Improving Access to Early Autism Screening, Diagnosis and Treatment for Young Children from Underserved Communities

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Objectives

- Identify 3 factors for different rates of ASD based on race, ethnicity, or income
- Briefly describe 2 research projects that addressed the need for improving access to early ASD diagnosis and treatment
- Describe the implementation and results of an existing, community-based program that is increasing access to care for underserved families
- Discuss practical cross cultural considerations in screening and assessment
Background

• Early diagnosis associated with earlier access to intervention increases optimal outcomes (Lord 1995; Wood & Weatherby, 2003)

• Research suggests that racial and income disparities exist in early detection and treatment of autism spectrum disorder (ASD)

• Thus, it is important to reduce disparities to improve early detection in underserved populations
• 115.8 million identify as minority race or ethnicity (2012, Esri)
  – 52.8 million Hispanics
  – 39.5 million blacks
  – 15.2 million Asians/American Indians/Pacific Islanders

• By 2050, Caucasian no longer the majority
  40% of children under age 5 will be Hispanic

Current Gender Differences in ASD Prevalence (USA)

1:42 boys and 1:189 girls
There are almost 5 times more boys with ASD than girls
Disparities in Diagnosis of ASD

- Children with low socio-economic status (SES), racial and ethnic minorities, and those with limited English proficiency less likely to be identified with ASD despite no known prevalence differences

- Low SES children with ASD identified at later age
  (Durkin et al, 2010, Fountain et al, 2010)

- Racial/ethnic minorities identified at later age
  (Mandell 2002, 2009)

- When identified early, racial/ethnic minorities are more severe than Caucasian, regardless of income
  (Liptak et al 2008; Tek & Landa, 2012)
1. Not recognizing red flags:

“He must think he’s big. I have to call him two or three times before he will look at me.”

“He’s strong; pain doesn’t bother him.”
Reasons for Disparities

2. Access to Screening/Evaluations:

- Not knowing where to go
- Limited places providing screening
- No transportation
- Insurance issues
3. Issues with Healthcare Provider:

- Healthcare provider not doing screening
- Communication/language issues with provider
- Lack of trust
- Provider misinterprets child behavior (i.e., hyperactive, cognitively impaired, oppositional)
Reducing Disparities Research: Children’s Specialized Hospital

Two studies funded by:

The New Jersey Governor’s Council for Medical Research and Treatment of Autism

(funded by speeding tickets)
Objectives

Reduce Disparities by:

• providing free screening and evaluation in underserved communities

• adapting/developing educational materials that are culturally relevant

• determining feasibility of screening within daycare/preschool settings
• Identified 6 low income cities in NJ: Newark, Plainfield, Trenton, New Brunswick, Elizabeth, Bridgeton

• Conducted focus groups to review educational materials

• Free developmental screening in federally-qualified community health clinics and daycares

• Free evaluations for those children screening positive for ASD

• Provided educational outreach for parents and providers on early development and screening
Findings

• Screened 1080 children in preschools (population-based sample).
  • 20% screened positive for ASD
  • 3.5% diagnosed with ASD. Teachers more accurate predictors than parents

• Evaluated 128 children in 6 FQHCs (at risk sample) 58% diagnosed with ASD
• Emphasize visual, reduce literacy demands

• Families requested more education on social communication milestones from daycare and medical providers

• Anticipatory guidance on development is lacking
Conclusions

- Community-based screening/evaluation identifies children previously not identified with ASD

- Early childhood educators can be trained to screen their students for ASD

- Neither parent nor preschool teacher is particularly accurate at identifying who does not have ASD (teachers have some tendency to over-identify ASD)

- Parents in underserved communities may fail to report early signs of ASD and often did not understand items traditionally used on ASD screening tools
• Direct eye contact is perceived as a form of disrespect

• Parents are trying to give the “right” answer on screeners

• Parents value independence which may delay recognition of early signs

• Poor understanding of questions

• Challenging behaviors are not connected to autism
Outcomes

“Watching My Child Grow” coloring book

Started idea of need for visual-based ASD screening tool
Objectives and Description:

- Improve identification of young children with ASD from underserved populations by refining and testing utility of new ASD screening tool designed for families with low English literacy and comprehension challenges.

- Evaluate screening within community early-childhood education sites as a model for reducing barriers to early screening and diagnosis of ASD.
Innovation:
Developmental Check-in (DCI)

• DCI uses pictures and has limited language/literacy demands

• May ensure that screening data better reflects parent observation of their child’s behavior

• No commonly used tools validated for use with children ages 30 to 48 months. DCI designed to include this age range.

• Very little research on screening for ASD in preschool settings. May improve access by bringing the service to where children are
DCI was piloted at CSH with an at risk population of children under 4 years old and results were similar to the MCHAT

Current Status

• The first phase is refining the DCI in high risk setting population

• The second phase will be to refine in a general day care population
Objectives:

- Increase access to care to low income and racial/ethnic minority
- Identify young children at developmental risk in these communities
- Help to insure that those children most in need are able to access care
Benefits of Screening

- First step in obtaining needed services for young children. Answers the question, “Does the child need further evaluation.”
- It is easy to administer
- Low cost
- Helps to increase access to care to families that are the most in need
- Encourages parental involvement
“Quick Peek”

Funded by Kohl’s Cares
• Screenings are free

• Offered primarily in communities which there is a large low income or racial/ethnic minority population.

