



Autism First Concerns

Family concerns and the path to diagnosis

Early recognition and response to first concerns about autism may help children receive targeted autism interventions in a timely manner. Early interventions for autism can have a positive effect on joint attention, expressive language, parent-child interaction, and cognitive and adaptive functioning.¹ Unfortunately, there are no

biological tests to tell us if a child is not developing as expected, and early signs of autism can sometimes go undetected.

This factsheet presents data from the Survey of Pathways to Diagnosis and Services (referred to as “Pathways”) conducted by the National Center for Health Statistics,

Centers for Disease Control and Prevention (CDC) in 2011.² This survey was given to families with children between the ages of 6 and 17 who reported the child had autism when they participated in a previous national survey. Read more about the Pathways survey in our “About the data” factsheet on autism.

When do parents first experience concerns about their child’s development?

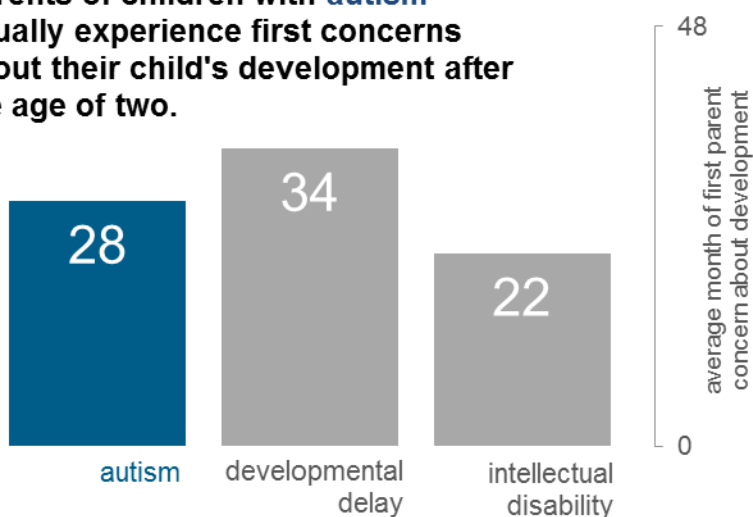
The majority of parents of children with autism recognize concerns about their child’s development before the age of two years.^{3,4} Parents of children who are diagnosed by the age of three are typically concerned by 18 months.⁵

However, in the Pathways data, the average age of first concerns about a child’s development in parents of children with autism was

28 months.

Parents of children with autism experienced first developmental concerns earlier than parents of children with developmental delays. First concerns about children’s development emerged earlier for parents of children with intellectual disabilities who are sometimes concerned from birth. Concerns in the autism group surfaced between one to four years. This is the age where delays in communication, social, and behavioral skills might be more easily noticed.

Parents of children with autism usually experience first concerns about their child’s development after the age of two.

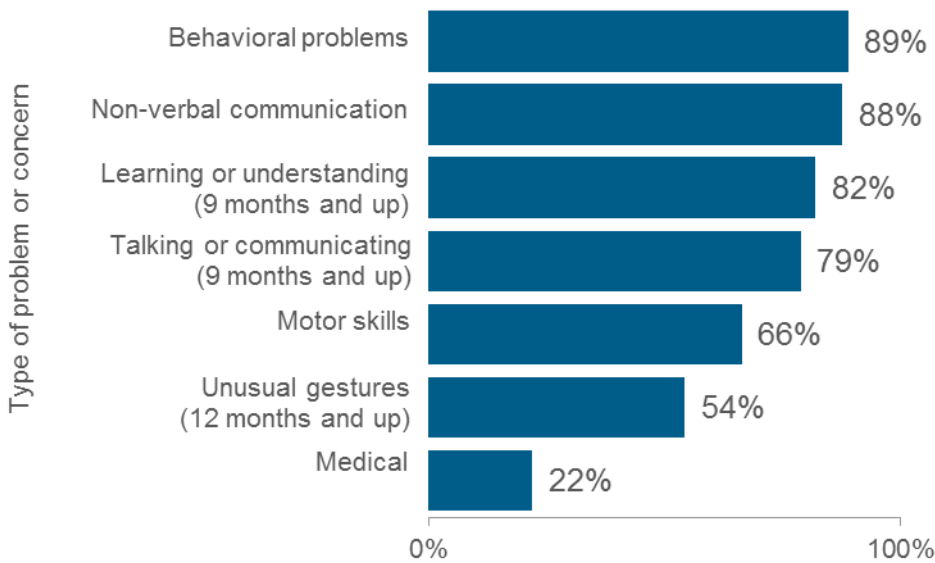


Parents may have recognized first concerns later in this study because, when asked about events from years prior, people may remember them as happening more recently than they did. This is called a telescoping effect.



