

SPARK SNAPSHOT



Report 1: UPDATED
Data from Dec 2015 - Jan 2019



Simons Powering Autism Research



Did you know that

59,179
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.

Who Is Participating in SPARK?

Children

Number of Children
with Autism

50,466

Adults

Number of Adults
with Autism

8,713

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.



2 to 1

Ratio of Males to Females
in Adults Over 18

The proportion of adult women with autism in SPARK is a little higher than expected, but it is lower than what's reported in other studies of autism in adults.



4 to 1

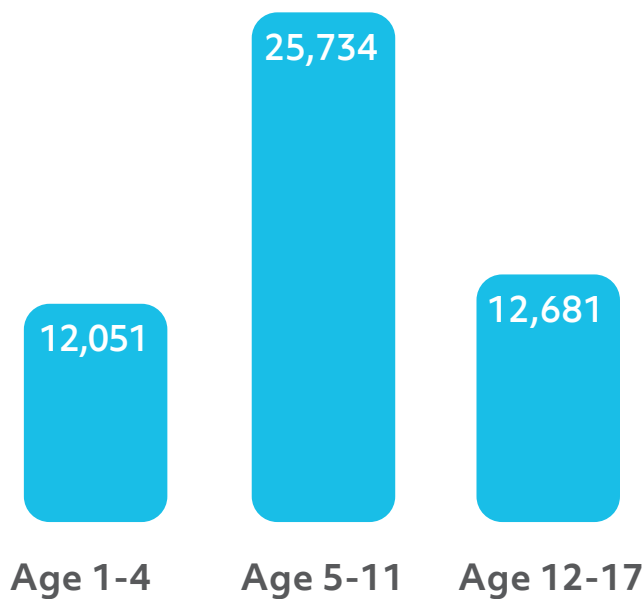
Ratio of Males to Females
in Children Under 18

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.

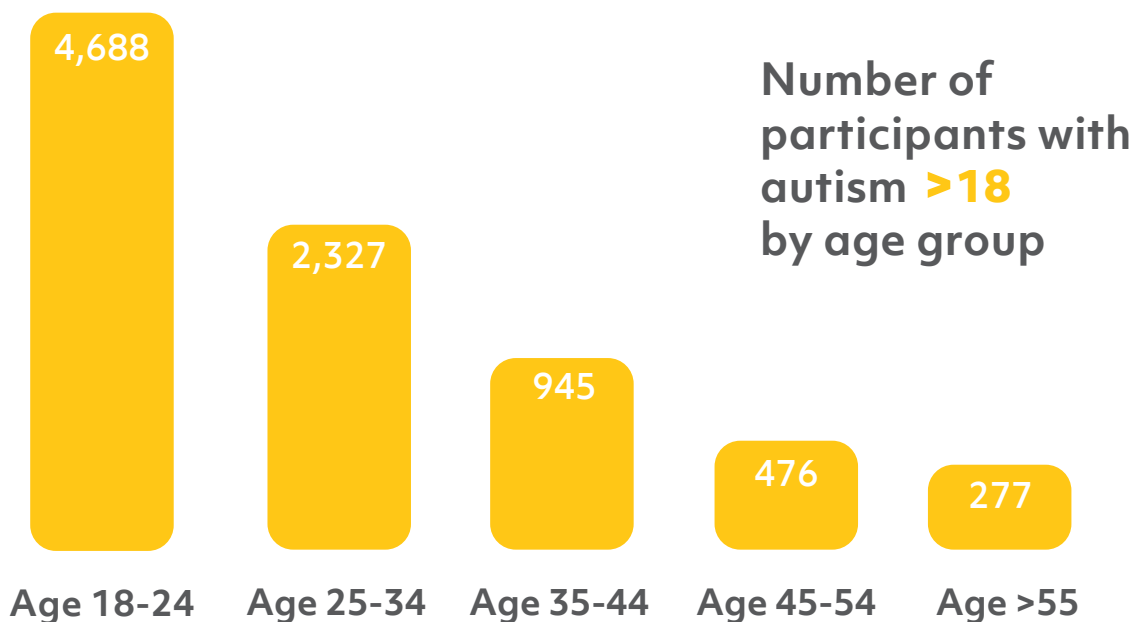
Who Is Participating in SPARK?

