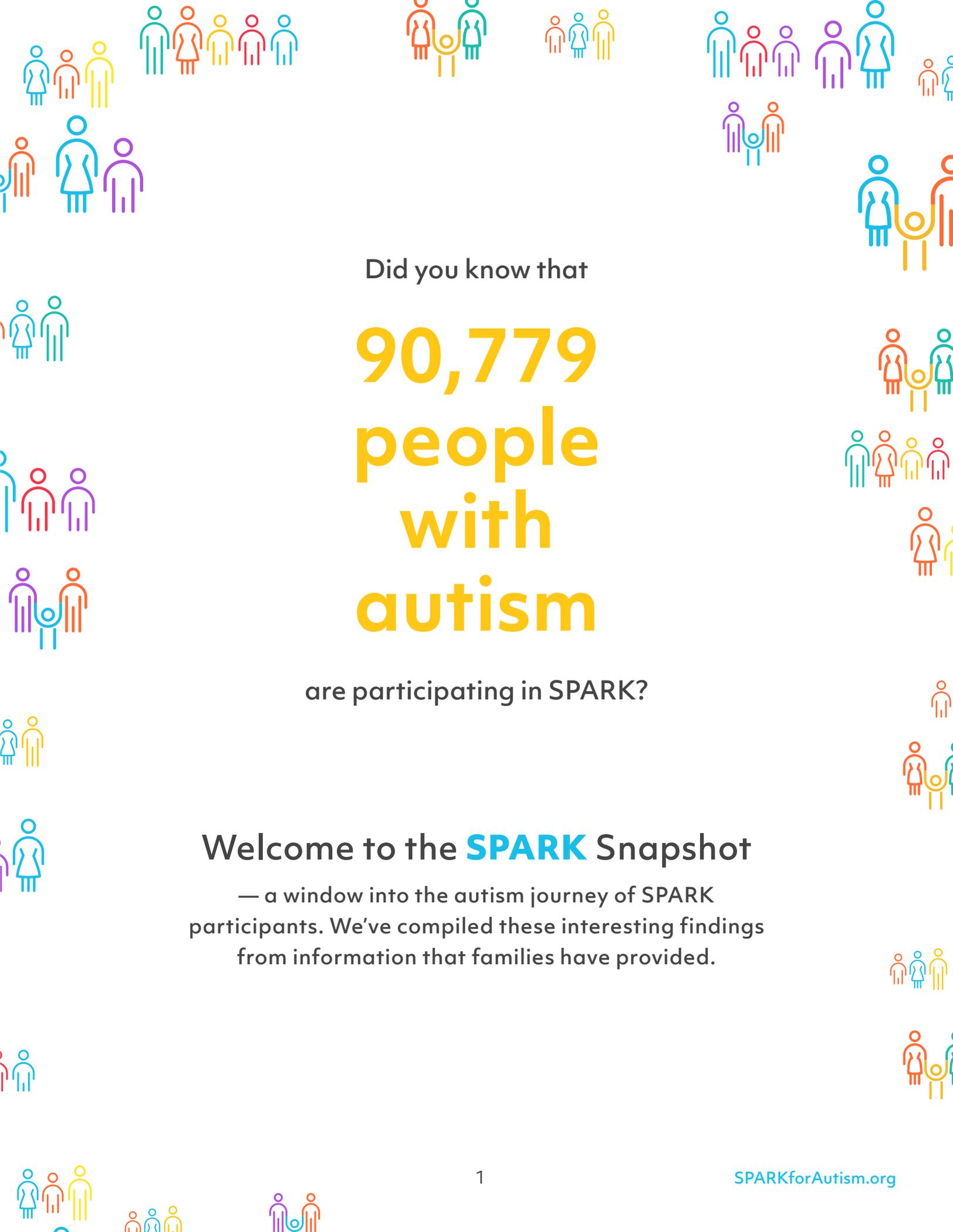


SPARK SNAPSHOT

Report 1: UPDATED | Data from Dec 2015 - Apr 2020



Simons Powering Autism Research



Did you know that

90,779
people
with
autism

are participating in SPARK?

