Presenter Disclosure

- Presenter: Sue Lin, MS
- No relationships to disclose
Emergency department (ED) health care professionals often care for pediatric patients with mental health emergencies and children with neurodevelopmental disabilities (ND).

Parents of young children often seek care in ED for non-urgent conditions when their pediatrician cannot be reached quickly. Overall, approximately 40 percent of ED visits are not urgent.

Heavy ED users typically have significant health needs and/or face barriers to receiving other kinds of care.

ED overcrowding threatens patient safety and public health.
Case Definitions

Emergency Department Use (EDU)

- EDU was dichotomized into two categories: 0–2 EDU and 3 or more EDU

- NS–CSHCN survey question on number of ER visits is as follows: ['During the past 12 months ’], how many times did (S.C.) visit a hospital emergency room? Response – ENTER NUMBER OF VISITS

Children with Neurodevelopmental Disabilities (ND)

- ND included the following conditions:
  - Attention Deficit Disorder
  - Autism
  - Down Syndrome
  - Mental Retardation
  - Cerebral Palsy
  - Muscular Dystrophy

- In NS–CSHCN, parent/caregivers responded to the following questions about his/her child’s conditions: “To the best of your knowledge, does subject child (S.C.) currently have the ______ conditions?”
Case Definitions cont...

- Maternal and Child Health Bureau (MCHB) Core Outcome #2: Children and youth with special health care needs (CSHCN) receive coordinated ongoing comprehensive care within a medical home
- MCHB utilize the core outcomes to measure progress towards comprehensive and family-centered systems of care
- Child's health care has caused financial problems
- Family member stopped working due to child's health
- Family members have cut work hours to care for child
- Family needed additional income for child's medical expenses

Access to Care

<table>
<thead>
<tr>
<th>Financial Hardship</th>
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Objectives

- Objective 1: Examine the association between the frequency of emergency department use (EDU) and parental report of access to care for children with neurodevelopmental disabilities (ND)
- Objective 2: Examine the association between the frequency of emergency department use (EDU) and financial hardships for families with children with neurodevelopmental disabilities (ND)

- Nationally representative, cross-sectional telephone health care survey
- Interviews conducted in English, Spanish, Cantonese, Korean, Vietnamese, and Mandarin
- Sample size of children with ND: N=15238 aged 17 years or younger
- Survey administered by CDC’s National Center on Health Statistics (NCHS) and funding support provided by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)
Methods

- Bivariate analysis ($\chi^2$ statistics) of EDU and sociodemographic variables, access to services, and financial hardship
- Multivariate logistics regression to examine associations between EDU and access to services and financial hardships while controlling for individual level sociodemographic variables (insurance status, race/ethnicity, family structure, gender, child age)
- Statistical Software Package: SAS version 9.3
Results

- 27.4% of Non-Hispanic Black Children with ND have 3 or more EDUs as compared to 15.7% in 0–2 EDU category
- More children with ND on public insurance had 3 or more EDUs 54.1% as compared to 32.7 in the 0–2 EDU category
- More children with ND age 0–5 years old had 3 or more EDU

<table>
<thead>
<tr>
<th>Table 1. Sociodemographic characteristics of Children with ND</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/Ethnicity</strong></td>
</tr>
<tr>
<td>Hispanic</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
</tr>
<tr>
<td>Non-Hispanic Multi-race/Other</td>
</tr>
<tr>
<td><strong>Insurance Type</strong></td>
</tr>
<tr>
<td>Private and Other comprehensive</td>
</tr>
<tr>
<td>Public</td>
</tr>
<tr>
<td>Uninsured</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>0–5 Years</td>
</tr>
<tr>
<td>6–11 Years</td>
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<tr>
<td>12–17 Years</td>
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</tbody>
</table>
## Results: Access to Care

### Table 2. Adjusted odds ratios for children with neurodevelopmental disabilities and 3 or more emergency room visits and access to care