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 <18 by age group



Number of participants with autism >18 by age group

Diagnosis



Average Age
When Boys
Were Diagnosed

4.2



Average Age
When Girls
Were Diagnosed

4.5

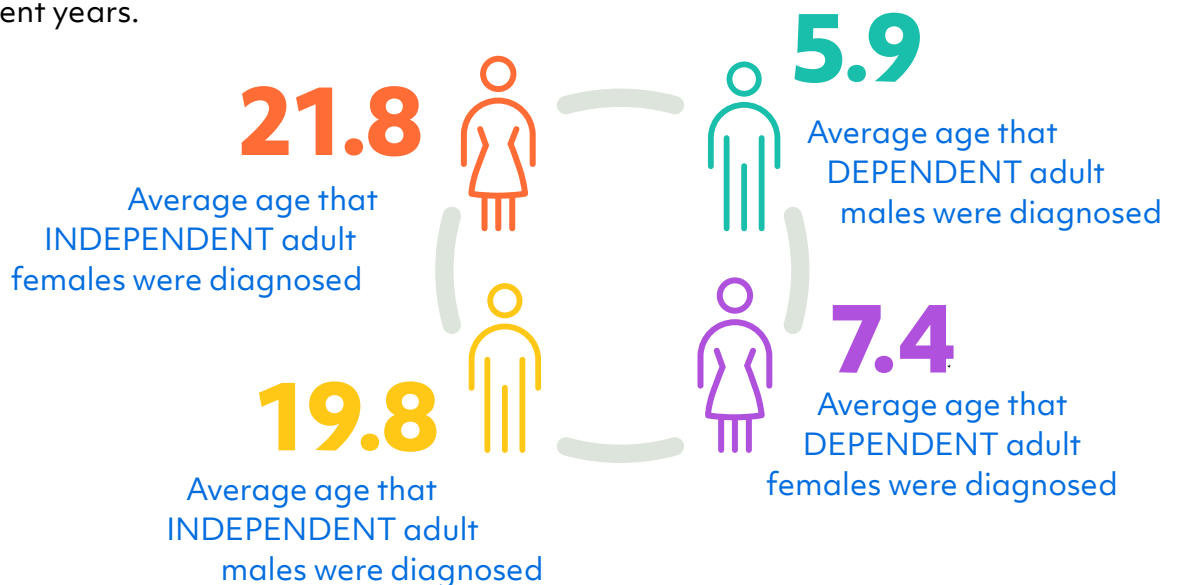
Children Under 18

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.



Independent adults with autism were diagnosed later than dependent adults with autism. Some adults were not diagnosed until their 60s or 70s, likely reflecting increased recognition of autism in recent years.

