

Incorporating Family and Demographic Variables in Outcome and Intervention Research

Themba Carr, M.S.
University of Michigan

International Meeting for Autism Research
Philadelphia, Pennsylvania
May 21, 2010

Conflict of Interest: None

Adults and ASD

- Limited research on adults and ASD
- Research has focused on two main areas:
 - Outcome
 - Predictors of Outcome



How is outcome defined?



- Multiple Domains
 - Independent living
 - Education and Employment
 - Social relationships
 - Co-occurring disorders

How is outcome defined?



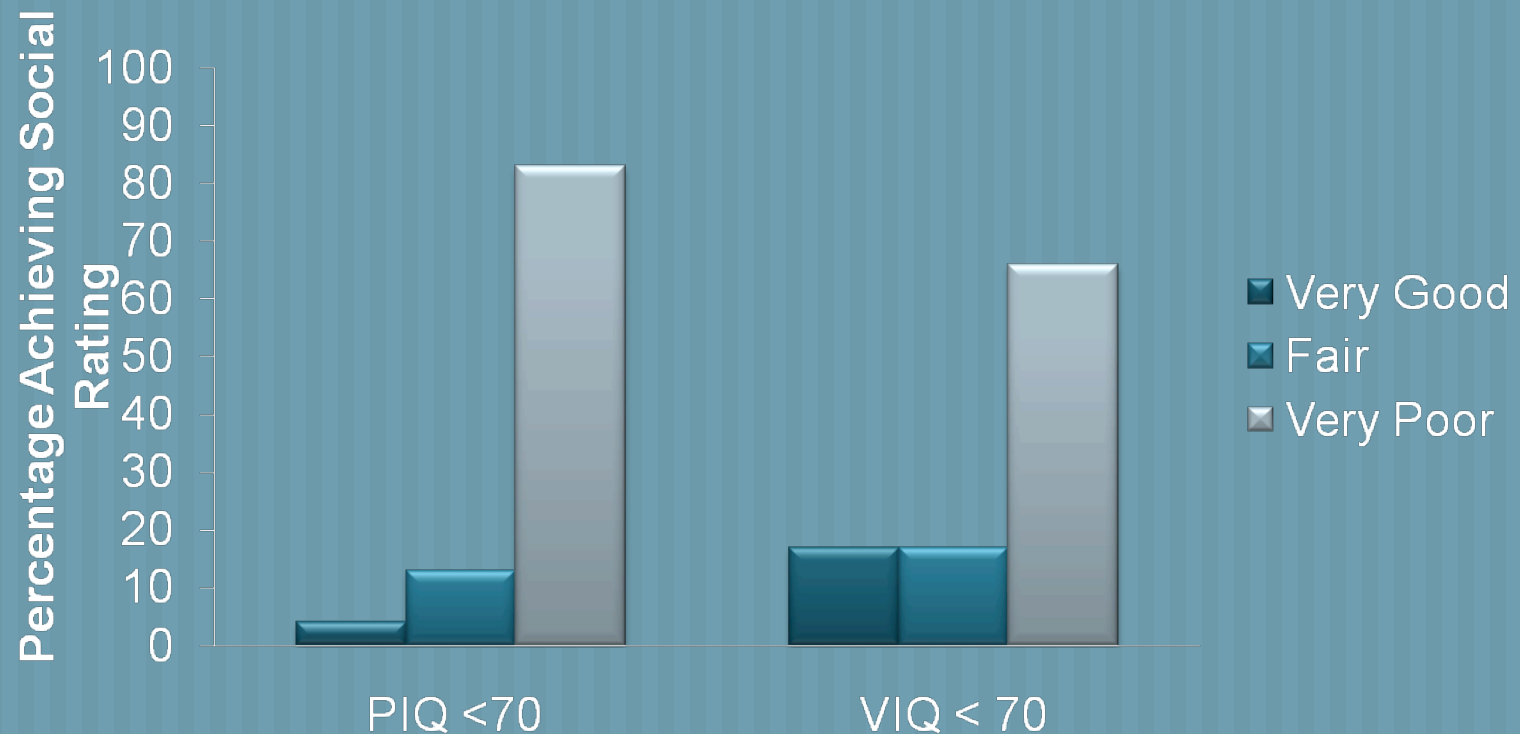
Predictors of Adult Outcome

- Many individual variables have emerged as important predictors
 - Diagnosis/Autism features
 - Cognitive Ability
 - Language Ability
 - Adaptive Behavior

Billstedt et al., 2005; Farley et al., 2009; Howlin et al., 2004

Predictors of Adult Outcome

Social Outcome Ratings: PIQ/VIQ < 70



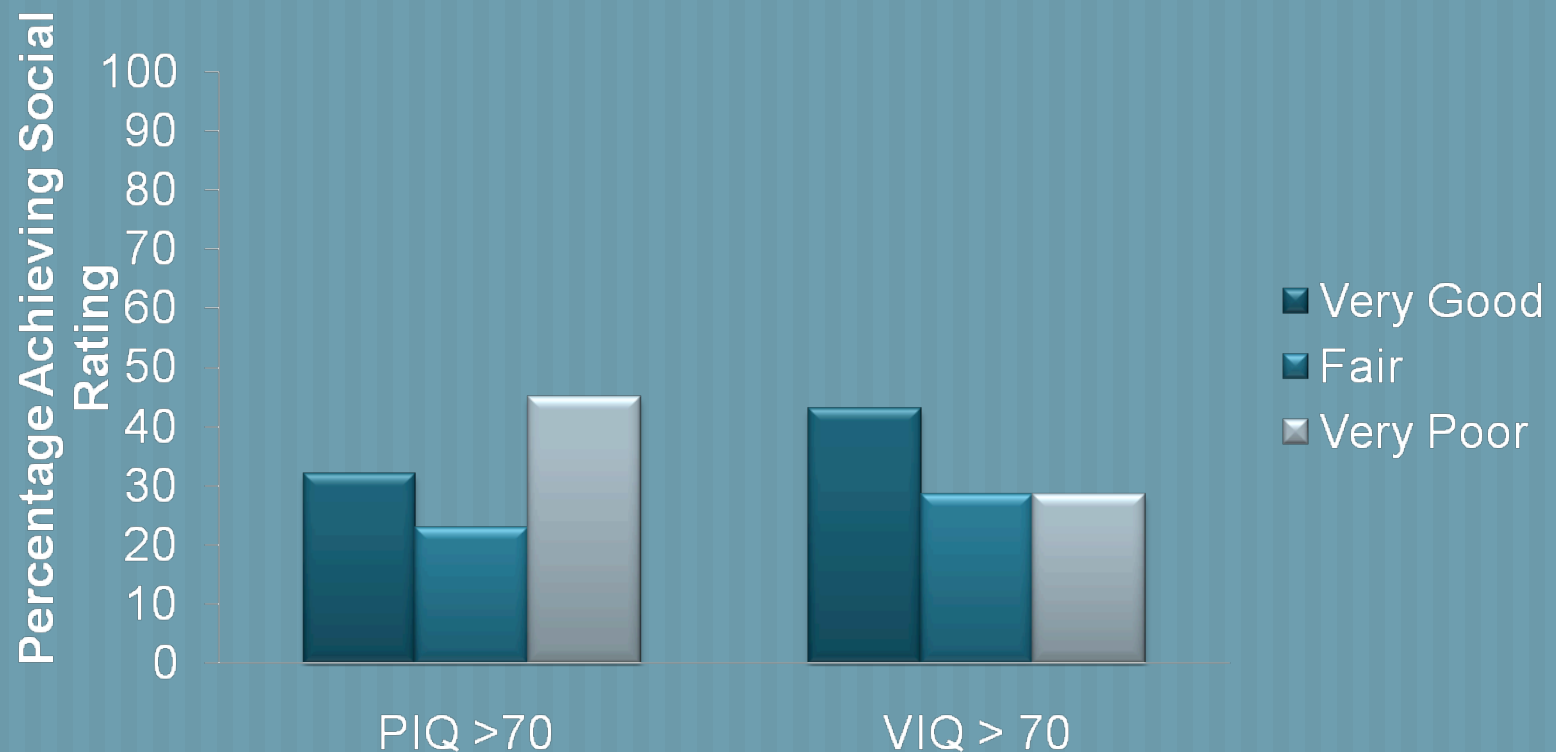
Adapted from: Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004)