<table>
<thead>
<tr>
<th>MCHB Core Outcome – Children receiving coordinated, ongoing, comprehensive care within a medical home</th>
<th>AOR</th>
<th>95% Confidence Interval</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors usually or always make the family feel like a partner</td>
<td>0.72</td>
<td>(0.57, 0.90)</td>
<td>0.005</td>
</tr>
<tr>
<td>Family is very satisfied with services received</td>
<td>0.74</td>
<td>(0.61, 0.91)</td>
<td>0.004</td>
</tr>
<tr>
<td>The child has a usual health care source</td>
<td>0.57</td>
<td>(0.42, 0.78)</td>
<td>0.00004</td>
</tr>
<tr>
<td>The child has a usual source for preventive care</td>
<td>0.71</td>
<td>(0.45, 1.12)</td>
<td>0.14</td>
</tr>
<tr>
<td>The child receives effective care coordination</td>
<td>0.87</td>
<td>(0.71, 1.06)</td>
<td>0.16</td>
</tr>
<tr>
<td>Family usually or always gets sufficient help coordinating care, if needed</td>
<td>0.88</td>
<td>(0.71, 1.09)</td>
<td>0.25</td>
</tr>
<tr>
<td>Doctors usually or always listen carefully</td>
<td>0.61</td>
<td>(0.49, 0.77)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Doctors are usually or always sensitive to values and customs</td>
<td>0.64</td>
<td>(0.51, 0.81)</td>
<td>0.0002</td>
</tr>
<tr>
<td>Doctors are usually or always provide the needed information</td>
<td>0.79</td>
<td>(0.64, 0.98)</td>
<td>0.03</td>
</tr>
</tbody>
</table>
Results: Financial Hardship

- Increased EDU are positively associated parental report financial problems as a result of the child’s health care.
- In addition, parents who need additional income to pay for medical expense and stopped working due to child’s health are twice as likely to report 3 or more EDU.

Table 3. Adjusted odds ratios for children with neurodevelopment disabilities and 3 or more emergency room visits and family financial difficulties

<table>
<thead>
<tr>
<th>Family financial difficulties</th>
<th>AOR</th>
<th>95% Confidence Interval</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's health care has caused financial problems</td>
<td>2.06</td>
<td>(1.69, 2.50)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Family member stopped working due to child's health</td>
<td>2.25</td>
<td>(1.83, 2.75)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Family members have cut work hours to care for child</td>
<td>1.95</td>
<td>(1.59, 2.38)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Family needed additional income for child's medical expenses</td>
<td>2.12</td>
<td>(1.74, 2.59)</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>
## Results

- Children with ND who had 3 or more EDU were:
  - 3 times as likely to have any bodily difficulties
  - Nearly twice as likely to have any activity or participation difficulties

<table>
<thead>
<tr>
<th></th>
<th>AOR</th>
<th>95% Confidence Interval</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any bodily difficulties</td>
<td>3.54</td>
<td>(2.77, 4.53)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Any activity or participation difficulties</td>
<td>1.94</td>
<td>(1.30, 2.90)</td>
<td>0.001</td>
</tr>
<tr>
<td>Any other emotional/behavioral difficulties</td>
<td>1.41</td>
<td>(1.12, 1.77)</td>
<td>0.004</td>
</tr>
</tbody>
</table>
Discussion

- Barriers to Access to Care
- Addressing Health Disparities
- Racial/Ethnic Disparities
- Families receiving public insurance
- Challenges in Financial Hardship
- Families experiencing downward spiral in economic status
- Family Partnership
- Usual Source of Care
- Patient and family satisfactions
Discussion: Strategies for Reduction of EDU

To facilitate the reduction of ER visits, possible strategies might involve the following:

1. Provide support to parents with young children with ND in the management of complex health care needs
2. Provide community supports to parents in accessing available public benefits and services and financial planning
3. Providing access to assistive technology services for children with physical difficulties
4. Clinical provider education and training to enhance supporting families of children with ND
Discussion: Policy Implication and Future Directions

- Optimization of healthcare
  - Support and implementation for Patient-Centered Medical Home (PCMH) in primary care especially in Federally Qualified Health Centers serving vulnerable population
  - Electronic Health Record (EHR) data facilitating coordination among primary care and specialty care serving children with ND

- Future direction:
  - Identify the leading cause of ED visits for children with neurodevelopmental disabilities
  - Develop categorization of frequency EDU for the ND population to better measure impact
### Strengths and Limitations

#### Scientific Contribution
- Exploratory analysis focused on children with neurodevelopmental disabilities and EDU in the US
- Identify access to care issues for children with ND with higher frequency of EDU

#### Policy Contribution
- Identify likely groups for EDU among children with ND
- Provide information to develop anticipatory guidance and/or community–supports for families

#### Survey Characteristics
- Largest survey for children with special health care needs
- Self-report data from parents or caregivers

#### Bias
- Respondent
- Recall

#### RDD Random Digit Dialing
- Nonresponse Bias
- Coverage Bias

#### Survey Design Limitations
- Cross-sectional survey
- Lack of additional information on cause of the ED visit and choice of ED services
Contact Information

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