

Common Evidence Based Challenges in Maternal and Child Health

*The Problem is Significant
but There is No Known Prevention Intervention
The Case of Autism*

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OVERVIEW

The purposes of this case study are to:

1. *Identify the key characteristics of this type of evidence-based challenge and the problems that fall into this challenge category,*
2. *Discuss potential courses of action when dealing with this type of challenge,*
3. *Identify strategies to overcome the challenge,*
4. *Identify recommendations for action that might apply across programs/interventions.*

This case study was developed for use in ***Leadership, Legacy, and Community: A Retreat to Advance Maternal and Child Health (MCH) Scholarship and Practice***. The Retreat was hosted by the MCH Program at the University of Illinois at Chicago School of Public Health, in Chicago, July 2008. This is one of four case studies developed for the Retreat. We encourage you to use this case study, as well as the others, to engage in a group dialogue around the many evidence-based challenges we face in our work related to MCH.

Each case study was designed to be used in a 3-hour workshop that may include two full-group discussions and two rounds of small group discussions. In the initial whole group discussion, you may choose to discuss the characteristics of this challenge and how to know when an agency/organization is experiencing this challenge. You may also choose to generate a list of issues/problems that characterize this type of challenge (Purpose #1). We encourage you to follow-up this discussion with 2 rounds of small group discussions (8-10 people per group). Each small group discussion should be 30 minutes and focus on a different set of questions designed to address and achieve purposes #2 and #3. Lastly, you may conclude your workshop/discussion with a large group discussion to identify recommendations to address this particular type of challenge across interventions/problems, purpose #4. All discussions can be guided by the set of **Discussion Questions on page 8**. The questions provided for each round are to be used as guides to focus the discussion, with an eye toward having the focus be distinct but complementary across rounds. *If you identify other key questions for that round's focus, that is wonderful.*

Disclaimer: We believe that these case studies will produce insightful and useful information. Therefore, we encourage you to share any information and recommendations/strategies that you identify with the UIC Maternal and Child Health Program. With your permission, we will post this information on our website at www.uic.edu/sph/mch. Please contact Kris Risley at kyrisley@uic.edu.

Note About Working With This Case Study

As a participant in a discussion about this evidence based challenge, we ask you to take a look around at your colleagues and note the different disciplines as well as the different generations present and be willing to learn from, discuss, and create with all participants. Whether you may have a lot or a limited amount of experience with the particular issue on which this case is based, you have much to offer in helping the field of MCH identify a process to address this type of challenge.

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The Case

Prior to the 1940s: Most likely, the conditions we now refer to as autism, classical autism, autistic spectrum disorders, Asperger's, or high-functioning autism have existed for as long as humans have been a species. Infantile autism was first characterized by Dr. Leo Kanner in 1943, followed the next year by Dr. Hans Asperger's characterization of the condition that now bears his name.

1960s to 1980s: Over time, developmentalists, child psychologists, and special educators developed therapies and interventions designed to work with children diagnosed with autism. Most likely during this period, many children with Asperger's went undiagnosed. Most of these interventions received less than rigorous scientific study. A feature film, the *Rain Man*, increased public awareness of autism.

1990s: For unknown reasons, the prevalence of autism/ASD continued to rise. ASD became a public health issue, with the publicity around the Brick township, NJ 'cluster' and subsequent investigations (Bertrand et al., 2001). CDC added ASD to the conditions under surveillance in the metropolitan Atlanta program. Concerns about need for early diagnosis began to arise. Early in the 1990s, autism became a specific exceptionality for special education services.

2000s: The prevalence of ASD continues to rise with each successive birth cohort (based on federal Department of Education December 1 special education counts) (Newschaffer et al., 2005) and in successive eight-year-old cohorts under surveillance in metropolitan Atlanta and the Autism and Developmental Disabilities Monitoring (ADDM) Network (Bhasin, 2006; CDC 2007a; CDC 2007b).

Challenges:

Since the cause of autism is not known, there is no means to prevent ASD. While there are any number of research hypotheses, many issues remain. ASD almost surely has a genetic component, yet to date the only genes that have been identified contribute to well under 5% of all cases. Are its origins in utero or due to acquired factors in infancy or early childhood? Some theorize that ASD results from environmental exposures, including heavy metals, while others speculate that ASD may result from unintended physiologic consequences of immune response to severe gastrointestinal infection in infancy. Until the etiology of ASD is better understood, there will be limited opportunities for primary prevention (Newschaffer et al., 2007).