Variability in Adult Outcome

- For individuals with IQ greater than 70, there is much greater variability in outcome

Variability in Adult Outcome

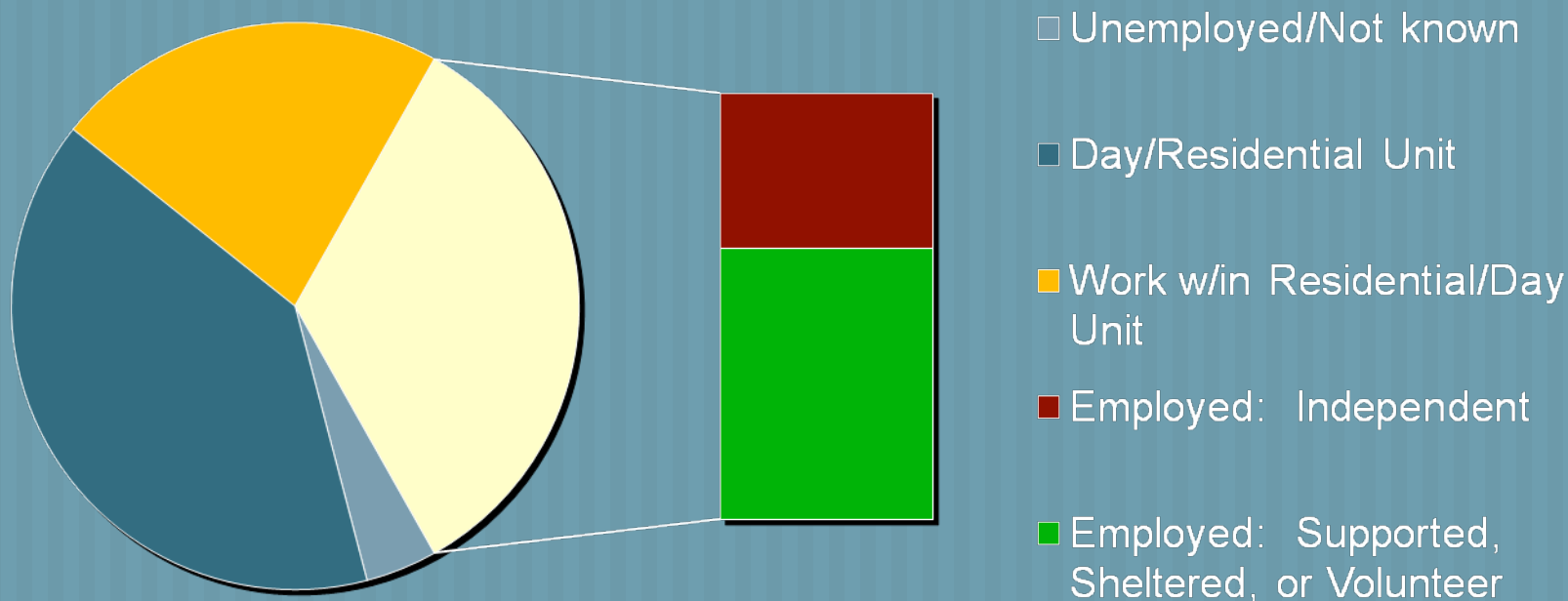
Social Outcome Ratings: PIQ/VIQ > 70



Adapted from: Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004)

Variability in Adult Outcome

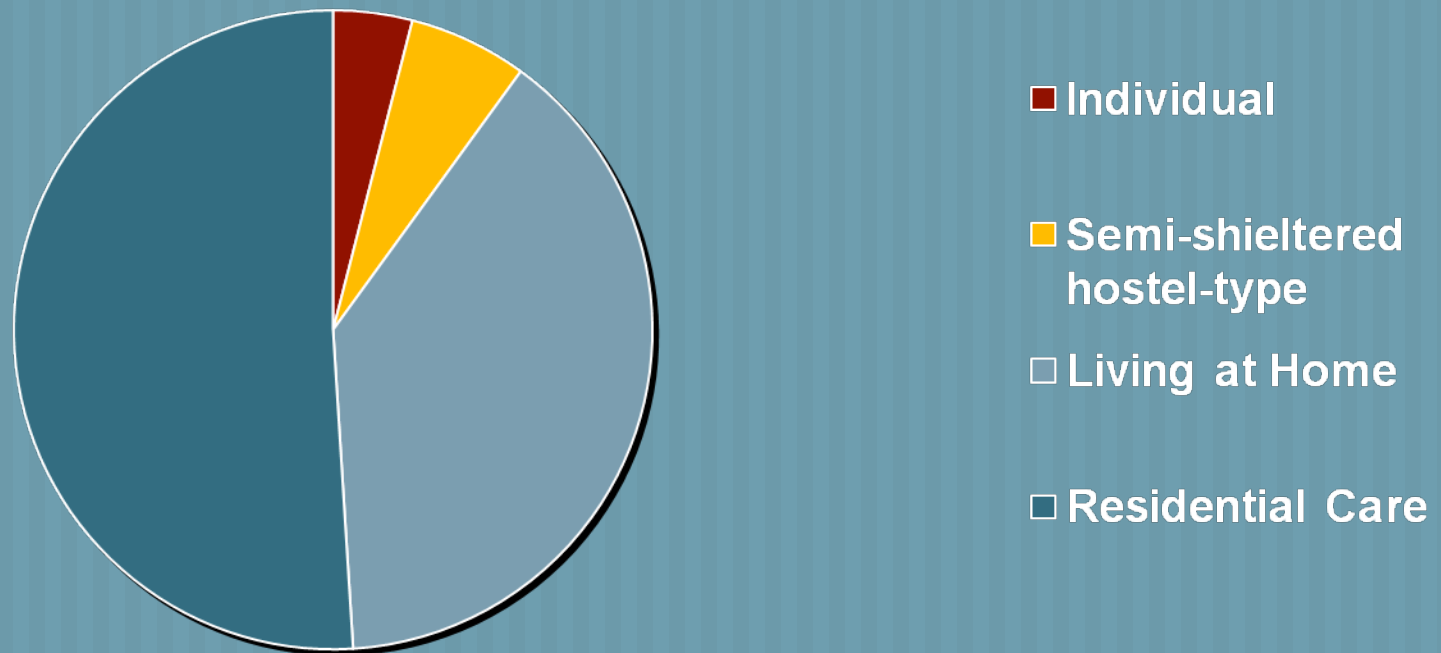
Employment Levels in Adulthood



Adapted from: Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004)

