Autism Spectrum Disorders: From identification to services

WAHCE
State Conference

September 18, 2007
10:30 – 11:45
Voyager Inn, Reedsburg
national MEDICAL HOME Autism Initiative
Autism ???

What comes to your mind when you hear the word “autism”? 
What’s in a name?

- Technically known as

**Pervasive Developmental Disorders (PDD)**


- **Pervasive Developmental Disorders**
  is sometimes referred to as the “umbrella category” that refers to a group of disorders characterized by a significant and widespread (pervasive) effect on the areas of
  - social interaction
  - communication
  - behavior.
Autism

- Affects approximately 1/150 based on the most recent CDC study
- Occurs 4 times more often in boys than girls
- Affects close to 26,000 individuals in Wisconsin
- Found in all racial, ethnic, and social groups across the world
- Recurs in 5-7% of families unless due to another, known cause. In families with two children with autism, the risk for each successive pregnancy is as high as 50%
- There is a 10-15% likelihood of having a primary relative with a related area of need, i.e., speech and language delays, not necessarily autis
Autism

- A “spectrum” disorder in which children may display a wide variety of characteristics
  - Signs may or may not be apparent in infancy, but become more obvious during early development and need to be present by 3
  - Early identification and appropriate intervention are key
  - Often occurs in combination with other conditions
Autism Spectrum Disorder “ASD”

- Autistic Disorder
- Asperger Disorder
- Childhood Disintegrative Disorder
- Rett Syndrome
- Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS)
What causes ASD?

- No known factors in the psychological environment of a child.

- Result of a neurological disorder that interferes with the normal development of the brain (in the areas of reasoning, social interaction and communication skills.)

- Changes in the brain (within cells and neurotransmitters) thought to occur during fetal development:
  - These changes cannot be detected by our current medical diagnostic technology.
  - Likely to be in the future by technological advances in imaging such as PET scans.

- Result of a neurological disorder that interferes with the normal development of the brain (in the areas of reasoning, social interaction and communication skills.)

- There is generally nothing that was done or not done during the pregnancy that caused the condition.
For the majority of children with ASD the exact cause cannot be determined

- Some known causes
  - metabolic (PKU)
  - genetic - i.e. fragile X, tuberous sclerosis

- Current thinking is that there is a genetic cause
  - one or more genes involved
  - common occurrence of more than one person with ASD in many families
What is the “cure”?

- There is no known “cure” for autism.
- Early identification and intervention can improve the skills and symptoms.
- Medicines may relieve symptoms in some cases.
Characteristics of Typical Development

- Social Development
- Joint Attention
- Language and Communication
- Behavior and Interests
Social Development

Key characteristics of interpersonal interactions

- **Reciprocity**
  - Does the child respond to social initiatives by others?

- **Initiation**
  - Does the child attempt to engage others?

- **Use of nonverbal behaviors**
  - Does the child utilize nonverbal behaviors/gestures (e.g., eye contact, smiling, responsiveness to name, etc)?

- **Interactions**
  - Is there social interaction with family members?
  - Does the child attempt to engage or show interest in peers?
Joint Attention

- Sharing one’s experience of object/event in some manner

- Ability to initiate/engage

- Gestures/actions
  - Pointing
    - To ask for something
    - Pointing to indicate interest
  - Following pointing – looks where other points
  - Following gaze – looks where other looks
  - Showing – holds toys out toward other
Characteristics of Language/Communication

- Use of words by expected ages
- Likely unaware of meaning of their first words, but soon learn the power of those words as others respond to them.
- Child has *communicative intent*
- By six months of age, most children recognize the basic sounds of their native language.
- By age 3 – 5 begins to master the rules of language.
Characteristics of Behaviors / Interests

- Interest in many objects and activities Intense preoccupation with certain object / parts of objects

- Enjoys social play such as peek-a-boo and imitates others

- Is interested in other children and adults

- Limited stereotyped and repetitive mannerisms
  - Some engagement in repetitive behaviors is typical for preschool age children
Autism

How well can you recognize the characteristics common to Autism?
Typical Characteristics of ASD

Think about a child you know ....

