

## Survey of Pathways to Diagnosis and Services (2011 "Pathways")

### ***FAST FACTS about the SURVEY***

#### **What is the Survey of Pathways to Diagnosis and Services?**

- Pathways was conducted in 2011, as a follow-back to the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN).
- Parents and guardians of CSHCN age 6- 17 years ever diagnosed with autism spectrum disorder, intellectual disability, or developmental delay as identified in the 2009/10 NS-CSHCN were invited to participate in an additional phone survey and self-administered mail-in questionnaire.
- Data collection for Pathways took place between February 2011 and June 2011.
- The NS-CSHCN used an independent random sample of all 50 states and the District of Columbia. Telephone numbers (landline and cell-phone) were randomly generated and dialed to locate households with CSHCN under 18 years old. Cell-phone numbers were only used if the respondent either did not own a landline or the respondent stated that they were unlikely to answer the landline. Trained interviewers asked parents or guardians a series of questions for all children in the household to identify those with special health care needs. Parents or guardians of children with special health care needs ages 6 to 17 years who indicated that their child had ever received a diagnosis of autism spectrum disorder, intellectual disability, or developmental delay were randomly selected for re-contact by telephone and asked to participate in Pathways.
- Pathways selected and attempted to recontact 6,090 parents or guardians of the 7,572 eligible cases from the 2009-2010 NS-CSHCN.
- A total of 4,032 phone interviews were completed. The phone interview took an average of 37 minutes to complete.
- Of the 4,032 parents and guardians who completed the phone interview, 3,997 agreed to complete the self-administered mail-in questionnaire (SAQ). A total of 2,988 SAQs were completed.

- Some data were omitted from the public use files to protect the confidentiality of the children and their families.
- Pathways was only administered in English.

### **What information is available for EACH state?**

- Due to limited sample size, no state-level estimates can be reliably produced.

### **What topics are covered by the Phone Interview?**

- Emergence of symptoms, early behavior signs, and parental concern
- Context and intricacies of diagnosis
- Developmental screening
- Early intervention/treatment from school and provider and referrals
- Use of health care and educational services and providers
- Adequacy of school and provider services
- Functioning Strength and Difficulties Questionnaire
- Severity and pattern of social/behavioral difficulties
- Wandering and wandering prevention

### **What topics are covered by the Self-Administered Questionnaire?**

- The Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997).
- The Children’s Social Behavior Questionnaire (CSBQ, Hartman et al., 2006).

### **Why is the Pathways or NS-CSHCN sometimes called “SLAITS”?**

- The sampling and data collection for the Pathways and the National Survey of CSHCN is conducted using the SLAITS mechanism.
- SLAITS is an acronym for the “State and Local Area Integrated Telephone Survey,” an approach developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the state and local levels.
- Other national surveys collected through the SLAITS program include: the National Survey of Children’s Health, the National Survey of Early Childhood Health, the National Asthma Survey, the National Survey of Adoptive Parents, the National Survey of Children in Nonparental Care, and the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome.

## **Who sponsored Pathways?**

- Pathways was sponsored by the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH), with funds available from the American Recovery and Reinvestment Act of 2009 (ARRA) (Public Law 111-5).
- The National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention oversaw the sampling and telephone interviews for the survey.

## **Are data from Pathways available to the public?**

- National results and other resources are easy to access online at [\[Link to ASD Portal\]](#).
- The NCHS released two datasets: 1) The Pathways public use file (PUF), which includes the Pathways phone interview and self-administered questionnaire, and 2) the Pathways imputation file, which contains imputed data for household income relative to the poverty threshold, adults in the household, highest education in the household, primary language spoken in the household, and the child's race and ethnicity.
- Data files for Pathways can be downloaded in SAS file format at no cost from the National Center for Health Statistics website: <http://www.cdc.gov/nchs/slait/spds.htm>
- Datasets with the core outcome and indicator variables included can also be requested at no charge in SAS/SPSS/STATA/CSV formats at <http://childhealthdata.org/help/dataset>
- Individuals can apply to use the restricted dataset through NCHS's Research Data Center at <http://www.cdc.gov/rdc/>

## **If I receive a dataset from the Data Resource Center (DRC), which dataset do I receive?**

- The Pathways dataset created for data users by the DRC links two public use files from the NCHS: the Pathways phone interview and self-administered questionnaire file, and the 2009/10 NS-CSHCN interview file.
- The Pathways and NS-CSHCN linked dataset created by the DRC uses the Pathways weights. Therefore, the resulting estimates are also representative of CSHCN age 6-17 years (at time of Pathways Phone Interview) who were ever diagnosed with ASD, intellectual disability and/or developmental delay.
- Further information on the Pathways dataset can be found in the DRC's codebook at [www.childhealthdata.org/learn/methods#Codebooks](http://www.childhealthdata.org/learn/methods#Codebooks)

Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Johns Hopkins Bloomberg School of Public Health. DRC is sponsored by Autism Speaks and the Maternal and Child Health Bureau, Health Resources and Services Administration.