Variability in Adult Outcome

Levels of Independent Living



Adapted from: Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004)

Examining predictors beyond the individual

- Importance of expanding our study of predictors of outcome to include family and demographic variables



Examining predictors beyond the individual

- How do family and demographic variables affect outcome?
- What individual, family, and demographic characteristics best predict positive outcome?
 - Identification of family and community *strengths*

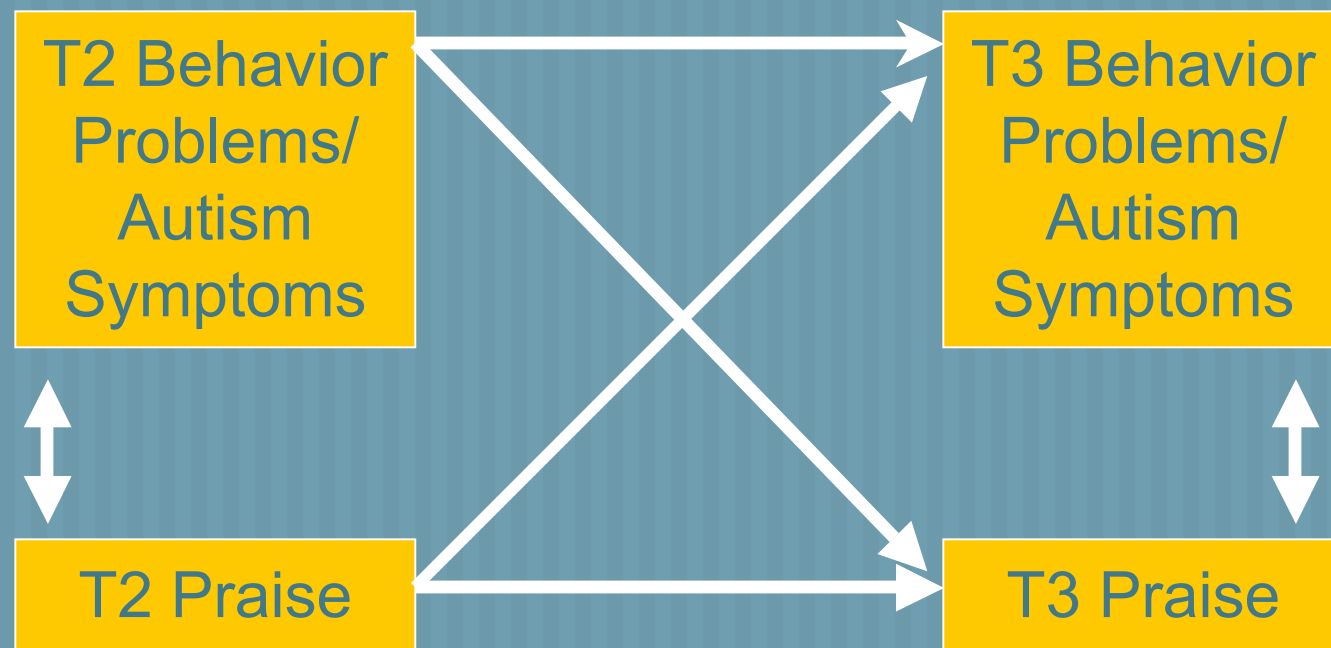
Family predictors of outcome

- Parental well-being
- Parental coping strategies
- Parent-child relationship



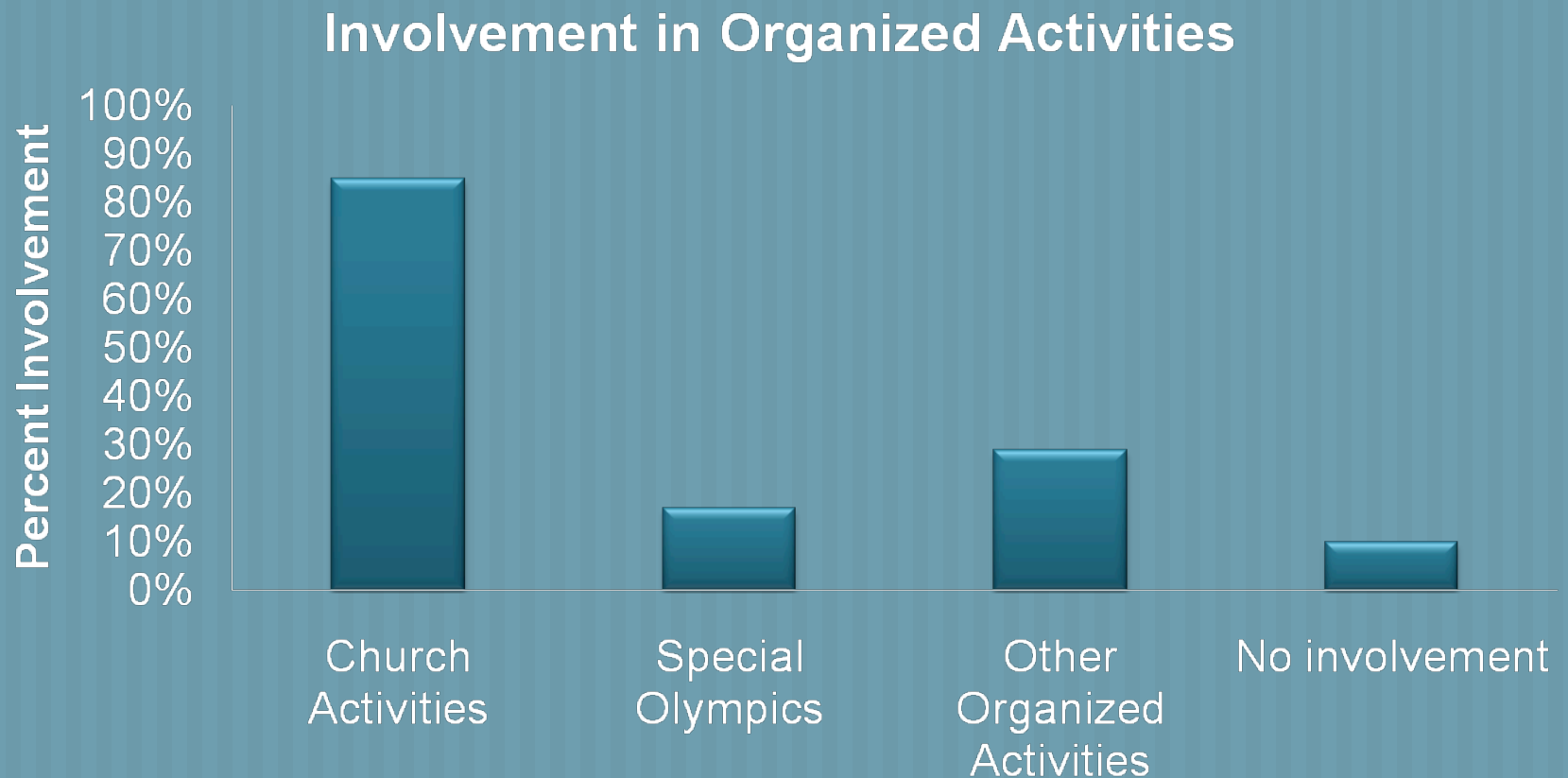
Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Blacher & McIntyre, 2006; Smith et al., 2008