What characteristics might link them to the autism puzzle?
Diagnosis of Autism Spectrum Disorders

- Medical (DSM IV)
- Educational (IDEA, WI PI 11)
DSM-IV

DSM IV Criteria for Autistic Disorder (299.0)

Diagnostic and Statistical Manual Of Mental Disorders
American Psychiatric Association,
Four Hallmarks of Autism
(Diagnostic Features -- DSM-IV)

- Impaired social development
- Impaired language and communication skills
- Resistance to change or insistence on sameness
- An onset in the first years of life before age three years
Impaired Social Interaction (at least 2)

- Markedly deficient regulation of social interaction by using multiple non-verbal behaviors such as eye contact, facial expression, body posture and gestures
- Lack of peer relationships that are appropriate to developmental level
- Doesn't seek to share achievements, interests or pleasure with others
- Lacks social or emotional reciprocity
Impaired Communication
(at least 1)

• Delayed or absent development of spoken language for which the individual doesn't try to compensate with gestures

• In individuals who can speak, inadequate attempts to begin or sustain a conversation

• Language that is repetitive, stereotyped or idiosyncratic

• Appropriate to developmental stage, absence of social imitative play or spontaneous, make-believe play
Impaired Behavior and Interests (at least 1)

Repetitive, restricted and stereotyped activities

- Preoccupation with abnormal (in focus or intensity) interests that are restricted and stereotyped (such as spinning things)

- Rigidly sticks to routines or rituals that don't appear to have a function

- Has stereotyped, repetitive motor mannerisms (such as hand-flapping)

- Persistently preoccupied with parts of objects
Before age three, the child shows delayed or abnormal functioning (in 1 or more of these areas)

- Social interaction
- Language used in social communication
- Imaginative or symbolic play
Characterized by a spectrum of abilities and challenges, ranging from mild to severe.

Abilities and evidence of learning may fluctuate day to day due to many influences.

May show affection, smile, laugh and a variety of emotions.

Other features of ASD
Autism Spectrum Disorders can be characterized as a "Hidden Disability".

Each person with ASD is a Unique individual.
Children with ASD are *children first* each with a unique personality, and with feelings, fears, and dreams. And their families are more like other families than different.
In practical terms, what does this mean?

- Human beings are social by nature

- Children with ASD are too

- But the features of ASD make it harder for them to understand the social world, to tolerate stimulation and to socially interact and communicate with others
Individuals/children with ASD find it more difficult to:

- Engage in typical forms of play
- Comprehend spoken and written language as well as “social” language
- Learn skills for self-care and everyday living (eating, toilet training)
- Socially interact and make friends
- Learn in school without individualized support
- Be successful in new environments or when routines change
Autism Spectrum Disorders “ASD”

- Autistic Disorder
- Asperger Disorder
- Childhood Disintegrative Disorder
- Rett Syndrome
- Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS)
Rett Syndrome

- Severe disability in young children, mostly girls
- Significant loss of functional skills after a period of relatively normal development (7-18 months)
- Characteristic pattern of hand-wrinking which interferes with their ability to use their hands
- Deceleration of head circumference within the first two years of life
- Mutation in a gene called MECP2 on the X chromosome identified in October, 2001, found to be related to Rett syndrome
- Mutation is not found in all girls who are suspected of having Rett syndrome, the diagnosis continues to be a clinical one based on characteristics
Childhood Disintegrative Disorder

- Rarely used term/diagnosis

- Reserved for children with profound loss of skills following relatively normal development for 2-10 years of life

- Very little recovery of skills
Asperger Syndrome

- Early language and cognitive development are typical prior to age 3 year
- May not be identified until school entry
- Normal language, though ability to communicate socially may be impaired
- Impairment in social skills and possibly restricted, focused areas of interest
- Usually intense and absorbing interests
- Significant problem with social communication even when verbal skills are good
- Normal cognition
Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

- Term used when fewer than six criteria (6) are met.

- This can be a confusing term, as Autism is often just referred to as PDD.

- Often used to describe those children who are more mildly affected

- May be used when children are not old enough or developmentally able enough to have some of the characteristics (like conversation)
Autistic Disorder

- Most severe features are seen

- May be considered to be “high functioning” if good verbal skills are present

- Total of 6 criteria indicated in DSM-IV are met.
First Signs is dedicated to the early identification and intervention of children with developmental delays and disorders.

http://www.firstsigns.org/
Who Can Make a Medical Diagnosis?

