Findings on Children’s Pathways To Diagnosis and Services

NCHS Data Users Conference

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Disclosures

• I have no personal financial relationships with commercial interests relevant to this presentation

• The views expressed are my own, and do not necessarily represent those of the NIH, NIMH, or the Federal Government
Summary of topics to be covered

• Basic demographics of 4 (mutually exclusive) groups of children

• Preliminary data on:
  – Initial problems noted by parents
  – Age of child when first diagnosed
  – Types and number of services used by children
  – Types and number of medications used by children
  – Cohort differences in age when first diagnosed
### Demographics

<table>
<thead>
<tr>
<th></th>
<th>Autism Spectrum Disorder (N=1,117)</th>
<th>Autism Spectrum Disorder w/ Intellectual Disability (N=303)</th>
<th>Intellectual Disability (N=657)</th>
<th>Developmental Delay (N=1,441)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-11</td>
<td>56.4%</td>
<td>48.7%</td>
<td>42%</td>
<td>50.3%</td>
</tr>
<tr>
<td>12-17</td>
<td>43.6%</td>
<td>51.3%</td>
<td>58%</td>
<td>49.7%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>82.6%</td>
<td>80.5%</td>
<td>51.4%</td>
<td>66.9%</td>
</tr>
<tr>
<td>Female</td>
<td>17.4%</td>
<td>19.5%</td>
<td>48.6%</td>
<td>33.1%</td>
</tr>
</tbody>
</table>
Child’s age when parent was first concerned

- ASD
  - 48+ months: 27.3%
  - 24-47 months: 15.2%
  - 12-23 months: 26.3%
  - 0-11 months: 31.3%

- ASD w/ ID
  - 48+ months: 28.5%
  - 24-47 months: 23.3%
  - 12-23 months: 35.2%
  - 0-11 months: 12.9%

- ID
  - 48+ months: 49.3%
  - 24-47 months: 11.1%
  - 12-23 months: 16.8%
  - 0-11 months: 22.7%

- DD
  - 48+ months: 44.5%
  - 24-47 months: 20.6%
  - 12-23 months: 10.3%
  - 0-11 months: 24.6%
Problems noted when parents were first concerned

- Categories assessed (20 items total):
  - Verbal Communication
  - Nonverbal Communication
  - Behavioral Difficulties
  - Learning and Understanding
  - Unusual Gestures or Movements
  - Motor Skills
  - Medical problems
Most commonly noted problems when parents were first concerned

<table>
<thead>
<tr>
<th>Autism Spectrum Disorder (ASD)</th>
<th>ASD with ID</th>
<th>Intellectual Disability (ID)</th>
<th>Developmental Delay (DD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Difficulties (90%)</td>
<td>Verbal Communication (96%)</td>
<td>Learning and Understanding (87%)</td>
<td>Behavior Difficulties (77%)</td>
</tr>
<tr>
<td>Nonverbal Communication (87%)</td>
<td>Learning and Understanding (93%)</td>
<td>Verbal Communication (85%)</td>
<td>Learning and Understanding (76%)</td>
</tr>
<tr>
<td>Learning and Understanding (79%)</td>
<td>Nonverbal Communication (90%)</td>
<td>Behavior Difficulties (76%)</td>
<td>Verbal Communication (61%)</td>
</tr>
<tr>
<td>Verbal Communication (74%)</td>
<td>Behavior Difficulties (86%)</td>
<td>Motor Skills (78%)</td>
<td>Nonverbal Communication (57%)</td>
</tr>
</tbody>
</table>
Child’s age when first diagnosed with ASD, ID or DD*

* Current diagnosis may be different from 1st diagnosis
Types of therapy or training services used

- Services assessed:
  - Behavioral intervention or modification services
  - Sensory integration therapy
  - Cognitive based therapy
  - Occupational therapy
  - Physical therapy
  - Social Skills training
  - Speech or language therapy
Number of therapy or training services currently used