Family predictors of outcome



Adapted from Smith, Greenberg, Seltzer & Ho (2008)

Family predictors of outcome



Adapted from Farley, McMahon, Fombonne, Jenson, Miller, Gardner, et al., 2009

Demographic predictors of outcome

- Social Disparities - Access to services
 - Income
 - Education
 - Geographic Region
 - Race/ethnicity

Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Ruble, Heflinger, Renfrew, & Saunders, 2005; Mandell, Wiggins, Carpenter, Daniels, DiGuseppi, Durkin et al., 2009; Flanders, Engelhart, Pandina, & McCracken, 2007

Demographic predictors of outcome

Percentage Children Diagnosed with Autism

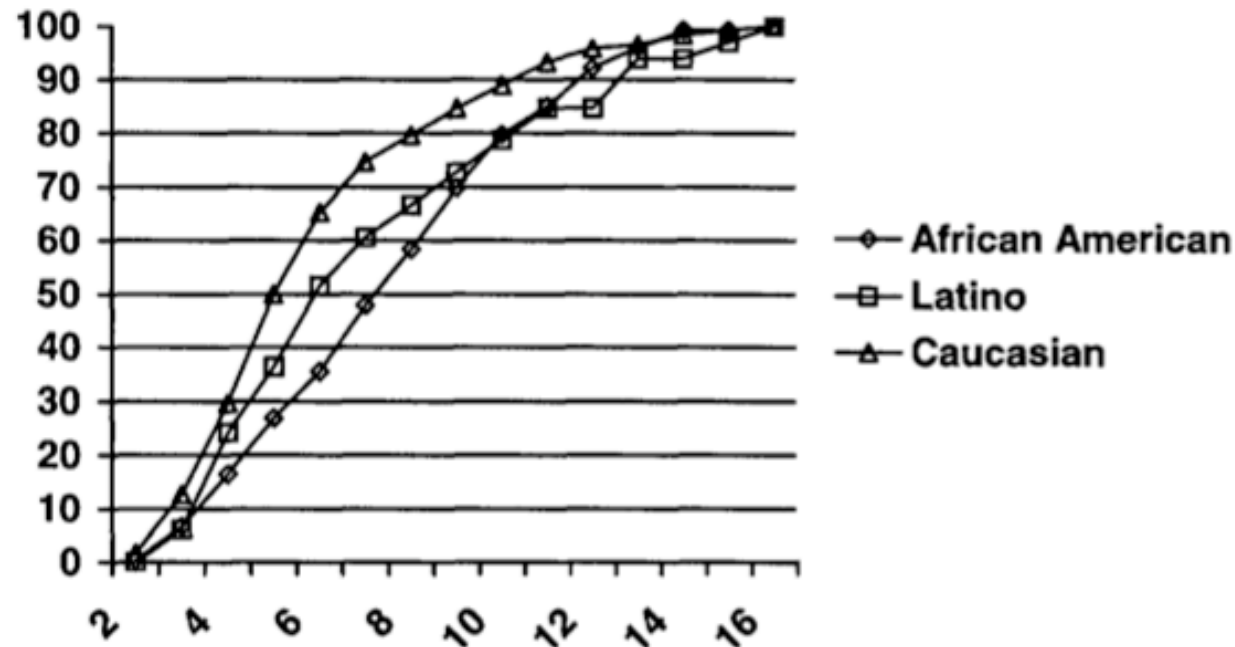


Fig. 1 Cumulative percentage of sample with autism by age at first diagnosis.

Mandell, Listerud, Levy, & Pinto-Martin (2002).

Demographic predictors of outcome

- Demographic differences in maternal experiences
 - Psychological distress, well-being (Magana and Smith, 2006)
 - Perceived negative impact (Bishop et al., 2007)

Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

■ Purpose

- Examine the stability and predictors of perceived negative impact in Caucasian and African American mothers across two time points
- Examine the direct effect of and interactions between child, mother, and demographic characteristics

Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

■ Methods

■ Sample drawn from Early Diagnosis Longitudinal Study

- North Carolina and Illinois
- Children directly assessed at 2,3,5,9; additional data collected through age 14 and beyond

Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

■ Methods

- Time 1 - 30 African American, 80 Caucasian families
- Time 2 - 17 African American, 68 Caucasian
- Mothers administered the Child and Adolescent Impact Assessment (CAIA; Messer, Angold, Costello, & Burns, 1996)

Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

■ Predictors of perceived negative impact:

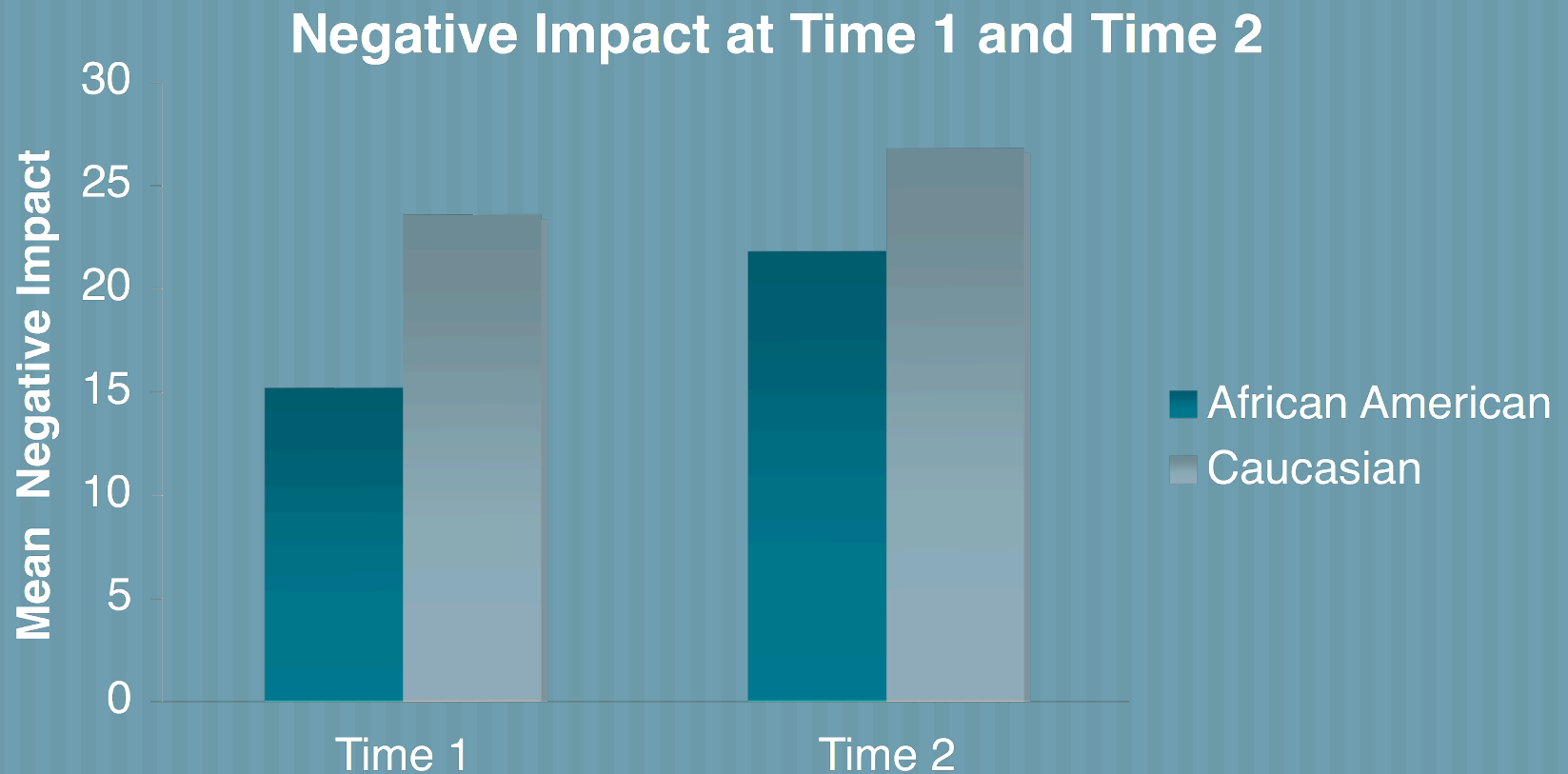
Individual	Family/Demographic
Gender	Ethnicity
Diagnosis	Marital Status
NVIQ	Education
Adaptive Behavior	No. of children
Behavior Problems	Social Support
Repetitive Behaviors	Evaluation Site

Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

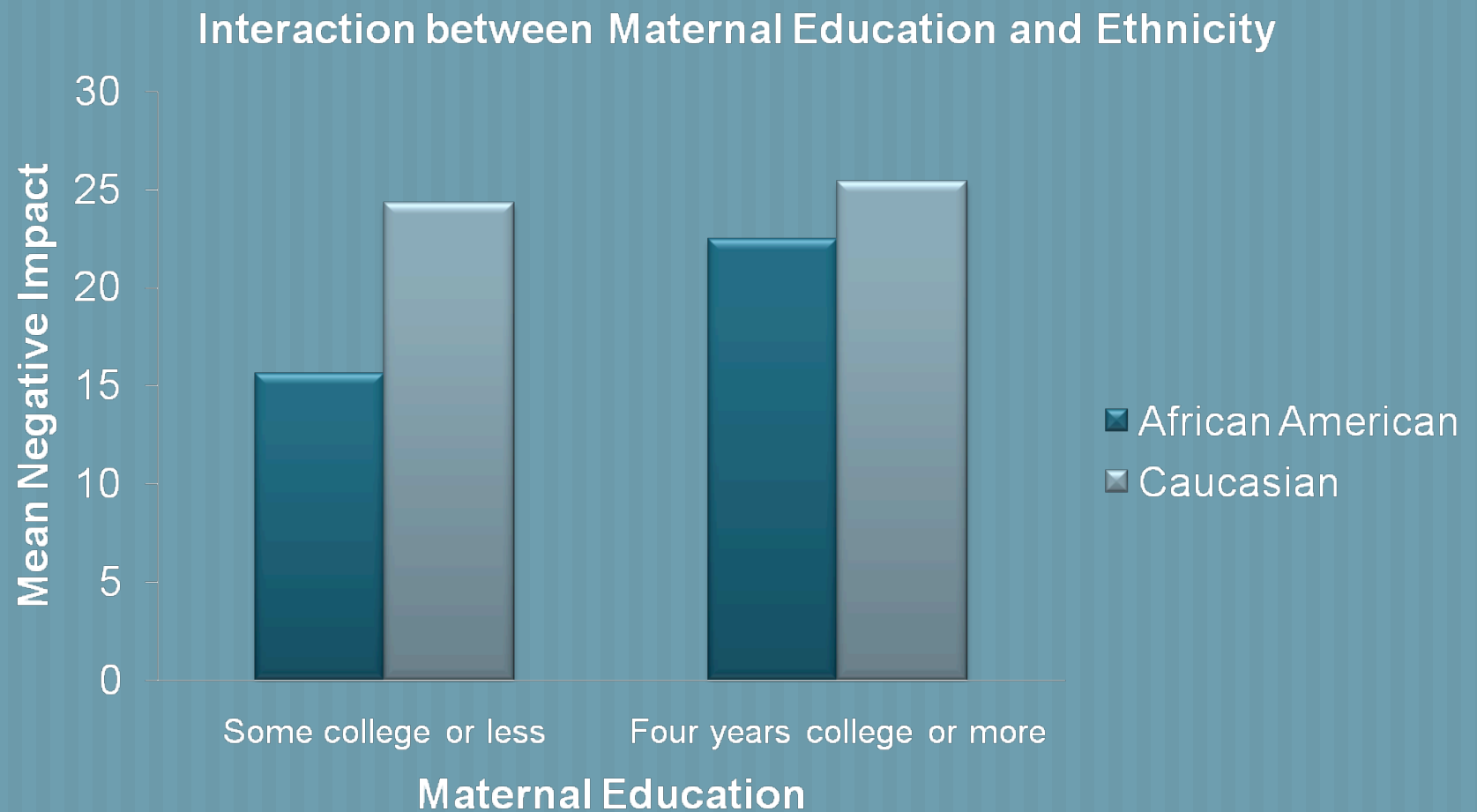
- Significant predictors over time:

Individual	Family/Demographic
Diagnosis*	Ethnicity*
NVIQ*	Education*
Adaptive Behavior*	Social Support*
Behavior Problems*	

Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD



Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

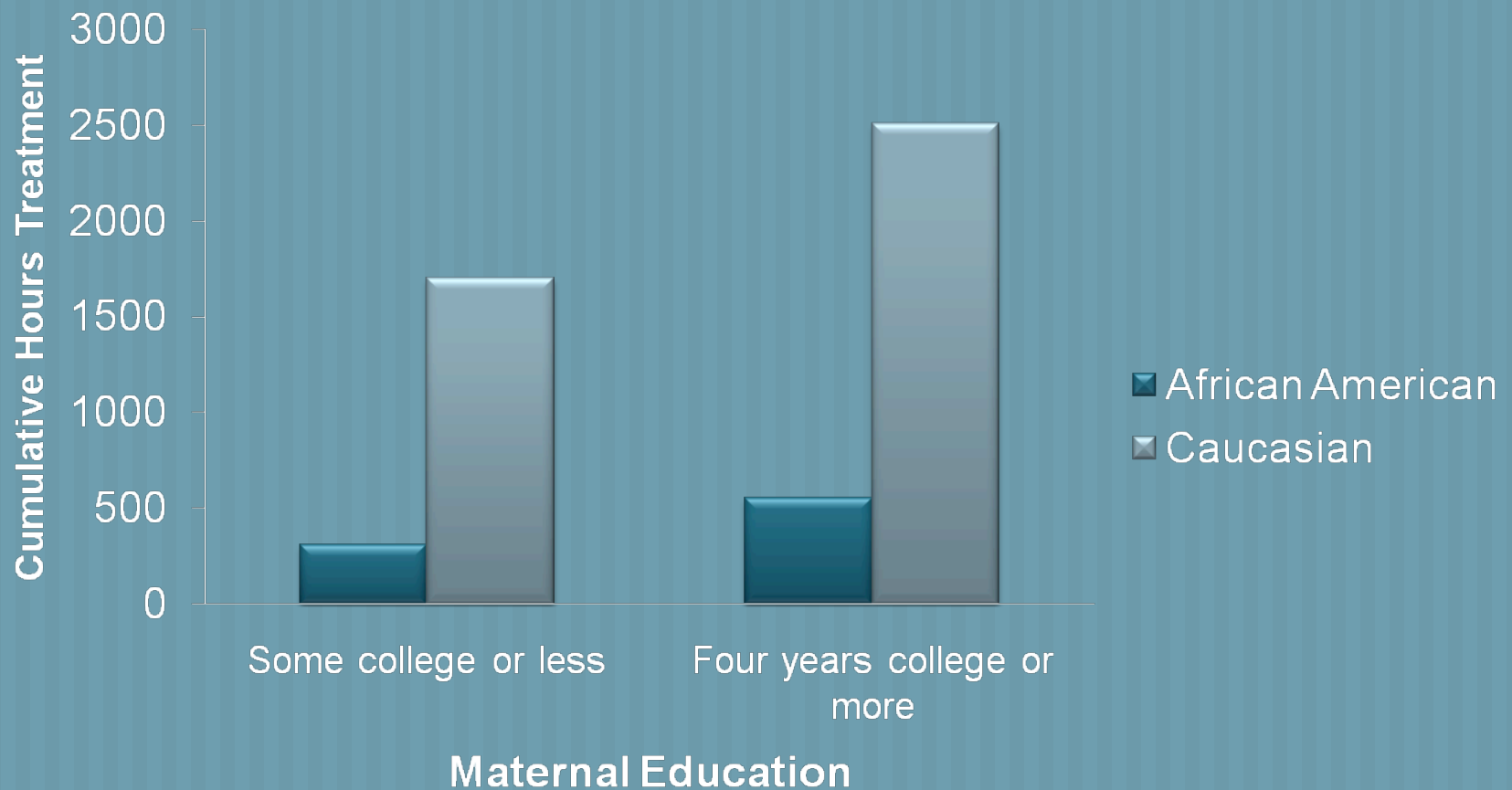


Predictors of perceived negative impact in African American and Caucasian mothers of children with ASD

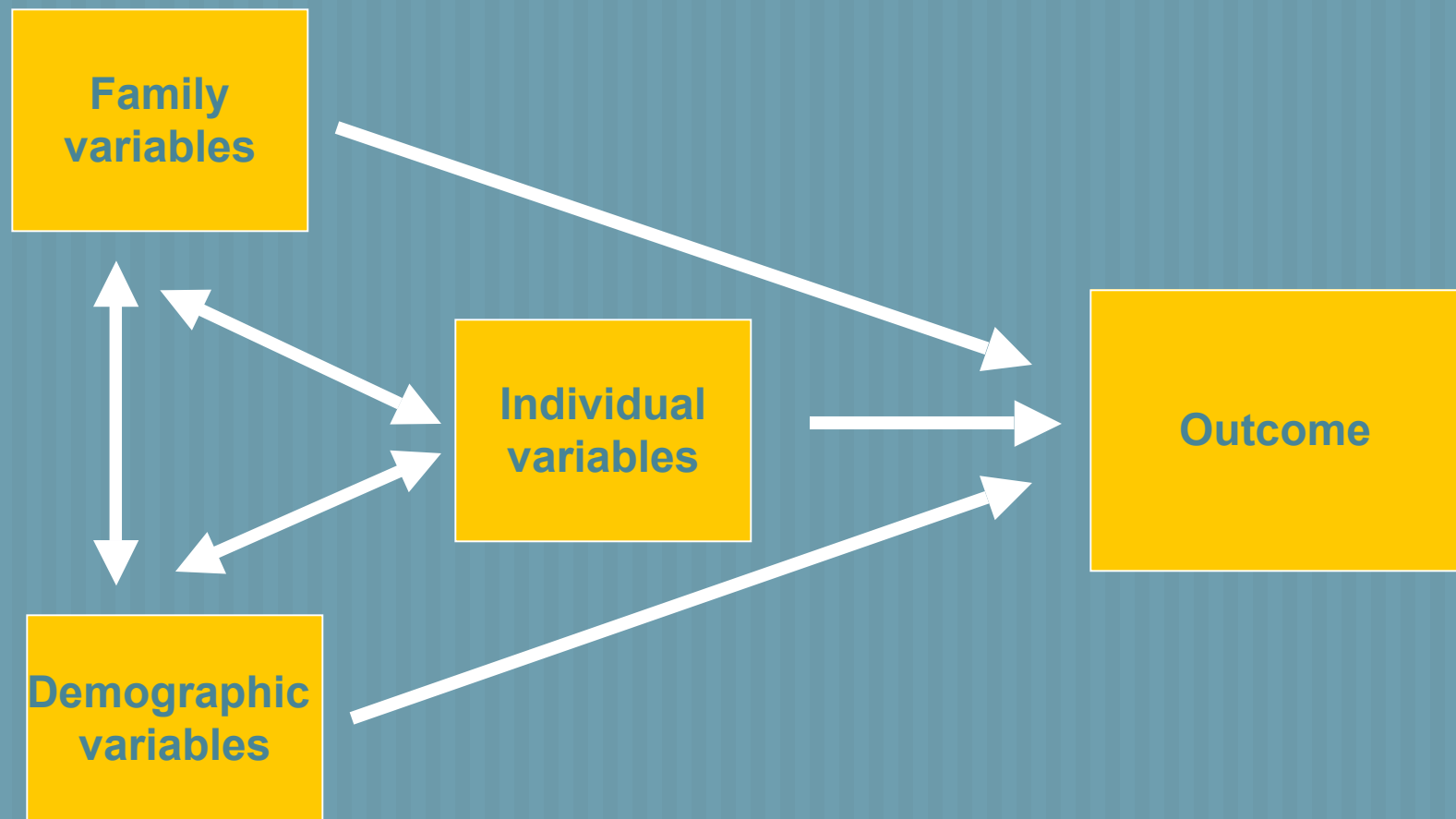
- What possible mechanisms are driving the interactions between family and demographic characteristics?
- Implications for outcome?