- Behavioral Psychologist
- Pediatrician/Family Practice Physician

Specialty Centers/Clincs
- Waisman Center – UW Madison
- Children’s Hospital – Milwaukee
- Gunderson Lutheran – LaCrosse
- Marshfield Clinic – Marshfield
Educational Diagnosis of Autism

• This is for educational purposes, and differs from the medical diagnosis.

• Based on a set of criteria identified in Federal Legislation IDEA 2004 (Individuals with Disabilities Education Act -- reauthorized in 2004).

• Includes processes to ensure parent input
**Education**

- **Individualized Education Program (IEP)**
  - document to specify individualized support for the child
  - may include Autism Consultant, training for teachers and specialized services as needed

- **Area of Impairment**
  - PI 11.36 Wisconsin Administrative Code since 1995
  - Individuals with Disabilities Education Act (IDEA)
  - DPI Program Consultants developed eligibility criteria checklists for areas of impairment
Criteria for Impairment
Section I. (Both must be checked Yes)

Yes  No  The child displays difficulties or differences or both in interacting with people and events. The child may be unable to establish and maintain reciprocal relationships with people. The child may seek consistency in environmental events to the point of exhibiting rigidity in routines.

Yes  No  The child displays problems which extend beyond speech and language to other aspects of social communication, both receptively, and expressively. The child’s verbal language may be absent or, if present, lacks the usual communicative form which may involve deviance or delay or both. The child may have a speech or language disorder or both in addition to communication difficulties associated with autism.
Criteria for Impairment
Section II.  (At least one must be checked Yes)

Yes No   The child exhibits delays, arrests, or regressions in motor, sensory, social or learning skills. The child may exhibit precocious or advanced skill development, while other skills may develop at normal or extremely depressed rates. The child may not follow developmental patterns in the acquisition of skills.

Yes No   The child exhibits abnormalities in the thinking process and in generalizing. The child exhibits strengths in concrete thinking while difficulties are demonstrated in abstract thinking, awareness and judgment. Perseverant thinking and impaired ability to process symbolic information may be present.

Yes No   The child exhibits unusual, inconsistent, repetitive or unconventional responses to sounds, sights, smells, tastes, touch or movement. The child may have a visual or hearing impairment or both in addition to sensory processing difficulties associated with autism.

Yes No   The child displays marked distress over changes, insistence on following routines, and a persistent preoccupation with or attachment to objects. The child’s capacity to use objects in an age-appropriate or functional manner may be absent, arrested or delayed. The child may have difficulty displaying a range of interests or imaginative activities or both. The child may exhibit stereotyped body movements.
Early Childhood Development

- The early years of a child's life are crucial for cognitive, social and emotional development.

- A child’s development can be measured through social, physical, and cognitive developmental milestones.
Why be concerned about delays? Won’t the child just grow out of it?

- Developmental delays can have future negative effects on your child, which may lead to speech and language difficulties, behavioral problems and learning problems.

- If children fail to develop properly they may be unable to reach their full potential.

- It is important to remember, however, that there is a range of what is considered normal development.

- Some babies may accomplish certain tasks or reach a specific developmental milestone sooner or later than others.
Trust Your Instincts

- Parents and child care providers generally begin to recognize signs of delay and have concerns that others may not yet recognize.

- Pay attention to your concerns and note unusual characteristics and signs.

- Talk with the family.
Early Identification

Learn the Signs. Act Early.

It’s time to change how we view a child’s growth!
Onset in the first years of life: before age three years
Developmental Milestones

- Lists will give you a general idea of the changes you can expect as a child grows and gets older.

