Medical Diagnosis vs. Educational Determination

What are the differences in assessments, services, and outcomes?

by Mary Ann Morris, PhD, BCSE
Presentation Outline

- Children’s Medical Center/NDD Clinic
- Medical Model
- Education Model
- Comparisons
- Research
- Resources
Children’s Medical Center (CMC)

- Ranked among the nation’s top pediatric hospitals by *U.S. News & World Report* and *Child* magazine
- Seventh largest pediatric healthcare provider in the nation; recognized as the largest provider of pediatric healthcare in North Texas with 50 subspecialty programs
- The Dallas hospital is the first designated Level I trauma center for pediatrics in Texas
- Locations: CMC Hospitals in Dallas and Plano; Specialty Care Center in Southlake
- Nine (9) *My Children’s* Pediatric Practices
- Patients at Children’s have received more than $200 million in uncompensated care in the past five years.
- Nation’s busiest pediatric air- and ground-transport services team
  - Helicopter, fixed-wing aircraft, and ground transport.
  - