

# National Autism Data Center Fact Sheet Series

April 2016; Issue 8



Life Course Outcomes  
Research Program



## First encounters with a health care provider

### What were the early experiences between parents of children with autism and health care providers?

Health care providers play a critical role in early recognition of developmental concerns. The American Academy of Pediatrics (AAP) recommends that all children be screened for autism at ages 18 and 24 months along with ongoing developmental surveillance.<sup>1</sup> The most recent data from Healthy People 2020 indicates that about 38% of children receive a developmental and autism

screening between 10-35 months of age (using data from the 2011-2012 National Survey of Children's Health).<sup>2</sup>

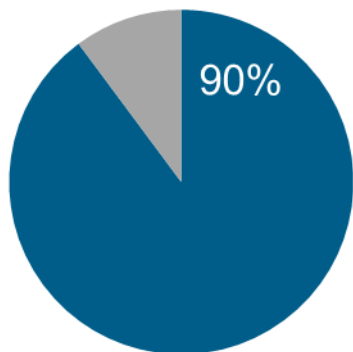
This factsheet presents data from the Survey of Pathways to Diagnosis and Services (referred to as "Pathways") conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC) in 2011.<sup>3</sup> This survey was given to

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.

We explore parent experiences with screening, professional responses to parent concerns, and diagnosis of autism.

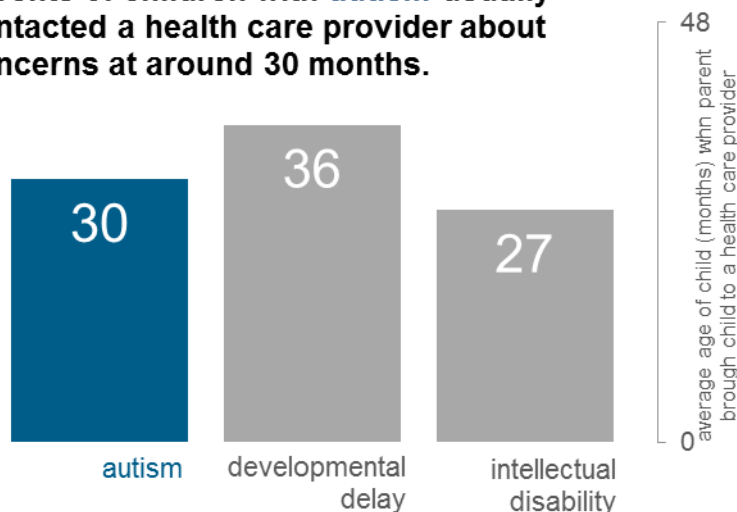
### Contacting a health care provider

Most parents contacted a health care provider with concerns about their child's development.



of parents of children with autism ever contacted a health care provider about their concerns with their child's development.

Parents of children with autism usually contacted a health care provider about concerns at around 30 months.



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## Race and ethnicity and income matters

The way parents act on their concerns about their child's development may vary based on race-ethnicity and income, possibly related to mistrust of the health care system and access to care. About 77% of parents of Hispanic children report contacting a health care provider about their concerns compared to 92% of parents of

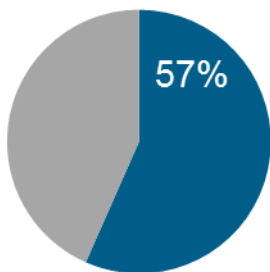
White children, 89% of parents of Black children, and 93% of parents of children of another race. However, about 98% of parents from lower income households (below 100% of the federal poverty level) contacted a health care provider compared to 86%-90% of parents from higher income households. Level of parent

education and sex of the child were not associated with whether parents contacted a health care provider. Most parents contacted their health care provider about their developmental concerns when their child was around 30 months, regardless of race, income, or other factors.