There is no known 'cure' for ASD. Many therapies and interventions have been developed and promoted, often directly to families, and often without comprehensive and rigorous scientific evaluation. There are some reported cases of children who were 'cured', but on closer evaluation all of these persons still exhibit latent tendencies and behaviors suggestive of ASD. Persons with ASD will continue to be affected through their lifetime, but with intensive intervention can learn behaviors that enable them to function better in daily tasks, vocationally and socially (Seida et al. 2009; Howlin et al., 2009).

ASD can be diagnosed in early childhood. Although the median age at initial diagnosis of ASD in a recent report was 5-6 years of age (CDC, 2007b), well-validated diagnostic tools are now available that can reliably diagnose ASD at 18-36 months of age (Shattuck and Grosse,

2007). *First Signs* (<http://www.firstsigns.org/>) and CDC's *Learn the Signs, Act Early* campaign (<http://www.cdc.gov/ncbddd/actearly/index.html>) focus on educating pediatric providers and parents concerning subtle as well as obvious behaviors and indications suggestive of the need for a diagnostic evaluation. The larger problem is the relatively small proportion of infants and young children who receive developmental assessments during the critical window of cognitive development.

A diagnosis of ASD may not improve access to needed services. In many states, ASD is not a covered condition for *Birth to Three* programs, and even where it is, availability of services is highly variable within states and difficult for many families to access. Children become eligible for special education based on the presence of specific conditions or behaviors (called 'exceptionalities' in federal law). ASD (or autism) has been an exceptionality for public education since the early 1990s, but school districts vary widely in their approach and frequently create administrative roadblocks that limit the ability of families to gain special education eligibility.

Even when a child can access appropriate services, family participation is essential. On average, a child with ASD should receive 25 hours per week of intensive intervention, supported throughout the remainder of the week by parents trained in the intervention and willing and able to provide a social environment in the home consistent with the evolving goals of the intervention. Many families are unable or unwilling to provide this level of intensive therapy; hence, the child's progress is often slower than it would be otherwise. Children whose parents work or who are not emotionally or physically capable of providing such therapy are particularly disadvantaged but likewise probably most in need of such services. In fact, most children with ASD receive a much smaller amount of structured intervention per week, placing even greater burdens on family members to provide the repetitive interactions and structured tasks necessary to support the child's development.

Current Responses to the Lack of Evidence

The Combating Autism Act of 2006 authorized a program for early detection, education and intervention activities focused on autism and other developmental disorders. This program supports activities to:

1. provide information and education on autism spectrum disorder and other developmental disabilities to increase public awareness;
2. promote research into the development and validation of reliable screening tools and interventions for autism spectrum disorder and other developmental disabilities and disseminate information; promote early screening of individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable, given evidence-based screening techniques and interventions;
3. increase the number of individuals who are able to confirm or rule out a diagnosis of autism spectrum disorder and other developmental disabilities; and,
4. increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with autism spectrum disorder or other developmental disabilities.

In FY 2008 Congress appropriated \$36,354,000 for this program, of which approximately \$20 million was moved from the Maternal and Child Health Block Grant training programs for

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Behavioral Pediatrics. Funds will be used to expand these programs, as well as support: grants to study interventions for Autism and related developmental disabilities; demonstration grants to develop models of systems of services for children with autism and other disabilities; grant(s) to disseminate current and accurate information to families and consumers on early identification, diagnosis and access to services; grants to disseminate screening intervention, and guideline information; and, other technical assistance and evaluation.

DISCUSSION QUESTIONS

Whole Group Discussion (30 minutes) (Purpose #1)

- What are the key characteristics of this type of problem (evidence-based challenge)?
- Is this a public health issue on which maternal and child health professionals should focus their attention? In fact, is the attention being provided to “autism” likely to distract from attention to other developmental disorders or more generic problems of Children and Youth with Special Health Care Needs (CYSHCN)?
- Is the focus on a very specific health status outcome with the adoption of outcome-targeted legislation, in the best interests of overall efforts to improve health status of a population, in this case, children? Or is this the only way to make progress in preventing at all levels (primary, secondary and tertiary) an intractable health problem?
- What other health status problems fit this profile?

Round I (30 minutes): **Given that autism is an important problem with a great deal of attention focused on it by the media and active parent groups but avenues for prevention are not available at this time, what are our *Course of Action* options?** (Purpose #2)

- How do we ensure that a balance is struck between research focused on prevention and research focused on a “cure”?
- How do we ensure that a balance is struck between “basic science” research and research that is conducted within an ecological framework, recognizing the interaction between biological and environmental causes?
- How do we ensure that a balance is struck between a focus on a “cure” and a focus on increased availability and access to services for families living daily with the problem?
- What is the role of the MCH academic and practice partnership in shaping the response to the problem?

Round II (30 minutes): **Given our desire to focus on prevention but recognizing that there are real challenges “now” in terms of access to services and ensuring the ability of families to participate in intensive services, how can we reframe our work related to this issue (Autism) to more than adequately meet the needs of children with Autism and their families while still pushing to increase a focus on prevention?** (Purpose #3).

