Disparities in Autism Diagnosis & Care

David S. Mandell, ScD

PENN CENTER FOR MENTAL HEALTH
Advancing research, policy, practice and training to improve lives
What do we mean by disparities?

• "...racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention." Institute of Medicine's *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (2003)

• "...differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.” National Institutes of Health (NIH) *Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities* (2000)
How do we conceptualize the study of disparities?

From detecting to understanding to reducing

- Detecting disparities in:
  - Diagnosis
  - Access to treatment
  - Quality of treatment

- A conceptual model for understanding reasons for disparities

- Strategies for disparity reduction
  - Caregiver empowerment
  - Band Aids on a broken system
  - Systemic change
Disparities in Identification

Disparities in Identification

Prevalence Ratio from CDC Surveillance Studies

- **white/black**
- **white/Hispanic**
Disparities in Age of Diagnosis

• **African American = white**
  - Mandell et al. 2005; Goin-Kochel et al., 2006; Perryman 2009; Adelman 2010; Mazurek et al., 2014

• **African-American > white**
  - Mandell et al., 2002; Rosenberg et al., 2011; Valicenti-McDermott et al., 2012

• **w/ ID, African > white** (Wiggins 2006)

• **Non-white > white** (Fountain et al., 2011)

• **“other races” > white** (Shattuck et al., 2009)

• **White > “visible minority”** (Coo et al., 2012)

• **Hispanic = white**
  - Mandell et al., 2005; Adelman 2010; Rosenberg et al., 2011

• **Hispanic > white**
  - Shattuck et al., 2009; Fountain et al., 2011; Valicenti-McDermott et al., 2012

Disparities in Education Classification

% of Children with ASD in Autism Category of Special Education

Why Education Classification Matters

Suspension Rates in Maryland by Race & Disability Group

Disparities in Perceived Health Care Needs

- Specialty physician
- Prescription
- Therapy
- Child MH care
- Respite
- Family MH care

White, Hispanic, Black
Disparities in Service and Medication Use

Odds of Endorsing Problem/Challenge

- Problem getting specialty care
- No personal doctor
- Problem getting advice
- Problem getting acute care
- Not visited a doctor for preventive care
- Not used prescription medication

### Post-High School Services

Table 2. Logistic Regression Models Predicting Post–High School Use of Services Among Young Adults With Autism Spectrum Disorders From Wave 4 (2007-2008) of the National Longitudinal Transition Transition Study 2

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No Services</td>
</tr>
<tr>
<td>Demographic factors</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>0.47 (0.11-1.94)</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>0.50 (0.13-1.88)</td>
</tr>
<tr>
<td>21</td>
<td>0.37 (0.09-1.47)</td>
</tr>
<tr>
<td>22</td>
<td>0.37 (0.09-1.54)</td>
</tr>
<tr>
<td>23</td>
<td>0.89 (0.19-4.08)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.33 (0.41-4.31)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>3.31 (1.29-8.48)</td>
</tr>
<tr>
<td>Other or mixed</td>
<td>1.30 (0.29-5.81)</td>
</tr>
</tbody>
</table>

“We don’t need yet another paper showing yet another disparity in health care.”
David Asch to a young post doc proud of his first first-authored publication
Parent knowledge?

Katherine E. Pickard, and Brooke R. Ingersoll. Autism. 2015;13623613:15569745
Parent endorsement of concerns

A hybrid type I randomized effectiveness-implementation trial of patient navigation to improve access to services for children with autism spectrum disorder

Sarabeth Broder-Fingert, Morgan Walls, Marilyn Augustyn, Rinad Beidas, David Mandell, Shannon Wiltsey-Stirman, Michael Silverstein and Emily Feinberg

Reducing Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial

Emily Feinberg, Sc.D., C.P.N.P., Marcela Abufhele, M.D., M.P.H., Jenna Sandler, M.P.H., Marilyn Augustyn, M.D., Howard Cabral, Ph.D., Ning Chen, M.S., Yaminette Diaz Linhart, M.S.W., M.P.H., Zhandra Cesar Levesque, M.P.H., Megan Aebi, M.P.H., Michael Silverstein, M.D., M.P.H.

Building Better Bridges
Doctor-Family Communication
Make it Easier to Diagnose

The Developmental Check-In: Development and initial testing of an autism screening tool targeting young children from underserved communities

Screening for autism spectrum disorder in underserved communities: Early childcare providers as reporters

Yvette M Janvier¹, Jill F Harris², Caroline N Coffield³, Barbara Louis⁴, Ming Xie⁵, Zuleyha Cidav⁴ and David S Mandell⁵
### Poverty Rates Among the Largest U.S. Cities

Philadelphia retains its distinction of having the highest poverty rate among the 10 largest U.S. cities, according to 2016 census estimates.

<table>
<thead>
<tr>
<th>City</th>
<th>Poverty rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philadelphia</td>
<td>25.7%</td>
</tr>
<tr>
<td>Houston</td>
<td>20.8%</td>
</tr>
<tr>
<td>Phoenix</td>
<td>20.3%</td>
</tr>
<tr>
<td>Los Angeles</td>
<td>19.5%</td>
</tr>
<tr>
<td>Dallas</td>
<td>19.4%</td>
</tr>
<tr>
<td>Chicago</td>
<td>19.1%</td>
</tr>
<tr>
<td>New York</td>
<td>18.9%</td>
</tr>
<tr>
<td>San Antonio</td>
<td>18.5%</td>
</tr>
<tr>
<td>San Diego</td>
<td>13.1%</td>
</tr>
<tr>
<td>San Jose, Calif.</td>
<td>10.7%</td>
</tr>
</tbody>
</table>

SOURCE: U.S. Census Bureau, 2016 American Community Survey

Staff Graphic

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*Boundaries on the maps above are based on Philadelphia City Planning Commission Districts.*

Sources: U.S. Census 1970, ACS 2013 3-Year
Policy Changes: Autism Medicaid Waivers

- Designed to keep people out of institutions
- Can expand eligibility
- Can expand covered services
- Require states to set:
  - Enrollment caps
  - Spending caps
- Are binding
Waivers Reduce Unmet Need in Children with ASD


Reduction in Parent-Reported Unmet Need Based on Average Waiver

- <150% poverty
- 150-400% poverty
- >400% poverty

African American
Where do we put our resources?

Systematic reform > change provider behavior > Band Aids > change parent behavior

But most importantly, reducing disparities is about partnering with the communities we want to help.
THANK YOU.