Evidence from the National Survey
Of SSI Children and Families

Presentation to the IOM Committee to Evaluate the SSI Disability Program for
Children with Speech and Language Disorders

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Social Security Administration

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Two Data Sources

- **SSA program data**
  - Background data on award cohorts of SSI children from 1985 to 2000
  - Large sample and can observe program entry patterns over time (flow), but...
  - ...limited information on recipient characteristics and virtually no information on family situation

- **National Survey of SSI Children and Families (NSCF)**
  - Primary focus of this presentation
  - Rich survey data on child and family characteristics at a single point in time (stock), but...
  - ...sample size limits subgroup analysis and data are nearly 15 years old
SSA Data on Speech and Language Delay

- **SSA diagnosis codes**
  - 3153 (Speech and Language Delays)
  - 7840 (Communication Impairment)

- **Award cohorts of SSI children (age 0-17 at award)**

- **At the time of award, SSI children with speech and language delay (SLD) are:**
  - More frequently male than other SSI children
  - Younger than other SSI children

- **Number and percentage of new awards with SLD growing over time**
  (see more recent data presented by Melissa Spencer on 1/26/15)
SLD Gender and Age Distribution by Award Cohort

**Gender (% male)**

- **Distribution**: 70-100% male

**Age Group**

- **Groups**: 0-5, 6-12, 13-17
- **Distribution**: 0-20% for 0-5, 10-40% for 6-12, 50-80% for 13-17
### Diagnosis Codes by Award Cohort

#### Number of new awards

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Award Year</th>
<th>1985</th>
<th>1990</th>
<th>1995</th>
<th>2000</th>
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<tbody>
<tr>
<td>Other Mental - SLD</td>
<td></td>
<td>90</td>
<td>142</td>
<td>4,423</td>
<td>9,109</td>
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<tr>
<td>Other &amp; Unknown - SLD</td>
<td></td>
<td>31</td>
<td>775</td>
<td>1,728</td>
<td>2,628</td>
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<tr>
<td>Other Mental - nonSLD</td>
<td></td>
<td>3,081</td>
<td>10,551</td>
<td>53,433</td>
<td>49,394</td>
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<tr>
<td>Other &amp; Unknown - nonSLD</td>
<td></td>
<td>3,292</td>
<td>5,409</td>
<td>23,914</td>
<td>22,667</td>
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<tr>
<td>ID/MR</td>
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<td>18,156</td>
<td>31,339</td>
<td>53,584</td>
<td>27,529</td>
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<tr>
<td>Physical</td>
<td></td>
<td>16,428</td>
<td>21,298</td>
<td>28,131</td>
<td>25,212</td>
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<tr>
<td>Other Identified</td>
<td></td>
<td>4,039</td>
<td>6,939</td>
<td>8,345</td>
<td>7,530</td>
</tr>
<tr>
<td>N</td>
<td></td>
<td>45,116</td>
<td>76,453</td>
<td>173,559</td>
<td>144,068</td>
</tr>
</tbody>
</table>

#### Percentage distribution of new awards

![Bar chart showing the percentage distribution of new awards by year and diagnosis codes]
National Survey of SSI Children and Families

- Conducted by SSA in 2001/2002 through contract with Mathematica Policy Research

- Goal was to answer a broad range of research and policy questions about SSI children and their families

- Sample frame included SSI children (0-17) and young adults (18-23) in three groups:
  - Receiving payments in December 2000
  - Receiving payments in December 1996
  - Former recipients and denied applicants since 1992
NSCF and SLD

- We focus on the NSCF sample of children aged 0-17 receiving SSI payments in December 2000 (n=3,651)

- About 5% of the sample was identified as having SLD based on SSA diagnosis code 3153 (3.7%, n=135) or SSA diagnosis code 7840 (1.2%, n=44)
  - Applying sample weights, 8.7% of the respondents have SLD

- We draw comparisons between SLD and non-SLD children in the NSCF for several key characteristics that cannot be measured in SSA program data, highlighting notable and statistically significant differences between the two groups
Context and Interpretation

- **NSCF sample is representative of SSI recipients, but quite different from general population**
  - SSI means test → low income
  - Disabilities of child meeting SSA screen
  - Parent knowledge and motivation to apply

- The average child in our sample has been on SSI for several years

- Both SLD and non-SLD recipients are affected by dual challenges of poverty and disabilities
  - One subgroup may have lower poverty rate than the other, but both may have high poverty rates compared to general population
  - SLD recipients may have higher or lower service needs compared to non-SLD recipients, but both may have higher service needs compared to children of comparable ages who do not receive SSI