- ASD: 64% (2+ services), 17% (1 Service), 19% (No Services)
- ASD W/ ID: 83% (2+ services), 15% (1 Service), 2% (No Services)
- ID: 69% (2+ services), 17% (1 Service), 14% (No Services)
- DD: 48% (2+ services), 25% (1 Service), 27% (No Services)
### Most commonly used types of therapy

<table>
<thead>
<tr>
<th>Autism Spectrum Disorder (ASD)</th>
<th>ASD with ID</th>
<th>Intellectual Disability (ID)</th>
<th>Developmental Delay (DD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Skills (56%)</td>
<td>Speech/Lang (81%)</td>
<td>Speech/Lang (63%)</td>
<td>Speech/Lang (40%)</td>
</tr>
<tr>
<td>Speech/Language (51%)</td>
<td>Social Skills (67%)</td>
<td>Occupational (54%)</td>
<td>Occupational (36%)</td>
</tr>
<tr>
<td>Occupational (39%)</td>
<td>Behavioral (44%)</td>
<td>Social Skills (45%)</td>
<td>Social Skills (31%)</td>
</tr>
<tr>
<td>Behavioral (38%)</td>
<td>Cognitive (43%)</td>
<td>Physical Therapy (31%)</td>
<td>Behavioral (23%)</td>
</tr>
</tbody>
</table>

Using 1 or more services: 81%

Using 1 or more services: 98%

Using 1 or more svcs: 86%

Using 1 or more services: 73%
Types of Medication Used

• Types of medication assessed:
  – Stimulant medications
  – Anti-depressant medications
  – Anti-anxiety or mood stabilizing medications
  – Anti-seizure medications
  – Anti-psychotic medications
  – Sleep medications
Number of types of medication currently used

<table>
<thead>
<tr>
<th>Group</th>
<th>No meds</th>
<th>1 type</th>
<th>2+ types</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>49%</td>
<td>31%</td>
<td>20%</td>
</tr>
<tr>
<td>ASD W/ ID</td>
<td>33%</td>
<td>38%</td>
<td>29%</td>
</tr>
<tr>
<td>ID</td>
<td>56%</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>DD</td>
<td>48%</td>
<td>19%</td>
<td>33%</td>
</tr>
</tbody>
</table>
### Most commonly used medication types by condition

<table>
<thead>
<tr>
<th>Autism Spectrum Disorder (ASD)</th>
<th>ASD with ID</th>
<th>Intellectual Disability (ID)</th>
<th>Developmental Delay (DD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stimulant meds (30%)</td>
<td>Anti-anxiety/ mood stabilizing meds (34%)</td>
<td>Stimulant meds (17%)</td>
<td>Stimulant meds (35%)</td>
</tr>
<tr>
<td>Anti-anxiety/mood stabilizing meds (22%)</td>
<td>Stimulant meds (28%)</td>
<td>Anti Seizure Meds (16%)</td>
<td>Sleep meds (13%)</td>
</tr>
<tr>
<td>Antidepressant meds (17%)</td>
<td>Antidepressant meds (27%)</td>
<td>Anti-anxiety/mood stabilizing meds (16%)</td>
<td>Anti-anxiety/mood stabilizing meds (9%)</td>
</tr>
<tr>
<td>Sleep Meds (17%)</td>
<td>Sleep meds (23%)</td>
<td>Antidepressant meds (14%)</td>
<td>Antidepressant meds (9%)</td>
</tr>
<tr>
<td>On 1 or more meds: 51%</td>
<td>On 1 or more meds: 66%</td>
<td>On 1 or more meds: 44%</td>
<td>On 1 or more meds: 51%</td>
</tr>
</tbody>
</table>
Child’s age when first diagnosed by current-age cohort

- 48+ months
- 24-47 months
- 12-23 months
- 0-11 months
Special Thanks!

• Stephen Blumberg
• Rosa Avila
• Michael Kogan
• Cathy Rice