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

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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

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U.S. Demographics

- 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

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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)

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Reasons for Disparities

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."

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Reasons for Disparities

2. Access to Screening/Evaluations:

- Not knowing where to go
- Limited places providing screening
- No transportation
- Insurance issues

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Reasons for Disparities

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)

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Reducing Disparities Research: Children's Specialized Hospital

Two studies funded by:

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

NJ Health
New Jersey Department of Health

(*funded by speeding tickets*)

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First Research Study

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

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Description of Project

- 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

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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

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Culturally Relevant Materials

- Emphasize visual, reduce literacy demands
- Families requested more education on social communication milestones from daycare and medical providers
- Anticipatory guidance on development is lacking

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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

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Observations

- 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

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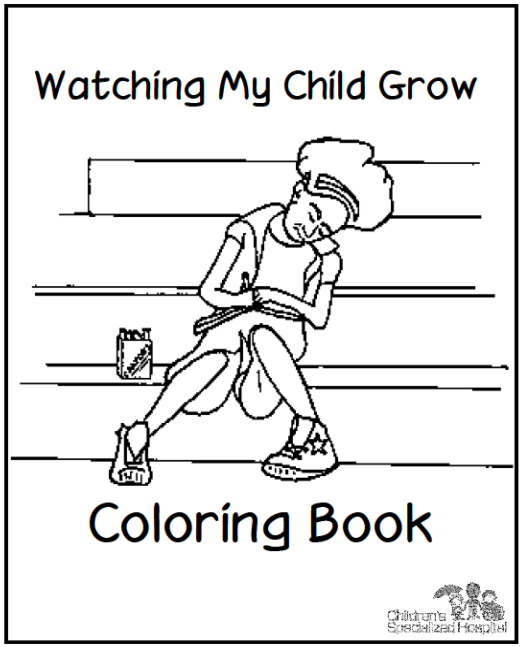
Outcomes

"Watching My Child Grow" coloring book



Started idea of need for
visual-based ASD screening tool

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Second Research Project

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

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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

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Sample Item

Comforts

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Results

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

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Free Community Screening Project

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

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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

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“Quick Peek”

Funded by Kohl’s Cares

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Reduce Disparities

- 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

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Reduce Disparities

- 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

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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

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“Quick Peek” Results

52 Clinics (since Dec 2012)

- Bergen
- Essex
- Hudson
- Hunterdon
- Mercer
- Middlesex
- Monmouth
- Morris
- Ocean
- Passaic
- Somerset
- Union

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“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

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“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

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“Quick Peek” Results: Referrals

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

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“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

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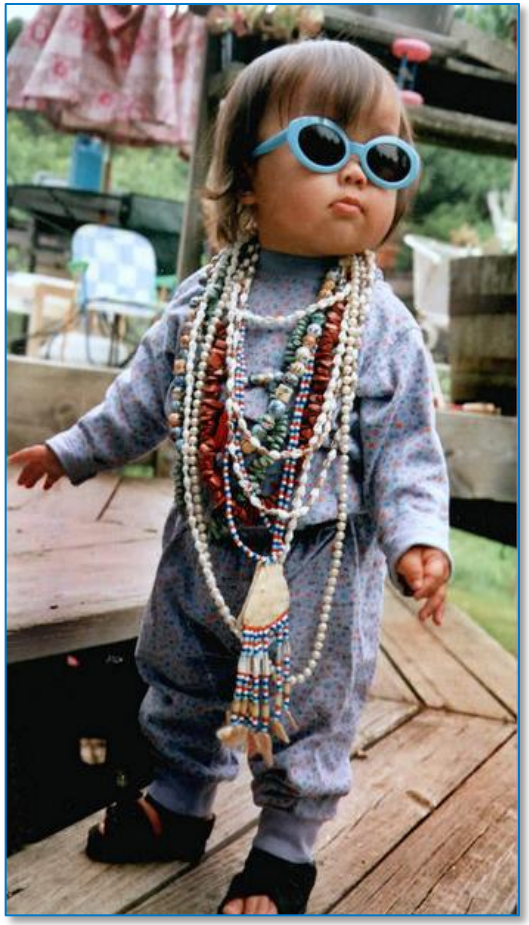
Cross-cultural Considerations



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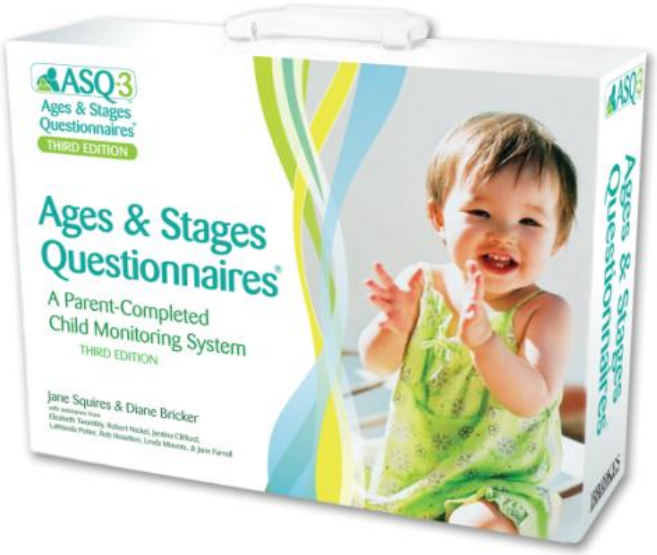
Features of ASQ-3

