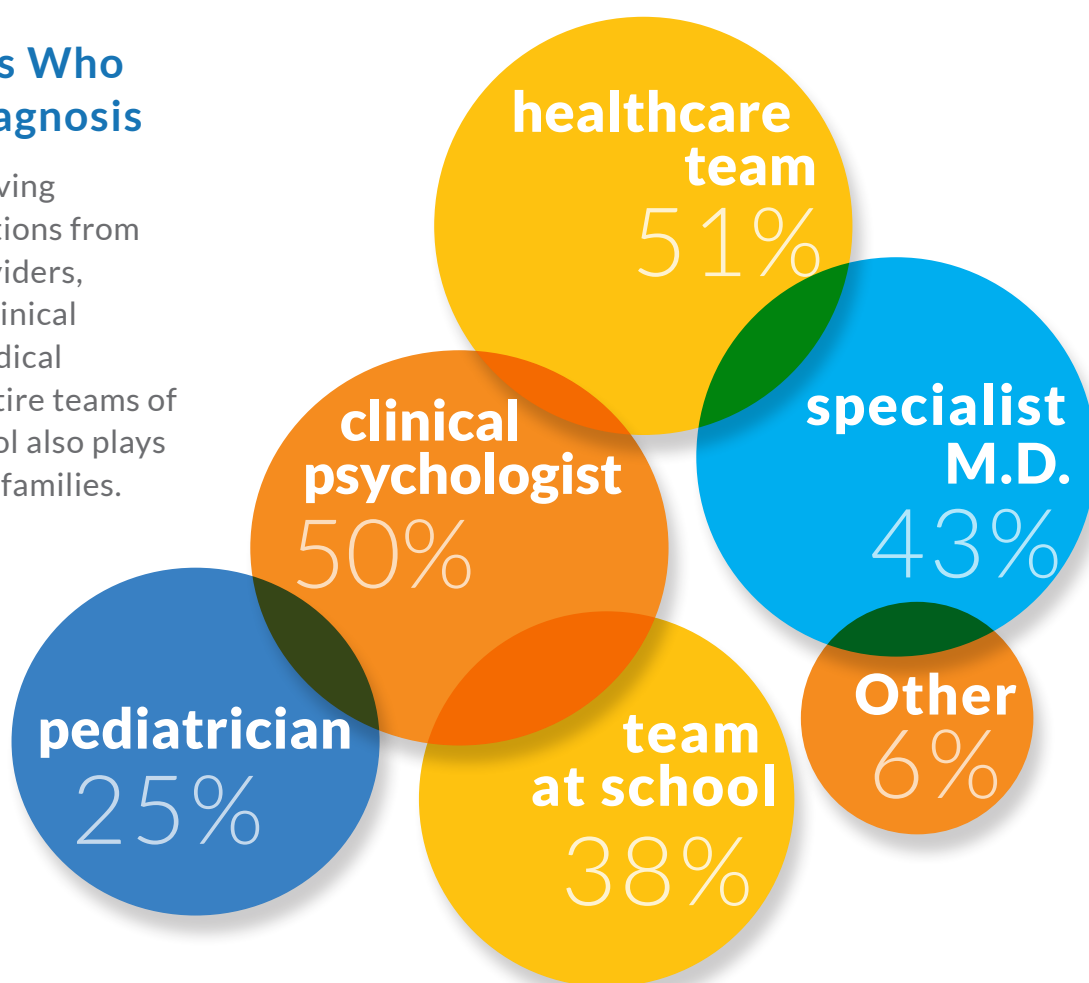
15.8

Average Age When  
Adult Females Were  
Diagnosed

People born before the year 2000 tended to receive diagnoses later in life than those who were born more recently. Some were not diagnosed until their 60s or 70s, likely reflecting increased recognition of autism in recent years.

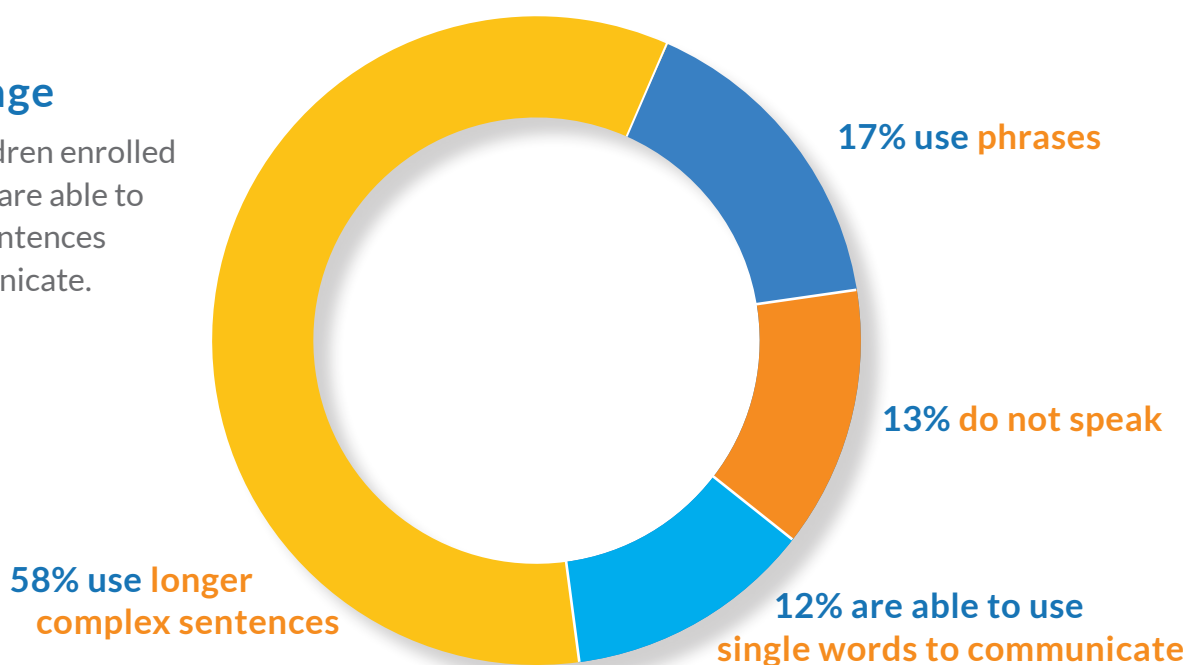
## Professionals Who Made the Diagnosis

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.



## Language

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





# Pregnancy, Birth History and Associated Conditions

## Percent with Birth Complications

7%



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%



Premature birth occurs slightly more often in babies who are later found to have autism than it does in other babies. Birth complications such as prematurity are known to increase the risk for developmental disability, and some research says it increases the risk for autism.

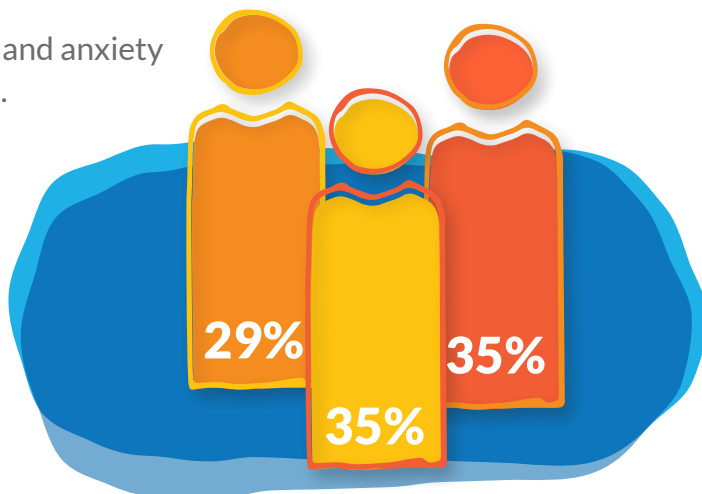
## Associated Conditions Reported by Adults with Autism

Adults with autism also struggle with depression and anxiety at nearly twice the rate of the general population.

