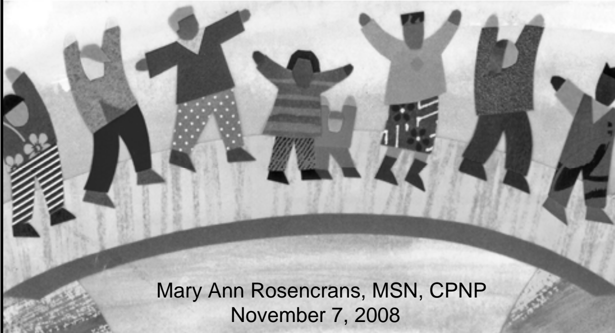
EARLY IDENTIFICATION AND EVALUATION OF CHILDREN WITH DEVELOPMENTAL DISORDERS AND AUTISM



Mary Ann Rosencrans, MSN, CPNP
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Objectives

- Understand the importance of early identification of infants and children with developmental delays
- Articulate AAP and CDC screening recommendations
- Identify developmental red flags seen in infants and toddlers during clinical visits
- Increase knowledge of available resources for evaluation and treatment of infants and children with developmental concerns
- Discuss strategies to coordinate care for children with developmental delays and autism spectrum disorders

Early identification of developmental disorders is critical to the wellbeing of children and families.

A developmental delay occurs when a child does not reach the same developmental milestone at the same time as other children of the same age.

Delayed or disordered development can be caused by specific medical conditions.

Autism spectrum disorders are a group of developmental disabilities caused by a problem with the brain.

Autism and Developmental Disabilities

- Autism affects 1 in 150 children in the US
  male to female ratios ranging from 2:1 to 6.5:1
- About 17% of US children under 18 years of age have developmental disabilities
- About 2% have serious delays
- Most causes unknown

Developmental Disabilities

- Group of severe chronic conditions manifested during developmental period
- Attributed to an impairment in physical cognitive speech, or language, psychological or self-care areas

ASD

- Autism Spectrum Disorders (ASD)
- An “umbrella category”
- Autism
- PDD-NOS (Atypical Autism)
  - Severe and pervasive impairment (social interaction, communication, stereotyped behavior, but criteria are not met for specific PDD
- Asperger’s Syndrome

DMS IV Social Criteria

1. Qualitative impairment in social interaction
   - A. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interactions.
   - B. Failure to develop peer relationships appropriate to developmental level.
   - C. Lack of spontaneous seeking to share enjoyments, interest, or achievements with other people with other people.
   - D. Lack of social or emotional reciprocity.

DMS IV Communication Criteria

2. Qualitative impairment in communication
   - A. Delay in, or total lack of, the development of spoken language.
   - B. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
   - C. Stereotyped and repetitive use of language or idiosyncratic language.
   - D. Lack of varied, spontaneous make-believe play or social play appropriate to developmental level.

DMS IV Behaviors/Interests

3. Restricted, repetitive and stereotyped patterns of behavior, interests, and activities.
   - A. Encompassing preoccupation with one or more stereotyped and restricted pattern of interest that is abnormal either in intensity or focus.
   - B. Apparently inflexible adherence to specific nonfunctional routines or rituals.
   - C. Stereotyped and repetitive motor mannerisms.
   - D. Persistent preoccupation with parts of objects.

Is autism on the rise?

- Real increase or methodologic changes?
- Awareness?
- Availability of services?
- Regardless-more children with autism

- Early signs may be subtle
- Lack of physical signs
- Inconsistent skills-strengths and weakness
- Regression in some children
- Parents often suspect their child
  - has a hearing loss
  - was “too” good as a baby
  - has language delays

Primary provider often first line of professional help

Everyone should be involved in identifying at risk infants & toddlers

- Parents
- Health Care Providers
- Early Childhood Educators

Developmental Domains

- Communication
- Gross motor
- Fine motor
- Problem Solving
- Personal-social

Developmental Surveillance

"A flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems" (AAP 2006)

- Longitudinal
- Continuous
- Cumulative

Developmental Surveillance

Surveillance can be useful for determining appropriate referrals, providing patient education and family-centered care in support of healthy development, and monitoring the effects of developmental health promotion through early intervention and therapy

Surveillance – Screening Why does it matter?

- Developmental delays common in early childhood: estimated 10% of children
- Studies suggest ~15-18 months lag between family's first report of concerns and eventual assessment
- Earlier identification leads to families being connected appropriate services
- YET <20% of children receive structured developmental screening

Developmental Screening

The administration of a brief standardized tool aiding the identification of children at risk of developmental disorder.

Brief
Standardized
Identification of risk
NOT DIAGNOSTIC

Developmental Screening Who?

All children, most of whom will not have identifiable risks or whose development appears to be proceeding typically, should receive periodic developmental screening using a standardized test at 9, 18, & 30 (or 24) months of age.

Uniform recommendations for developmental screening

- American Academy of Pediatrics
- American Academy of Family Physicians
- Center for Disease Control
- National Association of Pediatric Nurse Practitioners
- The Bureau of Maternal and Child Health
- EPSDT under Medicaid Administration
- US Preventive Services Task Force
- Institute of Medicine

General Developmental Screening Instruments

- Ages and Stages Questionnaire (ASQ)
- Battelle Developmental Inventory Screening Test
- Bayley Infant Neurodevelopmental Screen
- Parents' Evaluation of Developmental Status (PEDS)
- Denver II Developmental Screening Test
- Brigance II
- Child Development Inventory

Surveillance of ASD

Development of social skills and language is more delayed and characteristically 'out of sync' with motor, adaptive, and cognitive functioning.

Surveillance of ASD

- Direct observation /clinical probes
  - Careful physical exam
  - Developmental history
  - Observation of parent-child interaction
  - Probing questions for parents
  - Eliciting & Attending to parents' concerns

Surveillance for ASD

- Identify risk and protective factors
  - Environmental, genetic, biologic, social & demographic factors
  - Loving supportive family, connection to community, opportunities to interact with other children, environment with appropriate structure

Screening for ASD

- Screening for autism at 18 and 30 (24) months well child visit
- M-CHAT
  - Measures social reciprocity, language
  - Detects ASD, language impairment, MR
  - 23 yes –no questions
  - Parent report has many benefits

Early Development

- Babies start communicating and relating to others at birth
- Continued social-emotional development is key to forming strong relationship and continued learning

Early Warning Signs 6-9 months

- No big smiles or other warm, joyful expression by 6 months or thereafter
- No back-and-forth sharing of sounds, smiles, or other facial expression by 9 mo or thereafter
- No babbling or infrequent vocalizations
- Gaze aversion or abnormal pattern of focus or attention

Early warning signs 9-12 months

- Seem to hear environmental sounds better than the human voice
- Abnormalities in arousal to stimuli
- Joint Attention (JA) difficulties

JOINT ATTENTION (JA)

Deficits in JA one of the most distinguishing characteristics of very young children with ASD.

JA is a normal spontaneous occurring behavior where the infant shows enjoyment in sharing an object with another person by looking back and forth between the two.

JA Warning Sings

- Not looking at objects when another person points at them
- Seems unable to make an association between word and object
- Not pointing at objects to show interest like pointing at an airplane flying over

ASD Red Flags

- Prefer not to be held or cuddled or might cuddle only when they want to.
- Avoid eye contact or want to be alone
- Repeat or echo words or phrases said to them or repeats in place of normal language
- Have trouble expressing their needs using typical words or motions

More Red Flags

- Repeat actions over and over again
- Not playing pretend games
- Problems relating to others
  - Trouble understanding other people's feelings or talking about their own feelings
  - May be interested in people, but not know how to talk, play or relate to them
  - Appear unaware when someone is talking

Theory of Mind (ToM)

- ToM is the awareness that others have thoughts and emotions that are independent from one's own; it is the ability that allows one to infer state of mind on the basis of external behavior
- ToM impairments result in difficulties with empathy, sharing, & comforting
- "mindblindedness" (Barron-Cohen)

Regulation Disorders

Many children with ASD will have sensory problems, but not all children with sensory regulation disorders have ASD.

Regulation Disorders of Sensory Processing

- Represents a definite entity that requires a distinct behavioral pattern for diagnosis
- Not related to intelligence
- Sensory, motor, physiological, behavioral processing and organizational responses are all considered
- Affects daily adaptation, interactions and relationships

Developmental Evaluation or Assessment

- Aimed at identifying the specific developmental disorder or disorders affecting the child
- Completed on children who do not pass developmental screening
- Coupled with medical evaluation
- Diagnostic

DIAGNOSIS

- Complex process
- Based on observable behaviors
- Pattern of development-developmental history important
- Diagnostic Statistic Manual IV criteria
- There is no medical test to diagnose

Referral Challenges

- 50% to 80% of children who fail screens are not referred
- >80% of referrals from primary care providers made only to familiar services
- Non-medical providers may not respond like the ideal subspecialist

Referrals

- If screen positive, make three simultaneous referrals
  - Early intervention; in Ohio this is Help Me Grow (HMG) or school program
  - Comprehensive evaluation with ASD specialist/team
  - Audiology

Who is involved in diagnosis?

- There are many different specialist who might be involved in diagnosing a child with autism. This will vary based on resources in local community.
- Getting an evaluation my take months so refer to early intervention as soon as concern surface.

A couple of FAQ

- Will use of developmental screening increase length of well child visit?
- What about the false positives from screening with the M-CHAT?
- What is Early Intervention and who or what is Help Me Grow?
- Where is the money to get the diagnosis and treatment going to come from?

What is Early Intervention?

Early Intervention is the provision of support and resources to families of young children from the members of informal and formal social support networks that both directly and indirectly influence child, parent and family functioning

In Ohio IE is done by Help Me Grow (HMG) located in all 88 counties

Core HMG Services (at no cost to families)

- Child find
- Evaluation and assessment
- Service coordination
- An IFSP
- Procedural safeguards
- Family support

Evidence Based Practice Paradigm Shift

- Family-Centered
- Strength-based
- Inclusive communities
- Interagency collaboration
- Consultation
- Team-based
- Typical settings
- Functional outcomes

Autism Diagnostic Observation Schedule (ADOS)

ADOS is gold standard for assessing and diagnosing ASD & PPD across ages, developmental levels and language skills.

AVOID A DISCIPLINE SPECIFIC OR DOMAIN SPECIFIC FOCUSED APPROACH

Diagnostic Team

- Psychologist
- Neurologist
- Psychologist
- Developmental pediatrician
- Geneticist
- Nurse Practitioner
- Speech Language Pathologist
- Occupational Therapist
- Physical Therapist
- Special Educator
- Social worker

Etiological Investigation

- Neuroimaging
- EEG
- Laboratory testing as indicated
- Metabolic testing
- Genetic testing
  - Conditions associated with ASD
    - Fragile X, Neuromuscular disorders, Angelman syndrome, Retts syndrome, Smith Lemi-Opitz syndrome, chromosomal disorder

Bureau for Children with Medical Handicaps (BCMH)

- Diagnostic
  - No financial eligibility
  - Usually for 3 month period, but can be extended
  - Must refer to BCMH provider
- Services
  - Diagnostic specific
  - Financial eligibility

Developmental Screening: Coding

- 783.42 Delayed Milestones
- 728.25 Hypertonia
- 315.31 Language disorder developmental
- 315.9 Learning disorder, NOS
- 348.3 Static encephalophy

Developmental Screening: Billing

- 96110 Developmental testing; limited
  When a limited screening test is preformed along with any E/M service, both services should be reported and modifier 25 applied.

Resources

OCALI Ohio Center for Autism and Low Incidence www.ocali.org

Autism Speaks www.autismspeaks.org

First Signs www.firstsigns.org

Learn the Signs. Act Early www.cdc.gov/actearly

AAP National Center of Medical Home www.medicalhomeinfo.org

Developmental Behavioral Pediatrics www.dbped.org

National Institute of Child Health and Human Development www.nichd.mh.gov

HRSA: Maternal Child Health www.mchb.hrsa.gov