- ASQ address cultural diversity
  - implementation
  - scoring
- Screens in 5 domains:
  - communication
  - gross motor
  - fine motor
  - personal social
  - problem solving



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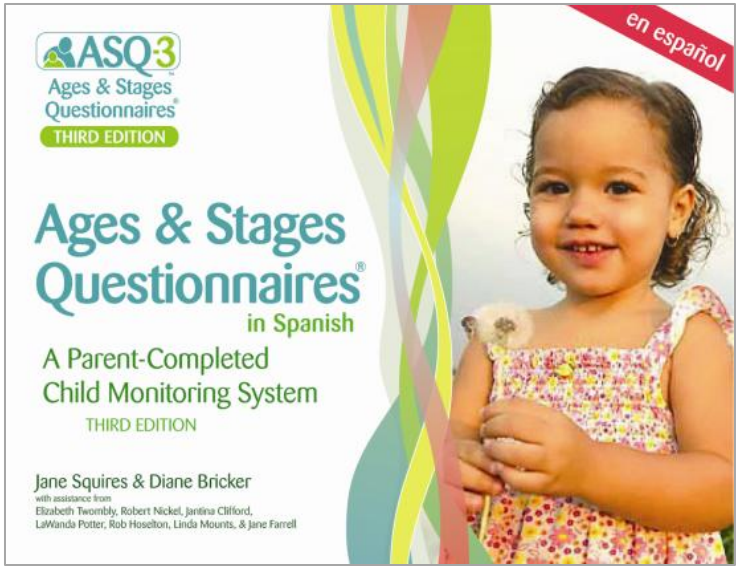
Features of ASQ-3

- designed for parents
- many languages
- 4-6 grade reading level



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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

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Research: ASQ-3 and Autism
Does ASQ-3 Identify Children with ASD

- 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

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Cross-Cultural Considerations

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?

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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

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Recommendations for Practitioners

- 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

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Recommendations for Practitioners

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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World-class Specialized Pediatric Services

Providing the best care possible so that every child reaches full potential

compassion ■ integrity ■ excellence innovation ■ teamwork and collaboration ■ fun

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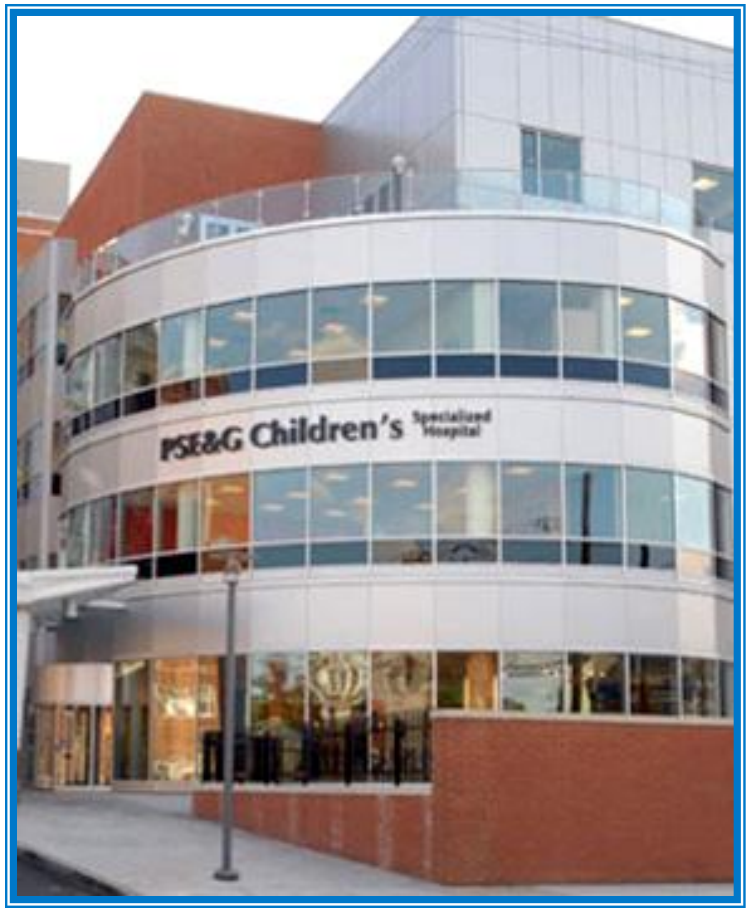
Hospital Sites



- 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

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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
- Physiatry
- 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
- Chronic pain management

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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More Information

Call: 888-CHILDREN

visit: www.childrens-specialized.org

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