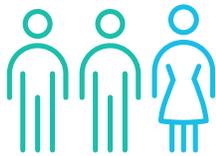
Welcome to the **SPARK** Snapshot

— 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

Adults



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

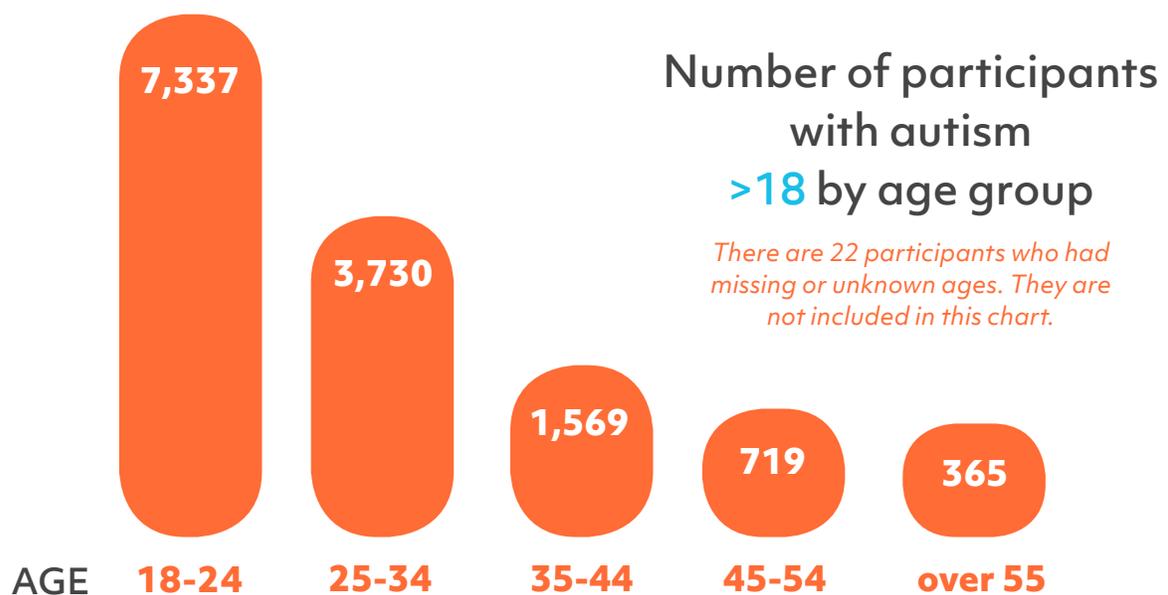
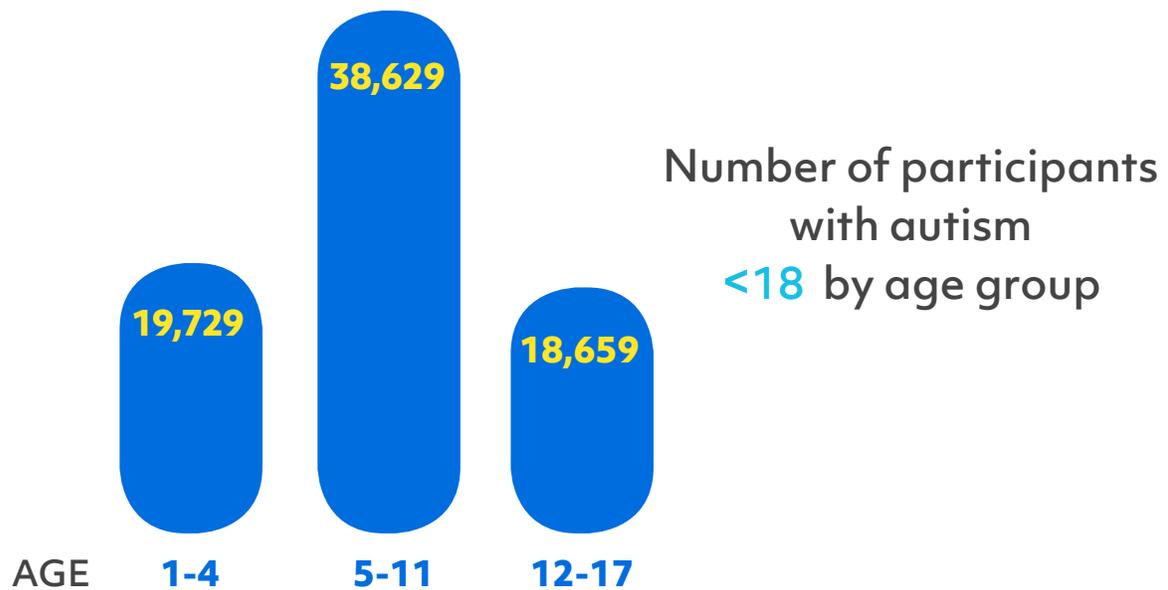
Ratio of Males to Females
in Children Under 18