- Results are descriptive, do not include regression-adjusted comparisons
Topics

- Demographic characteristics of children
- Disability and health status of children
- Functional limitations
- Health insurance and medical utilization
- Out of pocket expenses
- Services received and unmet needs
- School-based services
- Characteristics of parents and families
- Financial well-being
- Care and parental work
Demographics Characteristics of Children

Major difference is that SLD children tend to be relatively younger

SLD children more likely to be boys compared to non-SLD (majority is boys in both groups)

Race and ethnicity distributions are quite similar, but:

- Significantly lower proportion of whites in SLD
- Marginally significant overrepresentation of Hispanic ethnicity in SLD
Characteristics differ depending on perspective: awardee cohort versus prevalence in cross-section of “current” SSI recipients

- Awardee cohort perspective presented previously gave age, gender, and diagnosis distribution at first-ever SSI award

- NSCF analysis reflects characteristics of December 2000 cross-section of SSI recipients as of the 2001/2002 NSCF interview

- Possible sources of differences include differential exit patterns due to mortality and transition to nonrecipient status

- Results are consistent – median age for SLD recipients is lower and higher proportion of SLD recipients are boys in both the award data and the cross-section data
Disability and Health Status of Children

Overall distributions for general health status, severity, and ability to do things are remarkably similar based on respondent perceptions (mainly parents).

Differences are not statistically significant and difficult to interpret.
Functional Limitations

SLD children report significantly less need for help with physical functioning, as might be expected.

NSCF is lacking in measurement of social, cognitive, and psychological functioning.
Health Insurance and Medical Utilization

Due to Medicaid and SCHIP both SLD and non-SLD children are essentially fully insured.

Insurance coverage concerns among those losing SSI in adulthood are expected to be reduced under ACA due to Medicaid expansion and availability of subsidized insurance.

A relatively lower proportion of SLD children have 4+ annual doctors’ visits and have been hospitalized during previous year.
Out of Pocket (OOP) Expenses

Despite similarities in health insurance coverage, a smaller fraction of SLD children have any out of pocket (OOP) expenses for medical care, services, or therapies.

The distributions of the dollar values of OOP expenses (over the 12 months prior to the interview) are similar for SLD and non-SLD children.

The mean amount of OOP expenses (among those with positive values) was $423 for SLD children and $862 for non-SLD children.
Services Received and Unmet Needs

Significantly higher utilization of physical, occupational, speech services and audiology services among SLD children

Also significantly higher unmet need for physical, occupational, and speech services for SLD children

Unmet need for mental health counseling significantly lower among SLD children
School-Based Services

Vast majority ages 3-17 are in school in both groups

Percent of 3-5 years old in school is 94% for SLD children but only 88% for non-SLD children

Statistically significantly higher proportion of SLD children in school in 13-17 age group – relative odds of dropping out lower

For ages 3-17 combined, the majority of both groups has had experience with Special Ed and IEPs
### Characteristics of parents and families

Both SLD and non-SLD recipients are clearly disadvantaged: single parent, several children, parents with low education, about half live in household with at least one other person with disabilities.

A notable difference is that significantly smaller proportion of SLD children live with both parents – only about 21 percent – and a larger fraction live with mom only.

<table>
<thead>
<tr>
<th>Living Arrangements</th>
<th>0%</th>
<th>20%</th>
<th>40%</th>
<th>60%</th>
<th>80%</th>
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<tr>
<td>Two Parents**</td>
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<td>SLD</td>
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<tr>
<td>Mom***</td>
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<td></td>
<td>non-SLD</td>
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<tr>
<td>Dad*</td>
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<tr>
<td>Other Older Relative</td>
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<td>Other</td>
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<table>
<thead>
<tr>
<th>Number of Children in HH</th>
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<th>40%</th>
<th>60%</th>
<th>80%</th>
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<tr>
<td>1</td>
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<td>SLD</td>
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<td>2</td>
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<td></td>
<td></td>
<td></td>
<td>non-SLD</td>
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<td>3</td>
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<td>4</td>
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<table>
<thead>
<tr>
<th>Other HH Member with Disability</th>
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<th>60%</th>
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<th>100%</th>
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<tbody>
<tr>
<td></td>
<td>SLD</td>
<td>non-SLD</td>
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<tr>
<th>Mom Education (if present)</th>
<th>0%</th>
<th>20%</th>
<th>40%</th>
<th>60%</th>
<th>80%</th>
<th>100%</th>
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<tbody>
<tr>
<td>Less than HS</td>
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<tr>
<td>HS or GED</td>
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<tr>
<td>More than HS</td>
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<td>Missing</td>
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</table>