Additional Findings from the Longitudinal Study

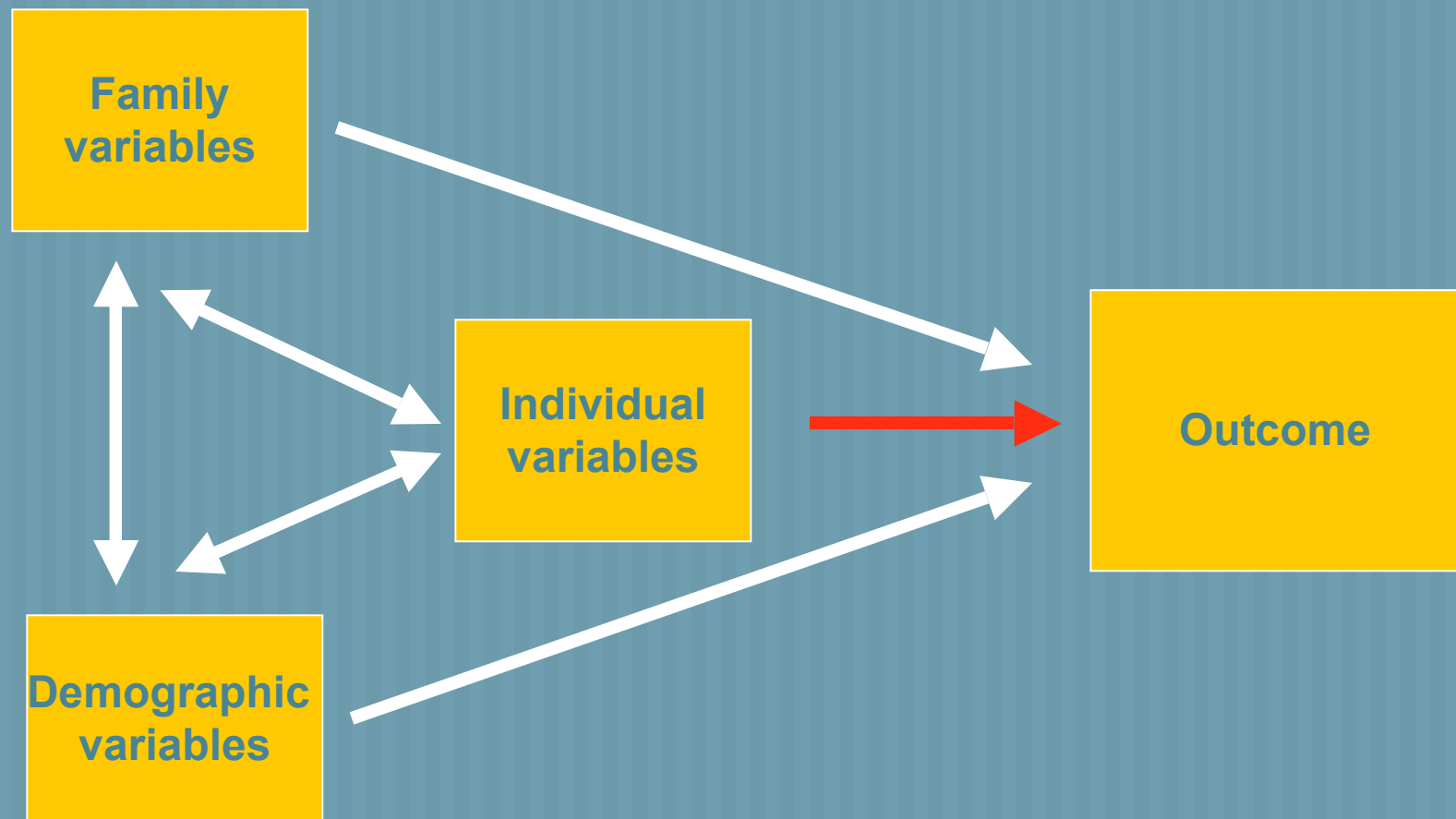
Hours of Individual Treatment: Ethnicity and Education



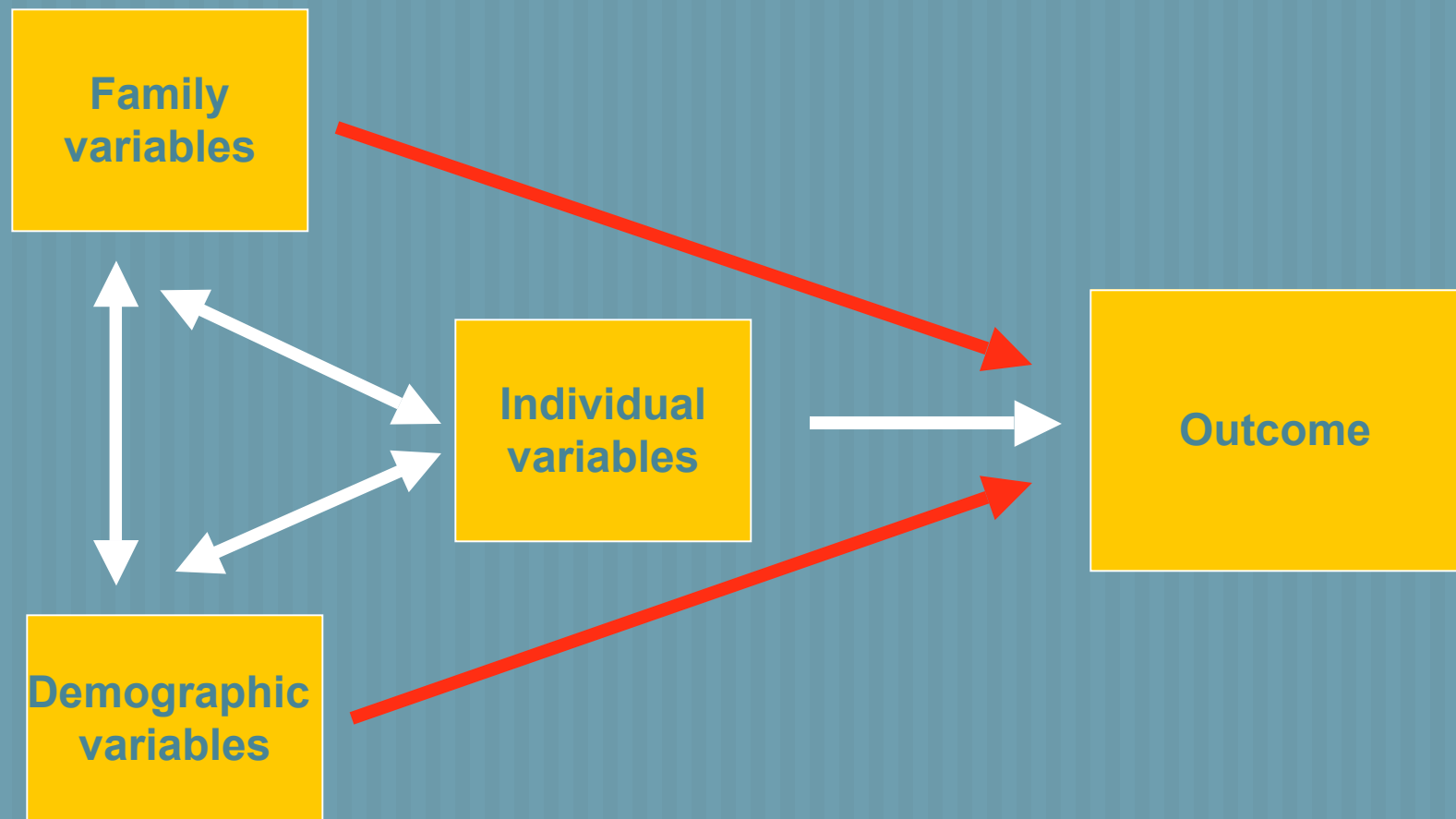
Intersections of individual, family, and demographic variables