• Offered in community setting where families can walk, drive or take public transportation

• Program is for children ages 1-5
• Staff comes to family in location which feels non-threatening

• Screening and educational information offered in English and Spanish

• Families immediately connected with a representative from SPANNJ to assist in making appointments

• Standardized screening tool used interactively which increases accuracy
Screening Procedure

- 30-minute slots
- Parent or caregiver must be present
- Consent forms and demographic Information
- Interactive standardized screening
- Written results and educational material and activities given in English and Spanish
- Clinics held during the week and on Saturdays
- Follow-up calls are made to every family recommended for further evaluations
“Quick Peek” Results

52 Clinics (since Dec 2012)

- Bergen
- Essex
- Hudson
- Hunterdon
- Mercer
- Middlesex

- Monmouth
- Morris
- Ocean
- Passaic
- Somerset
- Union
"Quick Peek" Results: Community

- child care providers
- family success centers
- health fairs
- Kohl’s stores
- public libraries
- resource and referral agencies
- Salvation Army
- WIC
- YMCA/YMHA
“Quick Peek” Results: Population

- 670 children screened
- 32.4% under 3 years old
- 67.6% over 3 years old
- 27.91% were non-English speaking
Of the 670 children screened:

- 50.44% of the children were recommended for further evaluations
- 8.63% were recommended for follow-up call
- Of the families who received follow-up calls, 68.2% were reached
- Of those reached by phone, 84% followed up with the recommendations
“Quick Peek” Results: Diagnosis

- autism spectrum disorder
- speech and language delay
- ADHD
- sensory integration disorder
- anxiety or conduct disorder
- developmental delay
- visual impairment
- hearing impairment
- feeding disorder
- spasticity
Cross-cultural Considerations
• ASQ address cultural diversity
  – implementation
  – scoring

• Screens in 5 domains:
  – communication
  – gross motor
  – fine motor
  – personal social
  – problem solving
Features of ASQ-3

- designed for parents
- many languages
- 4-6 grade reading level
ASQ-3 Cultural Adaptability

- Alternative administration methods for individuals from different cultural backgrounds
- Alternative materials for individuals from different cultural backgrounds
- Scoring permits omission of inappropriate items
- Normative sample includes diverse populations
Retrospective study on children diagnosed with ASD who had ASQ data

- N = 58; 81% < 3 years
- 100% identified
  - 96.6% failed communication
  - 86.2% failed personal-social
  - 81.0% failed problem solving
- 100% of parents identified concerns in overall items
- High sensitivity in identifying ASD
What issues may arise when:

• meeting with parents and introducing screening?
• administering the screening tool (ASQ-3)?
• communicating results or making follow-up suggestions in the home?
• making community referrals?
Recommendations for Practitioners

- Develop cultural awareness
- Consider families’ pre- and post-immigration experiences
- Use interpreters during process
- Ask families about cultural expectations of early development
- Clarify language and meaning of each item
- Reframe questions

Adapted from Cross-Cultural Lessons: Early Childhood Developmental Screening and Approaches to Research and Practice, CUP Partnership, Alberta, Canada
• Incorporate non-standardized methods into the screening process
• Interpret screening results with caution and integrate relevant cultural data
• Debrief the results with the family and together determine the most appropriate follow-up to screening results
• Throughout the process, validate the family’s cultural belief system

Adapted from Cross-Cultural Lessons: Early Childhood Developmental Screening and Approaches to Research and Practice, CUP Partnership, Alberta, Canada
Culturally sensitive questions to gather information from family members when concerns or problems arise:

- Is there a problem?
- Why is there a problem?
  - What do you think has caused the problem?
- What can be done?
  - What types of interventions would be appropriate?
- Who can help?

Adapted from Cross-Cultural Lessons: Early Childhood Developmental Screening and Approaches to Research and Practice, CUP Partnership, Alberta, Canada
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Hospital Sites

- Bayonne
- Clifton
- Egg Harbor Township
- Fanwood
- Hamilton
- Mountainside
- Newark
- New Brunswick
- New Brunswick - Plum Street
- Roselle Park
- Toms River - Stevens Road
- Toms River - Lakehurst Road
Programs and Services

Outpatient Services:
- Audiology
- Autism diagnosis and treatment
- Comprehensive feeding program
- Early Intervention
- Medical day care
- Neurodevelopmental services
- Neurorehabilitation program
- Nutritional services
- Occupational therapy
- Physical therapy
- Psychiatry
- Psychology
- Rehabilitation technology
- Specialty medical services
- Speech therapy

Comprehensive Inpatient Programs:
- Chronic medical illness
- General rehabilitation
- Infant and toddler habilitation
- Spinal cord injury and dysfunction
- Brain injury
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Long Term Care:
- Skilled nursing home for pediatric residents

Community Programs:
- Lightning Wheels sports team
- Adaptive aquatics
- Martial Arts
- Friday Night Fever
- Camp Open Arms
- Kohl’s Autism Awareness
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