What types of first concerns do parents experience?

Communication and behavior problems were the most common first concerns.



First concerns about children's behavior, non-verbal communication, learning and understanding were most common. Concerns related to receptive and expressive communication tended to emerge after the child was 9-12 months of age.

Behavioral problems included difficulty playing with others or with handling changes, or issues with sleeping or eating, wandering, aggression, or tantrums. Medical concerns included seizures, lack of physical growth, or stomach problems.

73% of parents reported noticing four or more of these types of first concerns.

Types of parent first concerns vary by the child's age.

A parent who notices concerns when their child is less than 9 months will likely have different concerns than a parent who first notices concerns when their child is 12 months or older.



Concerns at or before

9 months

Didn't make eye contact when talking or playing with others (82%).

Didn't seem to understand nonverbal communication, such as understanding what you meant by the tone of voice you used or your facial expressions (73%).

Concerns between
10-12 months

Didn't respond when called or didn't respond to sounds (79%).

Did not talk as well as other children that were the same age (78%).

Talked later than usual for most children (76%).

Concerns after
12 months

Had difficulty playing or interacting with others, or played along in his own world (88%).

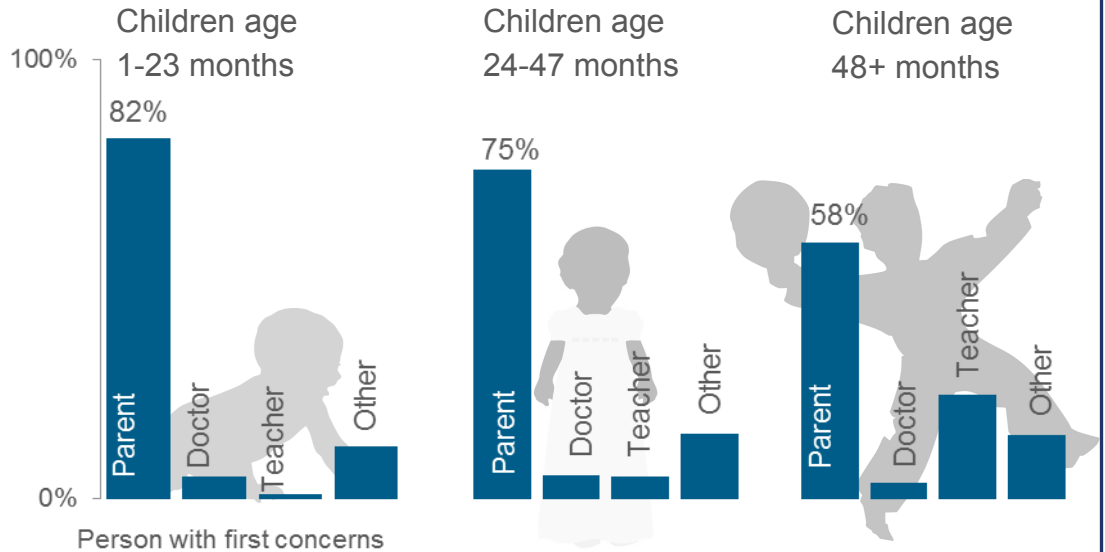
Insisted on sameness or had difficulty with change (79%).

Did not talk as well as other children that were the same age (72%).

Who had the first concerns about the child's development?

Different people are more likely to notice concerns about a child's development at different ages. During the first four years, **parents** often note concerns first. **Teachers**, school counselors, nurses, or others are more likely to notice first concerns once children are over age four. **Doctors** and other health care professionals are typically not the ones to express concerns first at any age.

Across ages, parents were usually the first to be concerned about a child's development. Once more children began to enter school, teachers were increasingly among those to voice first concerns.



