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Speakers

• Catherine Lord, Ph.D., University of Michigan
• 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