- How can MCH academics and practitioners focus attention on increased access to intervention services and ensuring equity in who receives services while not losing sight of the need for an “ecologic” response to the problem?
- How can we reconceptualize the problem so that we can truly make a difference for children and families? For example, in the case of autism, might the objective to improve developmental outcomes of children with ASD benefit from a holistic conceptualization of the domains of ‘health’, ‘education’, and ‘child growth and development’?
- Are there alternative models or delivery system changes that we can tap into that might help us to ensure that families have increased access to services and simultaneously allow us to promote an ecologic model of health? For example, care

coordination, case management and outcomes management have been utilized to enhance patient care delivery for chronic diseases. These approaches might be modified to coordinate delivery of care to children with ASD across the clinical, educational, and familial domains.

Whole Group Discussion (45 minutes): **Given what we have learned from this case, how can we take what we've learned and apply it to other programs/interventions that fall into this challenge** (those identified in the beginning of session)? (Purpose # 4)

- Given the challenge presented today, what are the recommendations/approaches to addressing the challenge that are universal in nature (ie, apply to other health status outcomes for which there are no known preventive interventions)?
- If an intervention does make a difference but it does not solve a problem, what is our responsibility related to improving access to such services?
- How do we think outside of the box when trying to address important MCH and public health issues like autism that place a huge burden on families affected by the problem but also demand a broad-based ecologic response as well?

DISCUSSION GUIDELINES

The Ultimate Purpose of this Session is to **Identify Global Recommendations and Strategies to Address this particular evidence-based challenge**. The guidelines presented below were adapted from the World Café model: www.worldcafe.com.

- 1) **Focus** on what matters!
- 2) Contribute your thinking.
- 3) Speak your mind and heart.
- 4) Listen to understand.
- 5) Link and connect ideas.
- 6) Listen together for insights and deeper questions.
- 7) Have fun!

Our assumption:

You have within you the wisdom and creativity to confront even the most difficult challenges. Given the appropriate context and focus, it is possible to access and use this deeper knowledge about what's important – the lives of the women, children, and families you serve.

FACILITATOR INSTRUCTIONS

Initial Whole Group Discussion: Discussion Questions, See Page 8

1. **Main facilitator introduces the Case and leads the participants into a group discussion that addresses purpose #1 (See page 4).** Main Facilitator also reviews World Café guidelines prior to beginning any discussion (**See page 10**).
 - i. **Facilitator identifies a participant** to take notes on flipcharts for any discussions involving the entire group. (The note-taker should pay special attention to comments resulting from the question: What other health status problems/issues fit this profile? [we will return to this question in the final group discussion]).

NOTE: You may use additional note-takers to keep up with group discussion.

ROUND 1: Discussion Questions, See Page 8

Ask each Small Group to identify 2-3 Take-Home Messages from this round that they will then share with the entire group.

2. **Main facilitator asks participants to break into small discussion groups of 8-10 people.**
3. **Main facilitator asks each table to identify an individual to facilitate the small group discussion for that round (*table facilitator*).**
4. **Main facilitator asks each table to identify a *table note-taker* who will take notes about the discussion.**
5. **Following the completion of that round (25 minutes), main facilitator asks each *table facilitator* to share the 2-3 take-home messages that were identified from the round.** This should last no more than 5-10 minutes.

NOTE: EACH DISCUSSION SHOULD LAST APPROXIMATELY 25 MINUTES AND BE FOLLOWED UP BY A WHOLE GROUP DEBRIEF THAT LASTS NO LONGER THAN 5-10 MINUTES.

ROUND 2: Discussion Questions, See Page 8

6. **Main facilitator asks individuals to move to a table with new people for the Round 2 discussion.**
7. **Main facilitator asks each table to identify a new individual to facilitate the small group discussion for that round (*table facilitator*).**
8. **Main facilitator asks each table to identify a new *table note-taker* who will take notes about their discussion .**
9. **Following the completion of that round (25 minutes), main facilitator asks each *table facilitator* to share the 2-3 take-home messages that were identified from the round.** This should last no more than 5-10 minutes.

Final Whole Group Discussion: Discussion Questions, See Page 8

The purpose of this final session is to identify several, tangible strategies/recommendations to address this particular type of challenge. They may be related to practice or academia.

10. **Main facilitator leads the entire group in a discussion to address the final Whole Group Discussion questions (See page 9).** Please leave about 45 minutes for this section.
 - i. Identify a note-taker to take notes during this session.

NOTE: You may choose to take a 10-15 min break between rounds 1 and 2 or round 2 and the final discussion.

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