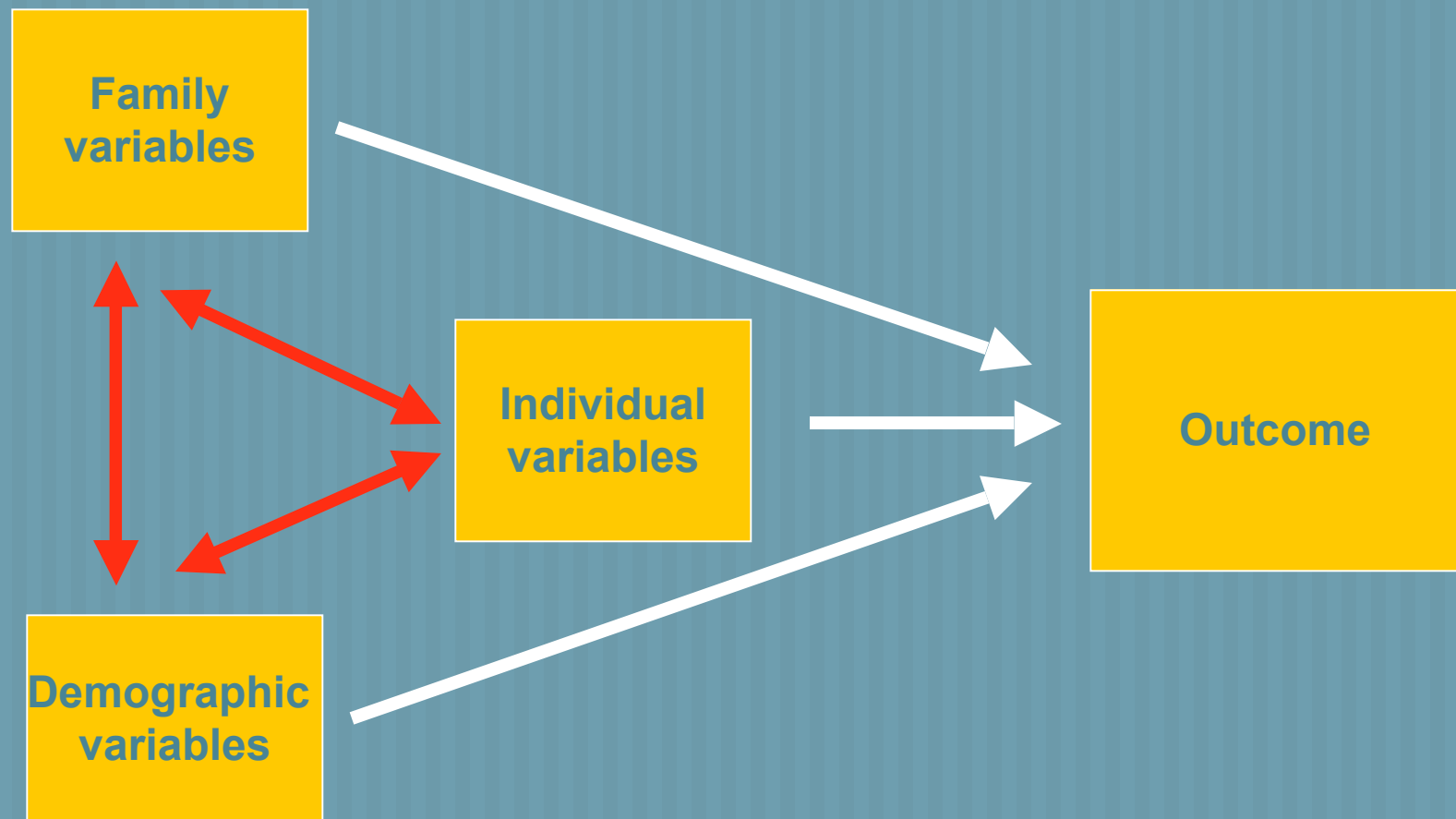
Intersections of individual, family, and demographic variables



Intersections of individual, family, and demographic variables



Intersections of individual, family, and demographic variables



Implications and Future Directions

- Research
- Evaluation and Treatment
- Public Policy



Research Implications

- Continued research examining multiple levels of predictors of outcome across wider demographics of families
 - How does outcome differ across diverse demographic contexts?
 - What are the mechanisms underlying relationships between these variables?
 - Can we reconstruct of outcome to include family variables?

Treatment Implications

- Extending evaluation and treatment services beyond the individual
 - Multidisciplinary approach
 - Support to individuals AND their families
 - Identification of community resources

Public Policy Implications

- Importance of continued policy development to support families of adults
- Importance of including underrepresented families in research

Acknowledgements

- University of Michigan Autism and Communication Disorders Center
 - Catherine Lord
- Funding Sources
 - NIMH (R01 MH081873)
 - Autism Speaks (2482)



Many thanks to the families participating in the Longitudinal Study

References:

Abbeduto, L., Seltzer, M.M., Shattuck, P., Krauss, M.W., Orsmond, G. & Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with autism, Down Syndrome, or Fragile X Syndrome. *American Journal on Mental Retardation*, 109, 237-254

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13-22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35, 351-360.

Bishop SL, Richler J, Cain AC, & Lord C. Perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation*, pp. 112, 450-461.

Blacher, J., & McIntyre, L.L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research*, 50, 184-198.

Farley, M., McMahon, W., Fombonne, E., Jenson, W., Miller, J., Gardner, M., et al. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2, 109-118. et al., 2009

References, cont'd:

Flanders, S.C., Engelhart, L., Pandina, G.J. & McCracken, J.T. (2007). Direct health care costs for children with Pervasive Developmental Disorders: 1996-2002. *Adm Policy Ment Health & Ment Health Serv Res*, 34, 213-220.

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212-229.

Liptak, G., Benzoni, L., Mruzek, D., Nolan, K., Thingvoll, M., Wade, C., & Fryer, G. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the national survey of children's health. *Journal of Developmental & Behavioral Pediatrics*, 29, 152-160.

Magana, S. & Smith, M.J. (2006). Psychological distress and well-being of Latina and Non-Latina White mothers of youth and adults with an Autism Spectrum Disorder: Cultural attitudes towards coresidence status. *American Journal of Orthopsychiatry*, 76, 346-357.

Mandell, D.S., Ittenbach, R.F., Levy, S., & Pinto-Martin, J (2007). Disparities in diagnoses received prior to a diagnosis of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 37, 1795-1802.

References, cont'd:

Mandell, Listerud, Levy, & Pinto-Martin (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41, 1447 – 1453.

Mandell, D.S. & Novak, M. (2005). The role of culture in families' treatment decisions for children with Autism Spectrum Disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11, 110-115.

Mandell, D.S., Wiggins, L.D., Carpenter, L.A., Daniels, J., DiGuseppi, C., Durkin, M.S., et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99, 493-498.

Newschaffer & Curran (2003). Autism: An emerging public health problem. *Public Health Reports*, 118, 393 – 399.

Ruble, Heflinger, Renfrew, & Saunders (2005). Access and service use by children with autism spectrum disorders in Medicaid managed care. *Journal of Autism and Developmental Disorders*, 35, 3 – 13.

Smith, L., Greenberg, J., Seltzer, & Ho, J. (2008). Symptoms and behavior problems of adolescents and adults with autism: Effects of mother-child relationship quality, warmth, and praise. *American Journal on Mental Retardation*, 113, 387-402