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.



Diagnosis



Average Age
When Boys
Were Diagnosed

4.2



Average Age
When Girls
Were Diagnosed

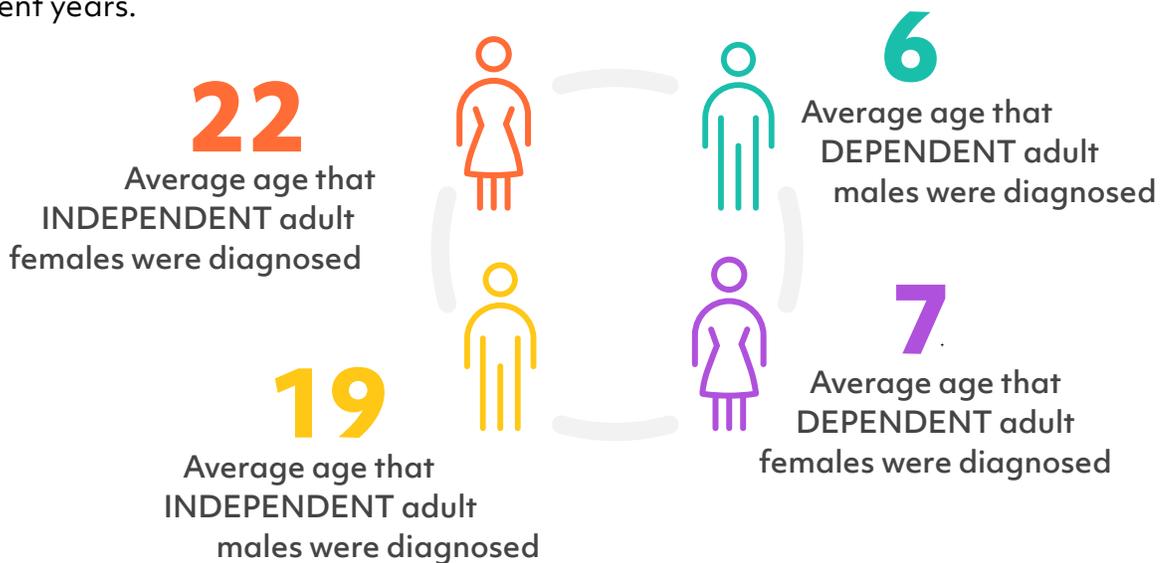
4.5

Children Under 18

Boys and girls were diagnosed on average between ages 4 and 4.5.

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.

