Disparities in the Identification of Children with Autism Spectrum Disorders:

A Meeting Report

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Speakers

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- Amy Wetherby, Ph.D., Florida State University
- Deborah Fein, Ph.D., University of Connecticut
- Olga Solomon, Ph.D., University of Southern California
- Pilar Bernal, M.D., Kaiser Permanente Division of Research/ Kaiser Northern California

Planning Committee

- Regina James, M.D. (NICHD) – Chair
- Alice Kau, Ph.D. (NICHD)
- Lisa Gilloty, Ph.D. (NIMH)
- Judith Cooper, Ph.D. (NIDCD)
- Cindy Lawler, Ph.D. (NIEHS)
- Courtney Ferrel Aklin, Ph.D. (NINDS)
- Eddie Billingslea, Ph.D. (NIA)

Background

- Autism has repercussions throughout all aspects of family members’ lives
- Early diagnosis is vital for receiving the long term benefits of early treatment
- But, autism is often diagnosed several years after the onset of symptoms
- This pattern of delayed and sometimes missed diagnosis may be exacerbated among medically underserved racial and ethnic minorities

Autism Disparities

- Children of ethnic minorities and low SES are screened and diagnosed later than children from higher SES and non-minority families
- Disparities based on geography, school system, race and ethnicity, parental social class and education, and patient age
- Gender-based disparities

Autism Disparities

- Barriers in diagnosis and care for low resource, minority families, especially those who speak another language
- Unequal application and dissemination of knowledge rather than a lack of information

Barriers-Health Care System

- Disparity in reimbursements between different insurance plans, Medicaid, and hospitals
- Cultural and language barriers
- Lack of buy-in among providers for autism screening
- Physicians’ unwillingness to give bad news and lack of knowledge about treatment services

Barriers – from Families

- Unaware of developmental milestones
- Different cultural expectations of development at different ages
- Denial of their child's problems
- Unconvinced of the importance of filling out forms

Barriers – Research Community

- Lack of consensus on the best ages to screen
- Lack of consensus on autism-specific screening tools
- Lack of validated diagnostic tools for children less than two years of age
- Lack of a cross culturally validated broad-band screening tool
- Lack of a reliable biomarker for screening and diagnosis

Needs

- More clinicians and researchers of diverse background and languages
- Autism researchers and service providers with a greater presence and role in communities
- Wider variety of autism screening tools
- Autism screening mandated and reimbursed
- Recognition that autism is a family problem, not an individual problem and that each family is unique

Recommendations

- Establish clearer and more systematic route for receiving diagnostic and treatment services after screening
- Obtain more information on different cultural views on autism and child development
- Gain more information on how clinicians should present the results of screening and diagnosis to patients of different cultures
- Educate medical communities about autism symptoms and the value of formal screening

Recommendations

- Encourage research to address questions of racial barriers to screening, diagnosis, and services
- Obtain a better sense of the number of false negatives in autism screening
- Publish all tools for families in multiple languages
- Increase parent training in implementing meaningful interventions at home