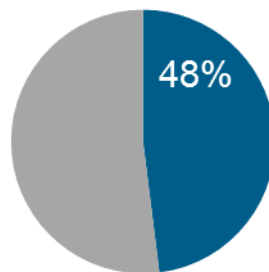
## How health care providers respond to parent concerns

**When parents expressed concerns about their child's development, the most common response by health care providers was to refer the child to a specialist.**

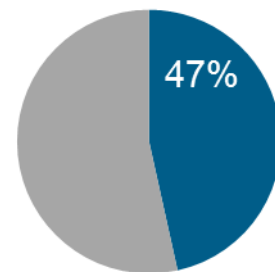
**Made a referral to a specialist.**



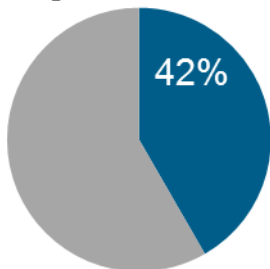
**Said that the child might grow out of it.**



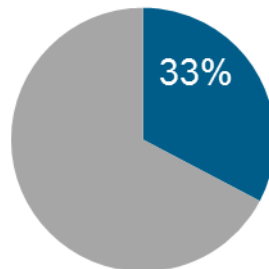
**Conducted a developmental screening.**



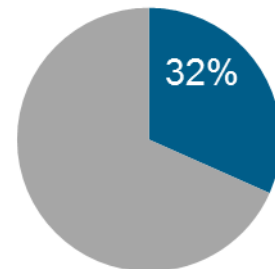
**Said it was too early to tell if anything was wrong.**



**Said nothing was wrong, the behavior was normal.**



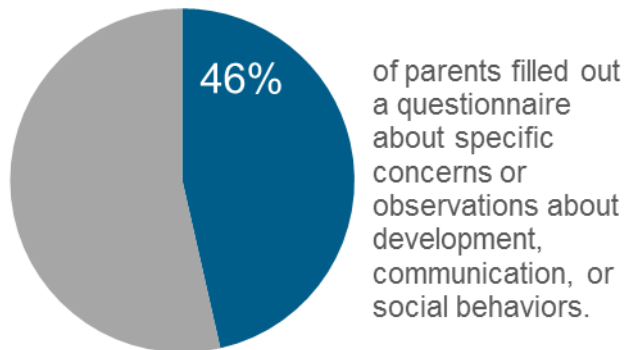
**Suggest discussing concerns with the school.**



Nearly 60% of parents said the health care provider referred them to a specialist. Yet, almost half of parents were told their child might grow out of the concerns, and almost half were not screened despite parental concerns. 13% of health care providers responded to concerns with one of these responses, 27% responded with two, and 60% responded with three or more. Parents were asked, "how did this doctor or health care provider respond to your concern?"

## Use of standardized screening tools

**Almost half of parents were asked by a doctor to fill out a developmental screening questionnaire.**



## Screening

Although screening has been recommended by the AAP for many years, recent discussion of screening practices highlights the need for more definitive research to confirm the effectiveness of autism screening.<sup>6</sup> Researchers in the field responded to these concerns by affirming the AAP's guidelines and offering research to back up the importance of routine screening.<sup>7</sup> Many tools exist to screen for autism in children as young as 12 months. Other screening measures exist for older children and adults for autism, including the Autism Screening Questionnaire (ASQ) and the Social Responsiveness Scales (SRS).

There are several tools commonly used to screen for autism. The most common is the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F), a parent questionnaire suggested for use in toddlers that are supported by research.