- Don’t be alarmed if a child takes a slightly different course.
Learn the Signs Act Early

Fact Sheets

- Developmental Screening Fact Sheet
- Autism Spectrum Disorders Fact Sheet
- Cerebral Palsy Fact Sheet
- Mental Retardation Fact Sheet
- Vision Loss Fact Sheet
- Hearing Loss Fact Sheet
- Attention-Deficit/Hyperactivity Disorder (ADHD)
- 3 Months
- 7 Months
- 1 Year
- 2 Years
- 3 Years
- 4 Years
- 5 Years

Additional Resources
- Tips for Talking to Parents
- Resources Fact Sheet
- Growth Chart
- Milestones Checklists
- Small Poster
- Flyer

Autism Spectrum Disorders

FACT SHEET

What are autism spectrum disorders? Autism spectrum disorders (ASD) are a group of development disabilities caused by a problem with the brain. Scientists do not yet fully understand what causes this problem. ASDs can impact a person's functioning at different levels, from very mild to severe. There is usually some kind of learning problem or unusual behaviors that set them apart from other people. They may have trouble communicating, learning, remembering, and dealing with things that are different from what others do. The thinking and behavior problems of people with ASD can range from mild to severe. A diagnosis of autism is made when a person shows at least six of the following clues:

1. Difficulty understanding or using body language
2. Difficulty understanding or using facial expressions
3. Difficulty understanding or using gestures
4. Difficulty understanding or using eye contact
5. Difficulty understanding or using language
6. Difficulty understanding or using nonverbal communication
7. Difficulty understanding or using social skills
8. Difficulty understanding or using emotional expression
9. Difficulty understanding or using social behavior
10. Difficulty understanding or using social interaction

What are the signs of ASD? People with ASD may have problems with social, emotional, and communication skills. They might have particular behaviors that might not be normal in their daily activities. People with ASD also have different ways of learning, paying attention, and reacting to things. ASD begins during early childhood and lasts throughout a person’s life.

A child with autism may have:

- difficulty being able to do things that other children can do
- difficulty understanding or using body language
- difficulty understanding or using facial expressions
- difficulty understanding or using gestures
- difficulty understanding or using eye contact
- difficulty understanding or using language
- difficulty understanding or using nonverbal communication
- difficulty understanding or using social skills
- difficulty understanding or using emotional expression
- difficulty understanding or using social interaction
- difficulty understanding or using social behavior
- difficulty understanding or using emotional expression
- difficulty understanding or using social interaction

Tips for Talking to Parents

- be very interested in people, but not how to talk, play, or relate to them
- ask or answer questions by saying yes or no, or repeat words or phrases instead of normal language skills
- have trouble expressing yourself using words or gestures
- have attention span and often get distracted
- have trouble altering when a routine changes
- have unusual communication in the way things are said, how things are said, how things are said, or how things are said
- have difficulty understanding or using language
- have trouble understanding what other people are saying
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What can I do if I think my child has ASD? If you are thinking about whether your child is at risk for ASD, you should talk to your child’s doctor. If there is a problem, and you are concerned about it, your doctor can talk to you about treatment options and other specialists you can contact. Your local early intervention agency for children under 3 or public school for children 3 and older. You can contact the National Autism Information Center (NAIC) by logging into the website using your social security number or birth date. The Center for Disease Control and Prevention (CDC) is a useful resource for families with ASD.

Additional Resources

- 1-800-CDC-INF 0  www.cdc.gov/actearly
- www.cdc.gov/actearly
- www.cdc.gov/actearly
- www.cdc.gov/actearly
- www.cdc.gov/actearly
Free Materials

Visit the website
www.cdc.gov/actearly

Download materials
Order resource kit for provider or parent
Use interactive tools for parents

Call 1-800-CDC-INFO
Other helpful Websites

- http://www.medicalhomeinfo.org/
- http://www.med.umich.edu/1libr/yourchild/devmile.htm
Early Intervention

- The intent is to lay a foundation, in conjunction with the family, to support infants and toddlers as they grow and mature into healthy individuals.

- Healthy means the best possible outcome for each child
  - Physical
  - Mental
  - Social functioning
  - General well-being
Partnerships & Coordination

Early Childhood professionals
Healthcare professionals
Community Service professionals
Parents and Families

*must work together as partners* to help children grow up healthy and strong.
Partnerships....

- Recognize the benefits of partnerships with parents, educators, primary care physicians and community professionals.