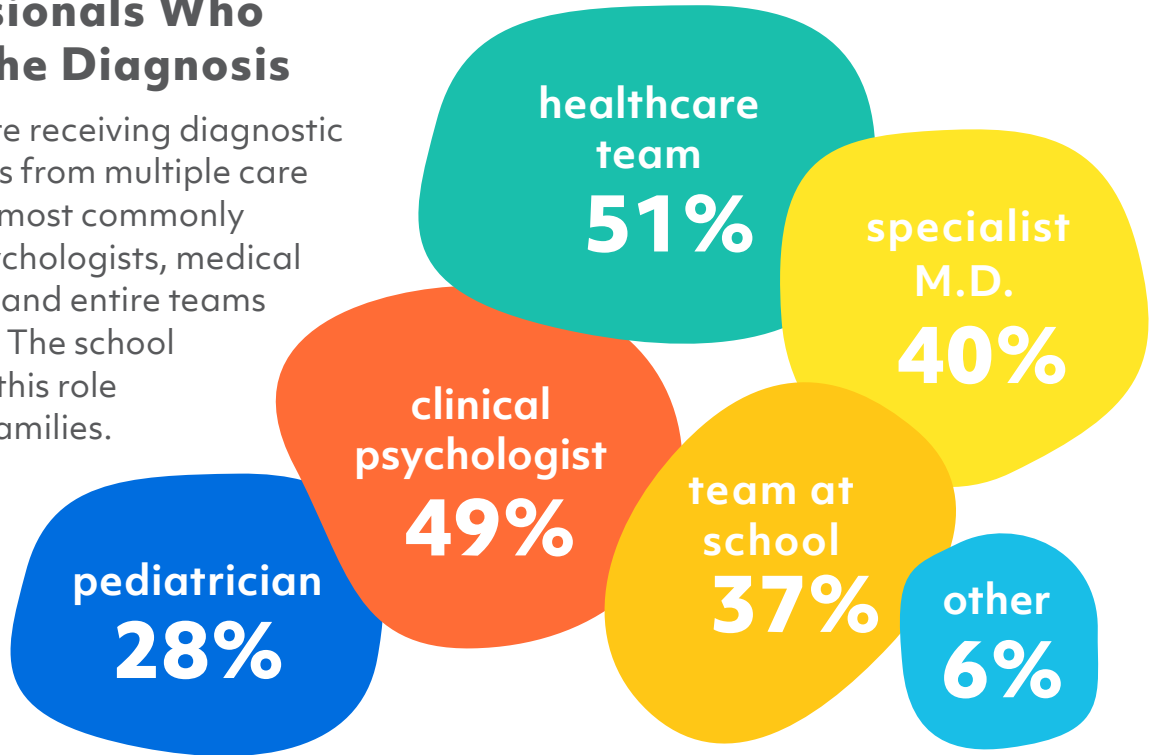
Adults Over 18



Diagnosis

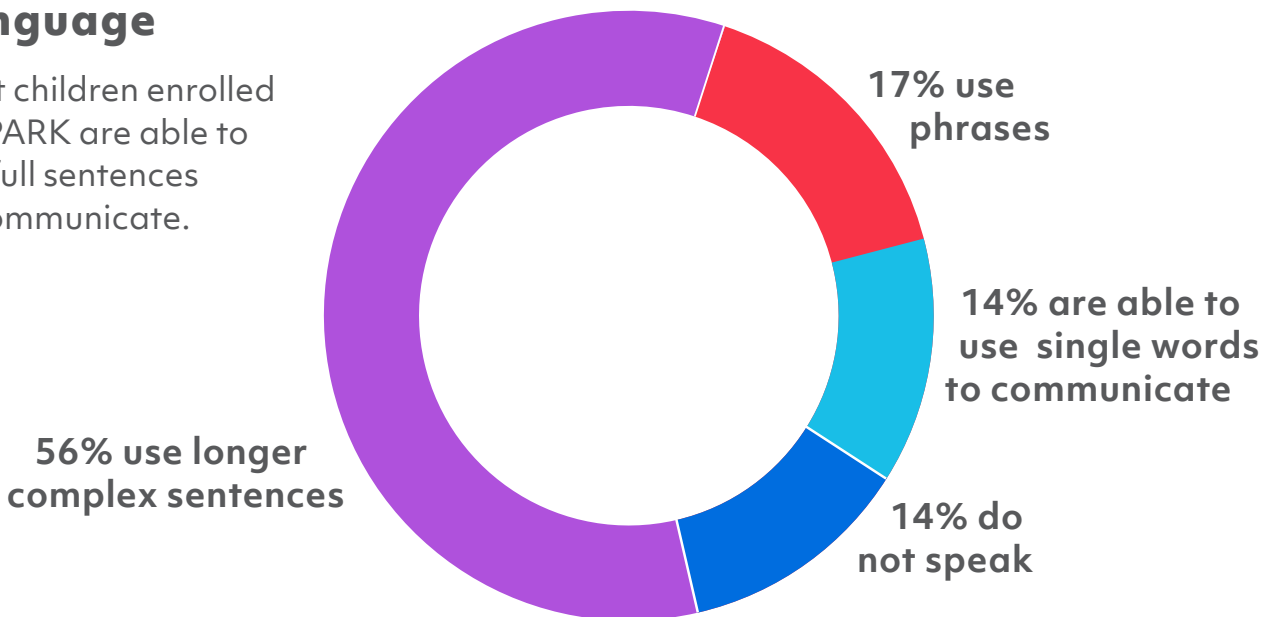
Professionals Who Made the Diagnosis

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.



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.



Adults with autism also struggle with depression and anxiety. Independent adults with autism report depression and anxiety at over three times the rate of the general population.



Associated conditions reported by **Dependent Adults with ASD**

20% have a diagnosis of depression

33% anxiety disorder

40% ADHD

Associated conditions reported by **Independent Adults with ASD**

49% have a diagnosis of depression

39% anxiety disorder

40% ADHD

Pregnancy, Birth History and Associated Conditions

eating problems
anxiety
ADHD
depression
cognitive impairment
sleep problems

Associated Conditions in Children with Autism

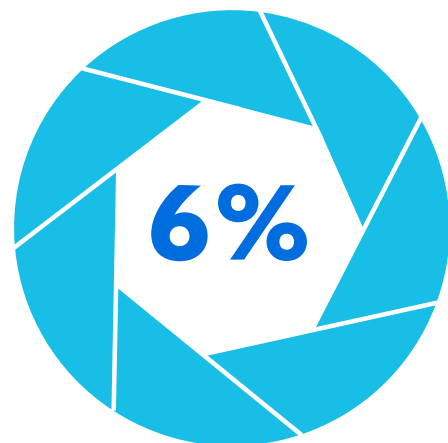
- 5%** have a diagnosis of depression
- 18%** have anxiety
- 36%** have ADHD
- 14%** have cognitive impairment
- 59%** have sleep problems
- 58%** have eating problems

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.

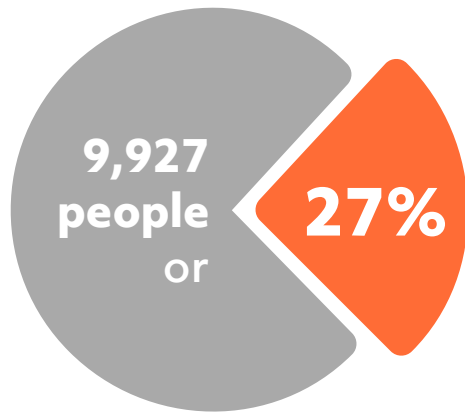
Over half of parents report that their child has problems with sleep and eating.

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



People Who 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.



Number of People	Genetic Diagnosis
207	Fragile X
77	15q11-q13 duplication
46	22q11 deletion
41	PTEN
36	7q11.23 deletion
30	Rett syndrome (MECP2)
30	22q13 deletion
28	15q deletion
17	NF1
27	Angelman syndrome
17	16p11.2 deletion
17	ADNP
15	Noonan syndrome
10	SCN2A
10	1p16.3 deletion
10	1q21.1 duplication



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