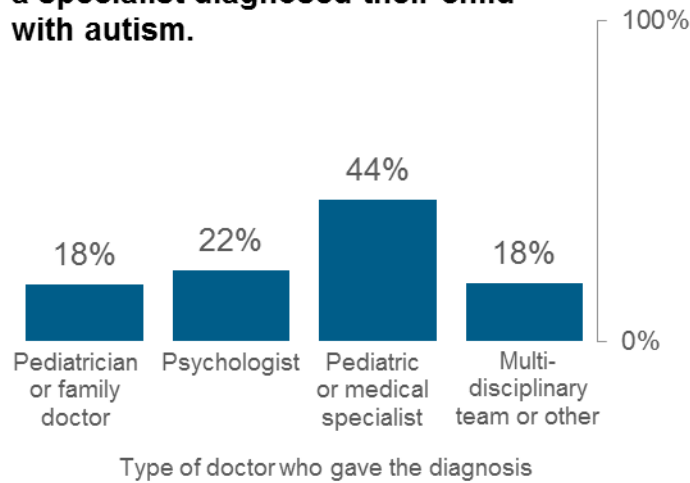
Many more children receive screening for developmental delay than for autism.<sup>4</sup> When children are screened for autism, some health care providers ask informal questions instead of using a standardized screening tool.<sup>5</sup> This is not considered screening. However, improvement in

is reflected in the most recent data from Healthy People 2020 indicating that about 38% of children received developmental and autism screening between 10-35 months of age using a questionnaire.<sup>2</sup>

Data from the Pathways survey indicates that 46% of parents of children with a diagnosis of autism remember being asked by a doctor to fill out a questionnaire, like those mentioned here. Slightly over half (53%) reported that their child's doctor performed a screening or assessment, whether with a questionnaire or not.

## Who made the diagnosis

Nearly half of parents reported that a specialist diagnosed their child with autism.



## Assessment

There are several “gold standard” instruments that are used for autism diagnosis. These include the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). Other well-known tools include the Diagnostic Interview for Social and Communication Disorders (DISCO). Ability of a diagnostic instrument to differentiate autism from other developmental disorders is important in autism evaluation.<sup>8</sup>

Diagnosis for autism includes evaluation of social communication skills, inferential thinking, communication skills, and differentiation from other developmental disorders. Diagnostic tools follow the definition of autism found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

In the Pathways survey, nearly half of parents of children with a current diagnosis of autism reported that their child's diagnosis was made by a specialist. In this survey, specialists

included pediatric specialists (such as a developmental pediatrician), psychiatrists, neurologists, or other types of specialist physicians. About 22% of parents reported that their child's diagnosis was made by a psychologist, while slightly fewer were diagnosed by a pediatrician or family doctor. The rest (18%) reported that their child's diagnosis was made by a multidisciplinary team or some other health care professional. These included school nurses or physical or occupational or other therapists.

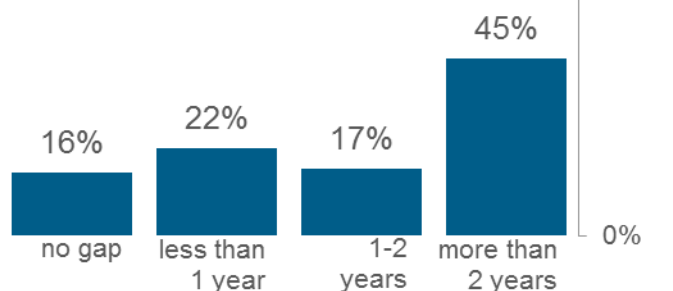
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Young Adults with Autism Spectrum Disorders for the grant amount of \$900,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

## Delays in diagnosis

Our previous work has shown an average age of diagnosis of 63 months.<sup>9</sup> It took an average of 34 months (nearly three years) from the time a parent first mentioned concerns about their child's development to a provider to the time of diagnosis. Few children (16%) received a diagnosis at the appointment where parents raised first concerns. In other literature, many parents report visiting several physicians before receiving a diagnosis.<sup>10</sup> There were no major differences in this time lag according to children's race, gender, family income, or parent education level.

**Nearly half of parents who contacted a health care professional with concerns received a diagnosis two or more years after their first contact.**



Gap between first contacting a health care provider about developmental concerns and diagnosis.

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*\*Please see the bottom of page four for our funding acknowledgement.*

*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.*