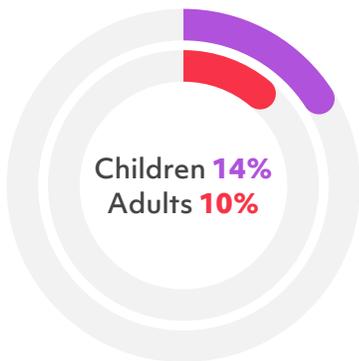
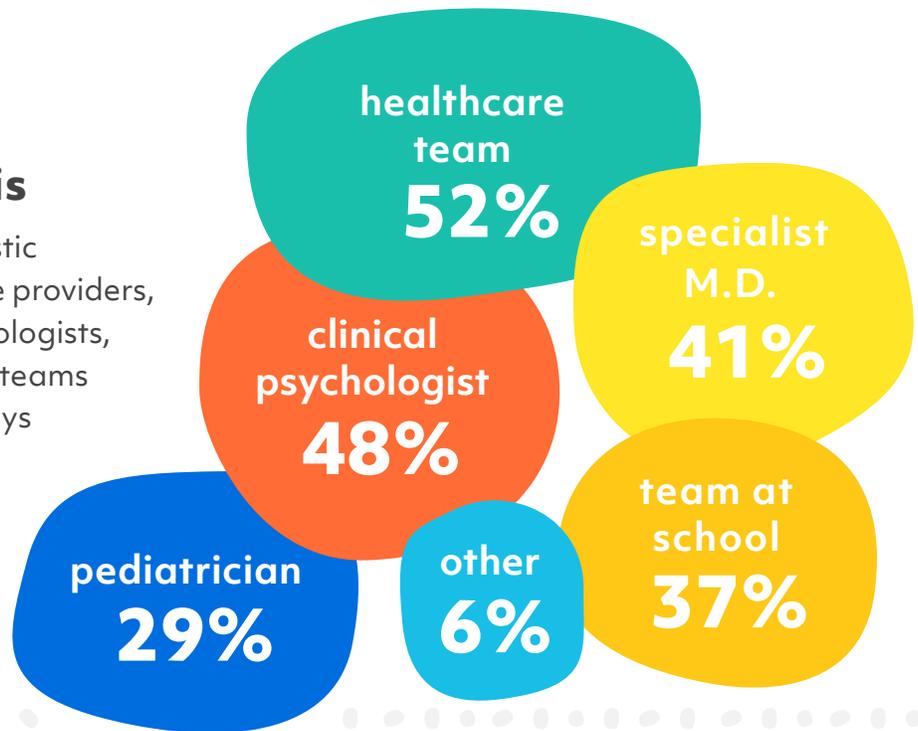
Adults Over 18



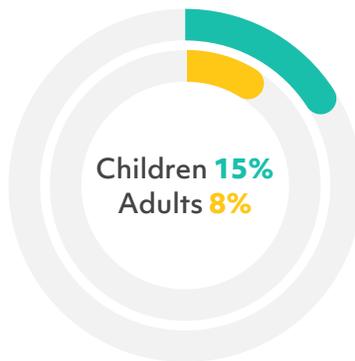
Diagnosis

Professionals Who Made the Diagnosis

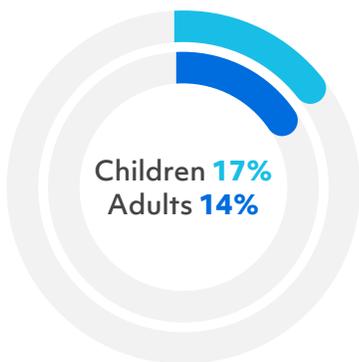
Families are receiving diagnostic evaluations from multiple care providers, most commonly clinical psychologists, medical specialists and entire teams of experts. The school also plays this role for many families.



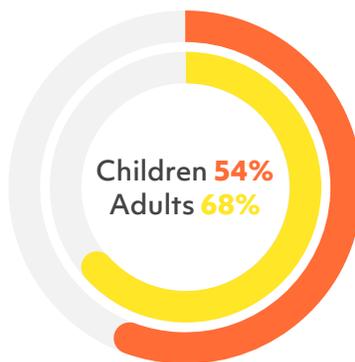
Do not speak



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 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.