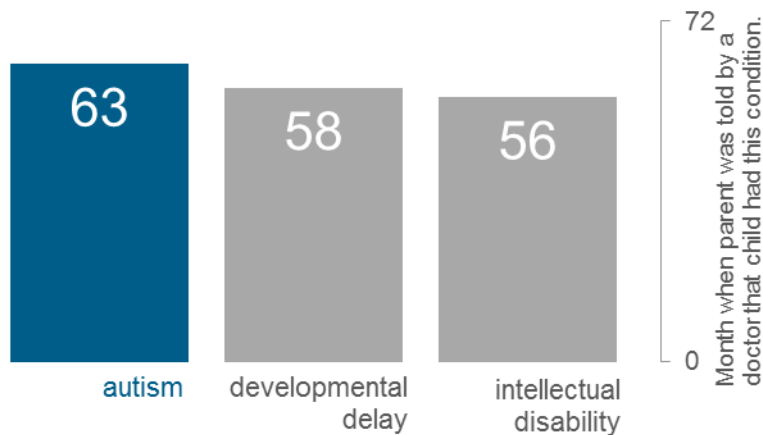
In the Pathways data, parents reported that the average age of diagnosis of autism by a health care professional was....

63 months.

This means that there was nearly a three year gap between the average age of first concerns (28 months) and the average age of autism diagnosis. Closing the gap between how early a child *can* be diagnosed with autism, and when they *are* actually diagnosed, is a vital concern for improving outcomes and quality of life.

Autism diagnosis usually occurs after the age of five.

Parents of children with autism were usually not told until after five years that their child has autism.

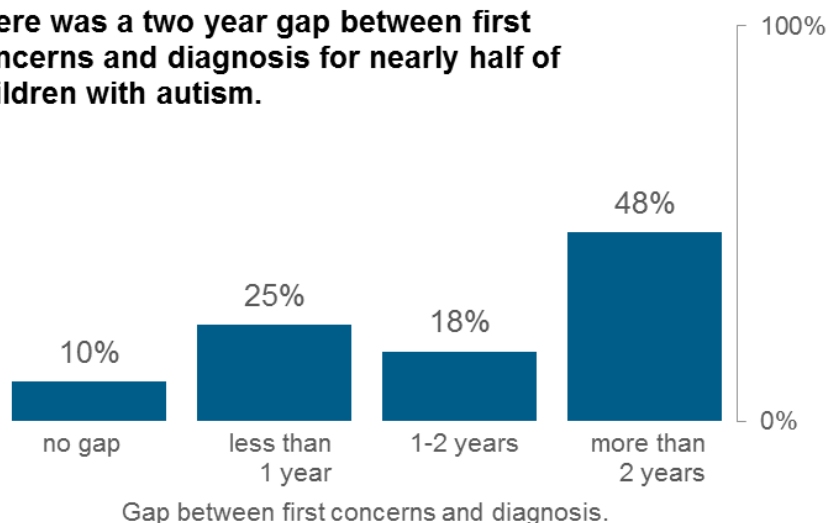


Diagnosis is happening earlier over time. The average age of diagnosis of children who were ages 6-11 when Pathways was conducted in 2011 was 53 months, compared to 74 months for those who were 12-17 years at the time of the survey

Note: The CDC reports a slightly different estimate for age of diagnosis than is reported above, due to differing research and analysis methods. The CDC reported the median age of diagnosis of eight year old children in 2010 as 53 months.⁶

The gap between first concerns and diagnosis is lengthy for many.

There was a two year gap between first concerns and diagnosis for nearly half of children with autism.



Screening for autism

The American Academy of Pediatrics recommends routine screening for autism and developmental delays at 18 and 24 months. Recent workgroups of practitioners and researchers reaffirmed the value of this practice guideline.^{9,10} However, only 45% of parents in the Pathways survey reported that their child received autism screening in the form of a questionnaire that asked about specific concerns regarding the child's development, communication, or social behaviors.

Autism can be reliably identified as early as age two,⁷ but is often not diagnosed until later, particularly among children from lower-income households, who were non-White, and whose parents had less education.⁸ The Centers for Disease Control and Prevention's Learn the Signs—Act Early campaign aims to help parents and professionals recognize and respond to first concerns about autism as soon as possible.

Sources:

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The Life Course Outcomes Research Program is building a base of knowledge about the things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.