Parent Perceptions of Autism Severity: Exploring the Social Ecological Context

Background

- “Autism is a neuro-developmental disorder characterized by impairments in social reciprocity, communication, stereotypic behaviors, and restricted and repetitive interests” (Hock & Ahmendani, 2012, p. 298)

- Estimated 1 in 110 school age children in the USA are diagnosed with an autism spectrum disorder (ASD)

- Little is known about contextual factors (i.e., physical & social environment) influencing parents’ perceptions of their child’s ASD related symptoms

(Hock & Ahmendani, 2012)
The aims of the current study are to:

1) compare the social ecological contexts (e.g., social & physical environment) of parents of children with ASD & parents of non-autistic children; and

2) explore the degree to which these social ecological forces are associated with parents’ perceptions of their child’s ASD severity.

(Hock & Ahmendani, 2012)
Methods

• Examined the data from the 2007 National Survey on Children’s Health (NSCH)
  - Random telephone survey data on parents about the health and well-being of their children under 18
  - Used only data from those who responded yes or no that they have a child who has ever been diagnosed with an ASD (n = 81,923; those who reported yes n = 1,427)

• Examined relationship of parent-perceived lifetime childhood ASD (e.g., whether their child had ever been diagnosed with an ASD) & parent-perceived ASD severity with the following variables:
  - Parent’s mental health (i.e., coping with parenthood)
  - Social environment (i.e., relationships in neighborhood)
  - Physical environment (i.e., condition of neighborhood such as litter, vandalism)

(Hock & Ahmendani, 2012)
Findings

• 1.7% of overall sample had parent-reported lifetime ASD, the majority of these were:
  ▪ male
  ▪ white/non-Hispanic
  ▪ had at least one family member who worked full time for at least 50 weeks during the previous year
  ▪ lived in families whose income was greater than 300% of the national poverty level

• Compared to other children in the overall sample, the subsample of those with lifetime ASD were:
  ▪ more likely to be male
  ▪ in the middle childhood age group
  ▪ living in a household with fewer children
  ▪ had lower levels of family employment
  ▪ family incomes were closer to the national poverty level

(Hock & Ahmendani, 2012)
Findings (cont.)

- Parents who reported their child had a lifetime ASD:
  - had increased odds of reporting poor neighborhood social capital
  - did not differ from parents of other children on physical neighborhood conditions including vandalism, garbage on the street, and rundown housing
  - had higher levels of aggravation
  - had lower levels of overall mental health
  - reported greater difficulty coping
  - reported lower levels of relationship satisfaction

- Parents of children with and without ASD did not differ from each other regarding whether they felt their children were safe in the community or at school

(Hock & Ahmendani, 2012)
Findings (cont.)

• More severe parent-reported ASD:
  ▪ was associated with living in neighborhoods with rundown housing and garbage on the street, but not vandalism
  ▪ did not vary from other parents in perceived safety at school and in the community
  ▪ was associated with lower parent relationship satisfaction
  ▪ was linked to parent mental health and aggravation
  ▪ was not associated with levels of parent coping

(Hock & Ahmendani, 2012)
Discussion: Physical Environment

• Two aspects of the physical environment, garbage on the street and rundown housing, were significantly related to parents’ perceptions of ASD severity. This may be related to either possibility:
  ▪ Parents may perceive their children’s ASD as being more severe if they have fewer resources to devote to their child’s services, or
  ▪ Families have less money to spend on housing when their children require more financial resources to address more severe ASD needs

(Hock & Ahmendani, 2012)


Discussion: Social Environment

• Parents of children with ASD report lower levels of neighborhood social capital than other parents. This may be related to the possibilities that:
  ▪ their unique parenting experiences cause them to rely less on neighbors and more on specialized support networks of treatment providers and other parents of children with special needs
  ▪ these parents experience stigma in their local communities

• Parents’ satisfaction with their partner relationship was associated with their perceptions of ASD severity. This may be related to the possibility that:
  ▪ They depend more heavily on their spouses for practical and emotional support than on their communities

• These findings suggest, “the relationship between parenting partners is more important than neighborhood social capital in understanding the ways that parents perceive their children’s symptoms” (Hock & Ahmendani, 2012, p. 302).
• The individual characteristics of parents (e.g., higher levels of aggravation, lower levels of mental health) were also related to their perceptions of their children’s ASD severity. This could be related to these possibilities:
  ▪ the more severe a child symptoms are may lead to greater parent aggravation and lower levels of mental health
  ▪ parents who are prone to aggravation and poor mental health tend to perceive their child’s symptoms as being more severe

• Parent coping was significantly associated with a lifetime report of ASD, but not with the differing levels of ASD severity. This could be related to:
  ▪ The parents’ overall sense of their own coping may be influenced by the unclear developmental expectations, specialized treatment needs and unpredictable parenting demands associated with a child with an ASD
Implications for Practice

• Health Professionals could:
  ▪ consider the findings in this study when using parents’ perceptions as part of their data for determining diagnoses of children with an ASD
  ▪ take into account the social ecological domains used in this study (i.e., parent’s mental health or level of aggravation) when assessing the context of the child and family & developing family-centered treatment plans
  ▪ address lower relationship satisfaction in parents of children with ASD by incorporating parent & relationship support into their treatment plans for children with ASD

(Hock & Ahmendani, 2012)