- Assure quality services and care for children with developmental delays including autism.
Family-Professional Partnerships
Resources for Supporting Parents & Families

Recognize and use resources within

Medical system

Educational system

Community Service system
A Medical Home is ...

- ACCESSIBLE
  - Care is provided in the child's community

- FAMILY-CENTERED
  - Recognition that the family is the principal caregiver and the center of strength and support for children

- COORDINATED
  - Families are linked to support, educational, and community based services

- CULTURALLY EFFECTIVE
  - Family's cultural background is recognized, valued, and respected
A Medical Home provides service that is

- **CONTINUOUS**
  - Same primary pediatric health care professionals are available from infancy through adolescence

- **COMPREHENSIVE**
  - Health care is available 24 hours a day, 7 days a week

- **COMPASSIONATE**
  - Concern for well-being of child and family is expressed and demonstrated
Families should come to expect
The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home.

What is a medical home?

A medical home is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician whom they know and trust.

The pediatric health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential.

Latest News
- 2004 Policy Statement Approved
- April 2003 Newsletter
- Spring Conferences Posted
- Funding Opportunities

Quick Links
- Medical Home Policy Statement
- Definition of CSHCN
- Discussion Board
- State Resources
- Grant Funding Opportunities
What is it?

- Federally-mandated program for infants and toddlers with developmental delays and disabilities and their families.

- Family-centered, collaborative care in natural environments

- Anyone can refer a child for an evaluation (parents must consent to evaluation)
Referral Process

- **Evaluation for program eligibility**
  - Child evaluated in 5 developmental areas (cognitive, physical, communication, social/emotional, and adaptive/self-help)
  - Child will not be given medical diagnosis

- **Eligibility criteria**
  - At least 25% delay in one area of development or atypical development
  - Diagnosis with high probability of resulting in developmental delays
Services and Costs

- IFSP document
  - Outlines plan to facilitate child’s development

- Costs
  - Evaluation and service coordination: free
  - If parents’ income markedly above Federal Poverty Guidelines, parents pay monthly parental cost share (not to exceed $1800 annually) for additional services/supports
Contact Information

Wisconsin Department of Health and Family Services Birth to 3 Program:
http://dhfs.wisconsin.gov/bdds/birthto3/

Local/County Birth to 3 Program
Early Childhood / Special Education Program

- Public Education Program
- Located in local public school system
- Referral can be made by any concerned person

- CESA 7 (Cooperative Educational Service Agency)
  - [http://www.specialed.us/Parents/plainlanguageindex.htm](http://www.specialed.us/Parents/plainlanguageindex.htm)
- Wisconsin FACETS  [www.wifacets.org](http://www.wifacets.org)  1-877-374-4677
Local School Referral Process

- Identify the local school district where family resides
- Determine steps for making a referral
- Determine person(s) to whom a referral may be made
- Identify information to be provided
- Provide assistance necessary to meet requirements
- Identify process for providing parents with notice of their rights
Wisconsin Resources

- Regional Children and Youth with Special Health Care Needs Centers
  [http://www.mch-hotlines.org](http://www.mch-hotlines.org)
  - Northeastern – St. Vincent Hospital – Green Bay
  - Northern – Dept. of Public Health – Wausau
  - Southeastern – Children’s Hospital – Milwaukee
  - Southern – Waisman Center – Madison
  - Western – Dept of Public Health – Chippewa Falls

- Autism Society of Wisconsin [www.asw4autism.org](http://www.asw4autism.org)
Resources continued . . .

- Department of Health and Family Services  
  http://dhfs.wisconsin.gov/programs/youth.htm?nav=mo

- Child Care Resource and Referral  
  http://www.wisconsincrr.org/

- Parent to Parent  
  1-888-266-0028

- Family Voices  
  http://www.wfv.org/fv/
Wisconsin First Step

Wisconsin First Step -- Help Book 2007
A Directory of Services for Children with Special Needs


Five regional directories are available, at no charge, each serving specific counties in Wisconsin.

Directories can also be provided in printed format by contacting Wisconsin First Step at (800) 642-7837
Reflection

What new piece of information will you use in your work in the coming week?
For More Info Contact

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National Medical Home Autism Initiative

http://www.waisman.wisc.edu/nmhai/index.html

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