<table>
<thead>
<tr>
<th>Dad Education (if present)</th>
<th>0%</th>
<th>20%</th>
<th>40%</th>
<th>60%</th>
<th>80%</th>
<th>100%</th>
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<tbody>
<tr>
<td>Less than HS</td>
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<td>HS or GED</td>
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<tr>
<td>More than HS</td>
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Financial Well-Being

Overall SSI children live in families with relatively high poverty rate – significantly higher for families of SLD children

SSI provides roughly half of average family income

Even though parents have relatively weak labor force attachment and low earnings capacity, many are not disabled and earnings is a substantial source of family income for many

Food Stamps and housing assistance are significantly more prevalent among families of SLD children
Care and Parental Work

Survey asked about caregiving hours specifically related to child’s disabilities

Significantly lower proportion of SLD children received care from family members

66% of SLD children reportedly did not receive any caregiving hours – family or nonfamily

Significantly more caregiving was provided for non-SLD children

Most of the care was provided by family members for both groups

About half of mothers reported no market work for both groups, but 20% worked full time
Conclusions – Child Characteristics

- Percent of SSI awardees with SLD dramatically increased between 1985 and 2000
  - Consistent with increase post-2000, but rate of increase declined post-2000
  - Percent classified as ID/MR substantially decreased
  - Change in diagnostic and/or classification practices?

- Overall SSI children with SLD tend to have characteristics that do not dramatically differ from non-SLD children on SSI on variables that were available for the analysis
  - Most importantly, overall distributions on responses to general health and severity questions are remarkably similar for SLD and non-SLD children and do not show statistically significant differences
  - SLD children appear significantly less limited on functional limitations measures from the NSCF, but NSCF functional limitations measures exclusively focus on physical disabilities
    - To get balanced and unbiased picture, more information on severe limitations in social functioning, cognitive and psychological variables would be extremely helpful
  - Although NSCF contains no comparable data for all (non-SSI) children, both SLD and non-SLD children show high proportion of minorities, high utilization of school-based services, virtually complete health insurance coverage. Both SLD and non-SLD children had modest reported OOP expenses, but small minority in both groups reported OOP expenses that are relatively high compared to SSI income guarantee (Federal Benefit Rate)

- Some notable differences.
  - SLD children tend to be younger, have less doctors visits and hospitalizations, received more physical/occupational/speech services and audiology services
Conclusions – Family Situation

- Generally, the family situation of both SLD and non-SLD children on SSI indicates high degree of financial vulnerability
  - Prevalence of poverty is high despite SSI cash benefits providing a large portion of family income
  - Family characteristics typically associated with poverty are common for both groups. These include: large proportion of single parent families, high prevalence of low educational attainment of parents, low employment levels, part time work and low wages

- About half of SLD children and non-SLD children on SSI live in households with at least one other person with a disability
  - Added source of stress and financial vulnerability
  - Increases caregiving needs

- Many report family and nonfamily caregiving hours specifically related to health care needs of both SLD and non-SLD children on SSI
  - However, substantially more report no family or nonfamily caregiving hours for children with SLD
## Classification of Childhood Population by SSI Eligibility and SLD Diagnosis

<table>
<thead>
<tr>
<th>Financially eligible for SSI under means test?</th>
<th>Serverely disabled according to SSA criteria?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, SLD</td>
<td>Yes, non-SLD</td>
<td>Not severe, but some disablement</td>
</tr>
<tr>
<td>YES</td>
<td>SSI (in NSCF) severe disablement + financially vulnerable</td>
<td>SSI (in NSCF) severe disablement + financially vulnerable</td>
</tr>
<tr>
<td>NO</td>
<td>SLD severe disablement + financially better off</td>
<td>non-SLD severe disablement + financially better off</td>
</tr>
</tbody>
</table>

- Usefulness of NSCF and other data sets to address SSI and SLD issues depends on questions of interest
- Questions of interest determine the comparison groups that are necessary and relevant
- Sample coverage is key
NSCF in Context

- NSCF is useful to answer questions where within-SSI comparisons are relevant, but broader questions require external standards and comparison with non-SSI populations.

Looking to future:
- Need for more current data
- Need for future data collection strategies that integrate SSI and SLD issues in an overall sample framework of all children in the United States
  - Need for sufficient SSI and SLD sample sizes
  - Accurate identification of SSI receipt is crucial (administrative data matches)
  - Use variables that are relevant for assessing nature and severity of disabling conditions for both SLD and non-SLD subgroups of children
  - Assessment of longer-term outcomes over the childhood, adolescent and adult portions of the life-cycle
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