**29% have a diagnosis of depression**

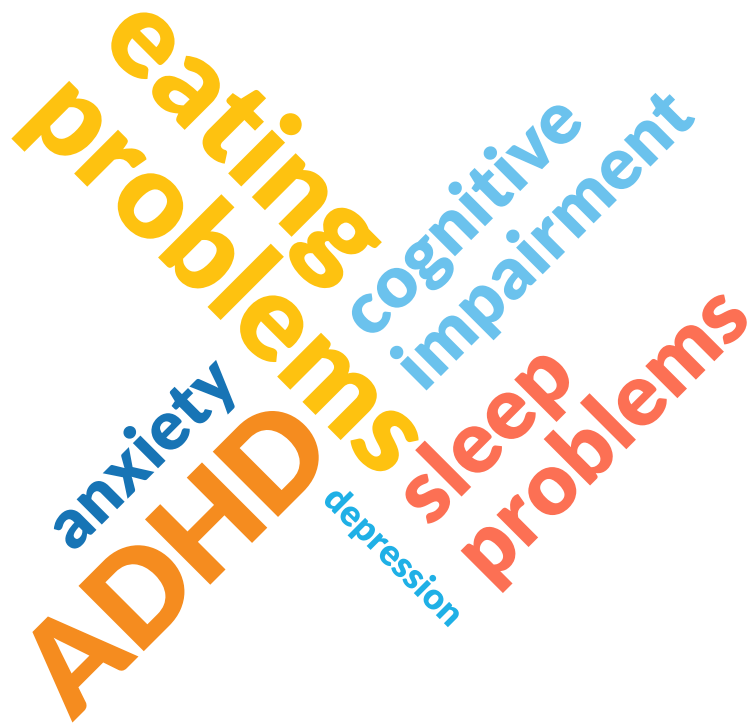
**35% have anxiety disorder**

**35% have ADHD**



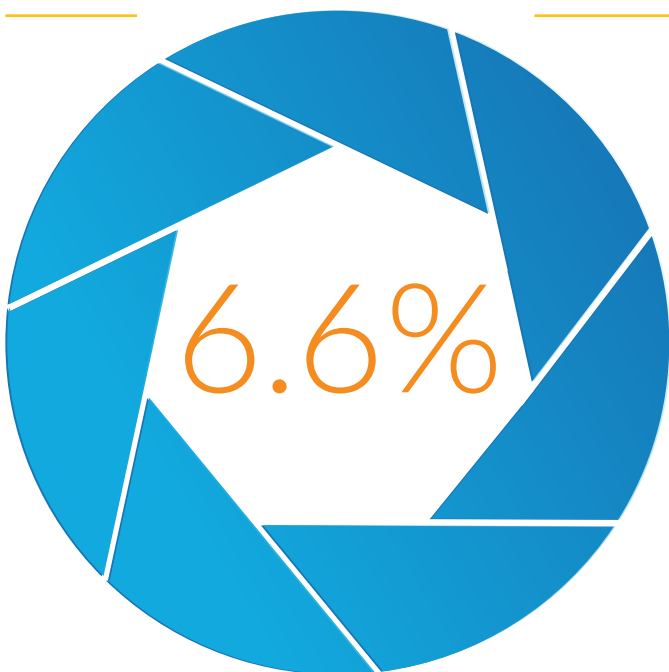
### Associated Conditions in Children with Autism

5% have a diagnosis of depression  
16.5% have anxiety  
32% have ADHD  
16% have cognitive impairment  
19% have sleep problems  
41% have eating problems



The rate of attention deficit (ADHD) in SPARK is 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.

About 1 in 5 parents reports that their child has problems with sleep, a proportion lower than expected. Twice that number report problems with eating.



### 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.



# Past Genetic Testing for Autism



1,917 - or - 16.6%

## How Many People Have Had Genetic Testing Related to Autism in the Past

Even though it is known that autism is strongly influenced by genetics, most families have not received genetic testing before.

## Most Common Genetic Findings Reported by Families in SPARK

A small number of families report they received a genetic diagnosis in the past that could explain their autism. The most common known genetic cause of autism, and the most common reported in SPARK, is Fragile X syndrome.

We still have much to learn about genetic causes, and SPARK offers the chance to increase our understanding.

- 88 Fragile X syndrome
- 31 15q11-q13 duplication
- 17 PTEN syndrome
- 16 DiGeorge syndrome
- 14 16p11.2 deletion syndrome
- 14 Noonan syndrome
- 12 Neurofibromatosis type 1
- 10 Phelan-McDermid syndrome
- 9 Williams syndrome
- 7 SCN2A

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**Thank you** to all of the participating families!  
Together, we can learn so much more.