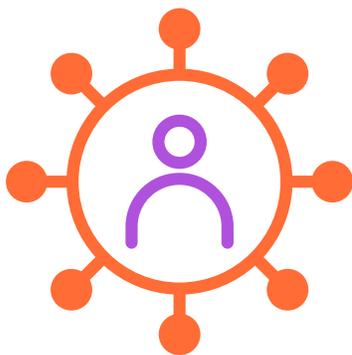
Percent Born Prematurely

12%



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

21% have a diagnosis of depression

34% anxiety disorder

40% ADHD

Associated conditions reported by Independent Adults with ASD

51% have a diagnosis of depression

52% anxiety disorder

43% ADHD

Pregnancy, Birth History and Associated Conditions

eating problems
anxiety
ADHD
depression
cognitive impairment
sleep problems

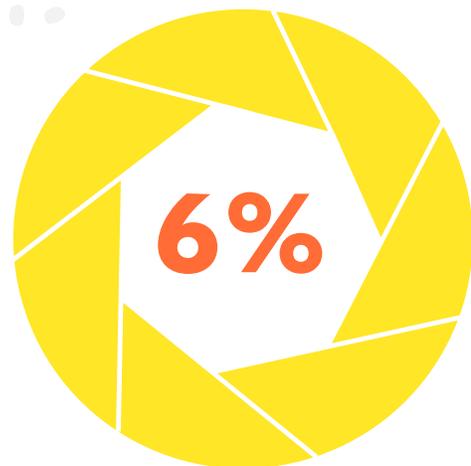
Associated Conditions in Children with Autism

- 7% have a diagnosis of depression
- 18% have anxiety
- 39% have sleep problems
- 41% have eating problems
- 36% have ADHD
- 16% have cognitive impairment

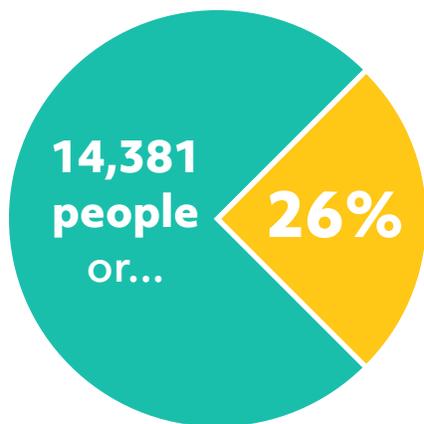
The rate of attention deficit (ADHD) in SPARK is over 3 times higher than it is in the general population. Diagnoses of conditions like ADHD and anxiety may rise now that the new diagnostic system used by doctors encourages all other conditions to be documented.

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
344	Fragile X
123	15q duplication
88	PTEN
66	22q11 deletion
65	7q11.23 deletion
62	22q13 deletion
57	Rett syndrome (MECP2)
44	NF1
41	Angelman syndrome
39	15q deletion
26	Noonan syndrome
24	16p11.2 deletion
20	ADNP
20	16p11.2 duplication
17	1q21.1 duplication
14	2p16.3 deletion
13	22q11 duplication
12	SCN2A

Development Milestones



Average age of first words
Children **1.7 years**
Dependent Adults **4.3 years**



Average age of first steps
Children **1.2 years**
Dependent Adults **1.4 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%**



Something else
Children **12%**
Dependent Adults **14%**



Late walking or other
motor milestones

Children **11%**
Dependent Adults **12%**



Mood or temperament
Children **9%**
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 **3%**



Development

Regression

- Dependent Adults



Percent who experienced a regression in language abilities **30%**

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 **3.6 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 **1.9 years**

Other types of regression

- Children



- Average age of non-language regression **2.9 years**
- Skills returned **34%**

The percentages shown are from the caregivers who responded to SPARK's Background History Survey. Of the children, 17% 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 34% 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 **9%**

Some support **32%**

Substantial support **34%**

Very substantial support **25%**





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