An Introduction to the Survey of Pathways to Diagnosis and Services, 2011

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National Center for Health Statistics

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Purpose

- Describe the design and content of the 2011 Survey of Pathways to Diagnosis and Services.

- Present key findings about the health care and diagnostic history of children with developmental conditions.

- Describe how researchers can access the data files to conduct their own analyses.
Survey of Pathways to Diagnosis and Services, 2011

- **Sponsor:** National Institute of Mental Health, with American Recovery and Reinvestment Act funds.

- **Conducted by:** CDC’s National Center for Health Statistics.

- **Survey sample:** The 2009-2010 National Survey of Children with Special Health Care Needs (CSHCN), a nationwide random-digit-dial telephone survey.
  - CSHCN: increased risk for chronic conditions and need health & related services beyond that required by children generally.
Survey of Pathways to Diagnosis and Services, 2011

- **Eligibility:** CSHCN aged 6-17 years identified as having ever been diagnosed with Autism Spectrum Disorder (ASD), Intellectual Disability, and/or Developmental Delay.

- **Respondent:** Parent or guardian knowledgeable about the health of the child.

- **Mode:** Telephone survey followed by a mailed Self-Administered Questionnaire (SAQ).
Survey Design

Telephone re-contact, screen for eligibility
N = 6,090

Eligible: Incomplete Phone Interview

Completed 1st Mailed SAQ

Incomplete 1st Mailed SAQ

Completed SAQ via Phone prompt

Completed SAQ via 2nd Mail-out

Did not complete SAQ

Not Eligible or Unable to Locate
Survey Design

Telephone re-contact, screen for eligibility

Eligible: Incomplete Phone Interview
N = 4,032

Eligible: Completed Phone Interview

Not Eligible or Unable to Locate

Completed 1st Mailed SAQ

Incomplete 1st Mailed SAQ

Completed SAQ via Phone prompt
Completed SAQ via 2nd Mail-out

Did not complete SAQ

6
Survey Design

Telephone re-contact, screen for eligibility

- Eligible: Incomplete Phone Interview
- Eligible: Completed Phone Interview
- Not Eligible or Unable to Locate

Completed 1st Mailed SAQ
Incomplete 1st Mailed SAQ
Completed SAQ via 2nd Mail-out
Completed SAQ via Phone prompt
Did not complete SAQ

N = 2,988
Sample Sizes

- 4,032 completed telephone interviews.
  - 1,420 CSHCN currently have **ASD**.
  - 657 CSHCN currently have intellectual disability (**INT**) but have no ASD.
  - 1,441 CSHCN currently have developmental delay only (**DEV**).

- Based on Parent/Guardian Report
Content

**Telephone Questionnaire** - Emergence of symptoms; diagnostic experience; current behavioral, diagnostic, and functional status; clinical treatments and educational services used; and other parental concerns or perspectives.

**SAQ** - Includes the Children’s Social Behavior Questionnaire, and the Strengths and Difficulties Questionnaire, and questions on the CSHCN’s positive skills.
What can you do with Pathways Data?

Analysis plan for the following examples:

- Compare CSHCN with ASD to INT and DEV.
- Data were weighted to permit nationally representative estimates.
## Socioeconomic & Demographic Characteristics

### Selected Characteristics

<table>
<thead>
<tr>
<th></th>
<th>ASD</th>
<th>INT</th>
<th>DEV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>82.1</td>
<td>51.4*</td>
<td>66.9*</td>
</tr>
<tr>
<td>Female</td>
<td>17.9</td>
<td>48.6*</td>
<td>33.1*</td>
</tr>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 to 11</td>
<td>54.7</td>
<td>42.0*</td>
<td>50.3</td>
</tr>
<tr>
<td>12 to 17</td>
<td>45.3</td>
<td>58.0*</td>
<td>49.7</td>
</tr>
<tr>
<td><strong>Race &amp; Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>13.0</td>
<td>11.0</td>
<td>14.5</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>10.7</td>
<td>18.7*</td>
<td>18.4*</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>66.2</td>
<td>57.9</td>
<td>60.4</td>
</tr>
<tr>
<td>Non-Hispanic Other</td>
<td>10.1</td>
<td>12.4</td>
<td>6.8</td>
</tr>
</tbody>
</table>

* Estimates are significantly different compared with ASD
Person First Concerned with Child’s Development

* Estimates are significantly different compared with ASD
Type of Doctor/Health Care Provider Who First Diagnosed Condition

* Estimates are significantly different compared with ASD
Selected Health Care Services Currently Used

* Estimates are significantly different compared with ASD
* Estimates are significantly different compared with ASD
Adequacy of Health Insurance Coverage for Needed Health Services

* Estimates are significantly different compared with ASD
CSHCN Who Ever Wandered Off or Became Lost in Past Year

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>33.9</td>
</tr>
<tr>
<td>INT</td>
<td>23.7</td>
</tr>
<tr>
<td>DEV</td>
<td>22.3*</td>
</tr>
</tbody>
</table>

* Estimates are significantly different compared with ASD
Parental Perception: Parent/Guardian Definitely Agree

<table>
<thead>
<tr>
<th>Statement</th>
<th>ASD</th>
<th>INT</th>
<th>DEV</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have the power to change child's condition</td>
<td>11.1</td>
<td>7.3</td>
<td>13.3</td>
</tr>
<tr>
<td>Condition is a mystery to me</td>
<td>17.8</td>
<td>13.0</td>
<td>12.6*</td>
</tr>
<tr>
<td>When I think about child's condition I get upset</td>
<td>28.4</td>
<td>26.2</td>
<td>30.9</td>
</tr>
</tbody>
</table>

* Estimates are significantly different compared with ASD
CSHCN’s Emotion, Concentration or Behavioral Difficulties Burden Family

<table>
<thead>
<tr>
<th></th>
<th>ASD</th>
<th>INT</th>
<th>DEV</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>37.9</td>
<td>43.9</td>
<td>49.6*</td>
</tr>
<tr>
<td></td>
<td>60.3</td>
<td>42.8*</td>
<td>40.9*</td>
</tr>
<tr>
<td></td>
<td>1.8</td>
<td>13.3*</td>
<td>9.5*</td>
</tr>
</tbody>
</table>

- Not at all/ a little
- A lot/ a great deal
- Has no difficulties

* Estimates are significantly different compared with ASD
Analysis Using Pathways Data

The Survey of Pathways to Diagnosis and Services provides the largest nationally representative survey data on the health care and diagnostic history of CSHCN identified as having (or having had) ASD, INT, and/or DEV.

- Data files and supporting materials are publicly available for anyone to use.
- Pathways data can be linked to the 2009-2010 NS-CSHCN.
How to Access Pathways Data

The Pathways home page is located at: www.cdc.gov/nchs/slaits/spds.htm

- The home page includes:
  - Data files and methodology reports
  - Questionnaires and codebooks
  - Sample SAS programs
  - Sampling weights for nationally representative estimates

Data not publically available can be accessed through the NCHS Research Data Center: www.cdc.gov/rdc/
Now Available…


www.cdc.gov/nchs/products/databriefs.htm
Contact Info

SLAITS@CDC.GOV

Visit us at: www.cdc.gov/nchs/slaits.htm