

National Autism Data Center Fact Sheet Series

Life Course Outcomes Research Program

Survey of Pathways to Diagnosis and Services
January 2016



Survey of Pathways to Diagnosis and Services

A national study of children and youth with autism

Data overview

What was the Pathways survey?

The Survey of Pathways to Diagnosis and Services (referred to as "Pathways") was a national survey conducted by the Centers for Disease Control and Prevention (CDC) in 2011. Participants were parents or guardians of children and youth age 6 to 17 with autism. The survey consisted of two parts: a telephone interview of parents of children and youth with autism, and

a supplemental mail questionnaire. Pathways was a nationally representative study, administered as a follow-up to the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Parents or guardians who participated in the 2009/10 NS-CSHCN were contacted to participate in Pathways if their child

or youth had one of three conditions; autism, intellectual disability, or developmental delay.

Over 4,000 interviews were conducted, and about 1,400 of them were on children or youth with autism. Almost 3,000 parents or guardians filled out the supplemental written questionnaire.

What questions we can answer

What topics were covered in the survey?

The Pathways survey questions covered many topics concerning families' experiences with diagnosis and services, including:

- Parental concerns before and during diagnosis
- Diagnostic experiences
- Health care services
- Educational services
- Unmet needs and insurance adequacy
- Functioning, strengths, and difficulties
- Wandering and wandering prevention
- Parental perceptions about the child's condition, services, and healthcare
- Family demographics

Autism outcomes and linking more information

It is possible to look at the outcomes of children and youth with autism separately from the outcomes of those with intellectual disability or developmental delay. Responses to telephone survey and mail questionnaire items can be compared across groups. Data from Pathways can also be linked to data from the 2009/10 NS-

CSHCN, so information from both surveys is available for those who participated.

A supplemental survey was also administered to some parents and guardians who participated in Pathways. The supplemental questionnaire was mailed to all parents and guardians who completed the telephone interview.

The questionnaire used questions from the Strengths and Difficulties Questionnaire and the Children's Social Behavior Questionnaire. There were five parts to the mailed questionnaire covering questions about child and youth behaviors, strengths, difficulties, qualities, and likes.

Where to learn more

Pathways was conducted by the CDC's National Center for Health Statistics, State and Local Area Integrated Telephone Survey program. The survey was sponsored by the National Institute of Mental Health of the National Institutes of Health.

Learn more about the Pathways survey administration from the CDC State and Local Area Integrated Telephone Survey.

<http://www.cdc.gov/nchs/slait/spds.htm>

Browse the data through the Data Resource Center for Child and Adolescent Health and learn more about the survey.

<http://www.childhealthdata.org/learn/pathways>

The Strengths and Difficulties Questionnaire (Goodman, 1997) and the Children's Social Behavior Questionnaire (Hartman *et al.*, 2006) used in the self-administered mailed questionnaire can also be found on the CDC's website.

<http://www.cdc.gov/nchs/data/slait/PathwaysSAQ.pdf>

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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.