Building Comprehensive and Culturally Competent Systems of Care for Children and Youth with ASD/DD: Challenges and Opportunities

Sunday, January 26, 2014
1:00PM-2:00PM
The New York City Korean Community Autism Project: A culturally-informed approach to enhancing early detection in a linguistic minority community

Amy Daniels, PhD
AMCHP Annual Conference
January 26, 2014

Collaborators: David S. Mandell, Christina S. Kangyi & Megan McCarthy, University of Pennsylvania; Richard Grinker, George Washington University
The Challenge

- **Delayed diagnosis**
  
  Large gap between age at which reliable diagnosis of autism can be made (24 months) and average age at diagnosis (4-5 years)

- **Ethnic disparities in identification and diagnosis**
  
  Racial and ethnic minorities are identified less frequently and diagnosed later than white counterparts.

- **Culturally-specific barriers may compound structural barriers to care**

- **Little known about Korean American community**
NYC-KCAP Goals

- To understand cultural and structural barriers to early detection and access to care

- To deliver appropriate solutions for lowering age of diagnosis and increasing access to early intervention services
NYC-KCAP Phase I: Understanding the barriers

- Systematic literature review
  Presentation and response to ASD in Korean culture

- Stakeholder meetings
  Approaches to caring for individuals with autism and their families

- In-depth interviews with caregivers
  Caregiving and care seeking behavior
NYC-KCAP Phase II: Delivering Solutions

- Formation of community advisory board
  - Important stakeholders in the community to inform process; identify solutions; establish connections

- Cultural adaptation of materials
  - Informed by Phase I findings and...

- Ongoing input from CAB
NYC-KCAP Phase II: Delivering Solutions

- Building an awareness campaign
  - Media outreach
  - Materials dissemination
    - Channels
      - Print
      - Web
      - In-person events
  - Target audience
    - Parents
    - Care providers
    - Clergy
NY-KCAP Evaluation

- Mixed methods
- Qualitative
  - In-depth interviews with parents and professionals
- Quantitative
  - Changes in frequencies of referrals to EI agencies
Lessons learned

- Building community trust and partnerships (may take a long time) are essential
- The process is iterative
- Consider sustainability from day one
Thank you!

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Massachusetts Act Early
Cultural Competence & State Planning Projects
AMCHP Annual Conference
January 26, 2014
Elaine Gabovitch, MPA
Considering Culture in Autism Screening

AMCHP State Systems Grant 2011-12
Deborah Munroe Noonan Memorial Research Fund 2013-14
Background

• Average age of diagnosis is 25.6 months for MA children served by EI
• Incidence rate is one in 85 (MA DPH, 2013)

However, certain populations of children still do not receive timely screening & evaluation. These include:
• Children from families with English as secondary language
• Children from families who are foreign born
• Children whose mothers are under the age of 24

• Manning et al., 2011
Purpose: Develop a culturally & linguistically competent ASD screening kit for clinicians working with children from non-English speaking families.

Goals:

• Interview cultural liaisons from 4 Greater Boston community health centers

• Develop clinician tips guide based on CHC findings for screening children from non-English speaking families for ASD

• Include the guide, translated versions of the M-CHAT, and other materials in the screening kit

• Review the final screening kit with cultural experts and informants for feedback before publication.
What’s included?

- **Guide components:**
  - Considering Culture guide for physicians
  - Referral at a Glance
  - Pediatric Staff Roles
  - Fact sheets

- **M-CHAT components:**
  - Screening tool in English, Spanish, Chinese, Haitian, Vietnamese
  - Instructions
  - Scoring guide
  - Follow up interview
Lessons learned to date

• It’s more than translation
• Start with the family’s perspective
• The term “autism” may present linguistic challenges
• Eye contact & pointing may be considered rude in certain cultures
• Follow up – help families do the legwork with resources
• Finding common ground may take time based on your concerns
• Cultural liaisons may provide insights to increase sensitivity
Considering Culture in Autism Screening: Training Curriculum for Pediatric Providers

**Purpose:** Develop, implement, and evaluate an educational module that trains pediatric providers in culturally & linguistically competent screening, evaluation, and referral to intervention services for children with ASD

**Goals:**

- Develop live training module will include didactic information, case studies, and supplementary materials
- Will feature 4 case study videos with retrospective interviews from culturally diverse families; will address the role of cultural liaison
- Will pilot test training on pediatric and family medicine residents from 2 Greater Boston teaching hospitals
- Will evaluate efficacy and feasibility via pre-tests and post-test measures of knowledge, applied knowledge, and attitude, as well as post-tests of satisfaction
Lessons learned to date

• The importance of cultural liaisons
• Early childhood educators may serve as key partners
• Second generation Americans may face considerable family issues
• Eye contact & pointing concerns may affect M-CHAT usage
• Immigrant families bring unique concerns
• Disability stigma may vary by culture
Healthy People 2020
Massachusetts Autism Roadmap for Children and Youth with ASD/DD

HRSA MCHB State Autism Planning Grant 2013-15
Recommendations from the Massachusetts Autism Commission Report’s Priority #6 call for “implementing a plan for consistent statewide data collection related to services and supports for people with ASD in MA.”

The Massachusetts state autism planning grant will develop a comprehensive statewide approach to address the needs of MA children and youth with autism and developmental disorders by implementing consistent statewide data collection practices.
Goals

(1) assess state needs of children with ASD and DD that align with six MCHB core indicators (i.e., screening, medical home, access, family involvement, transition, and financing);

(2) refine the existing state plan to address identified needs; and

(3) outline a comprehensive evaluation plan and program surveillance strategy to monitor and report on future state ASD/DD outcomes.

Focus on underserved children and youth by race, culture, language, immigrant status, region, transition age, insurance coverage, level of function, and mental health status.
Methods

1. Data mapping and quantitative analysis

2. Qualitative data from 3 different sources
   - Focus groups with multidisciplinary professionals, conducted topically on the 6 core indicators, with diverse and regional representation.
   - Focus groups with family and parent leaders, conducted regionally, on the 6 core indicators.
   - Key informant interviews from informants with ASD and topic experts
Lessons to date

• Networking critical on multiple levels
• Act Early partnerships will streamline and facilitate much of the project
• State planning plan may serve as a springboard for other funded projects resulting from Commission report, e.g., state autism registry
Considering Culture Kit Team

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Thank You!
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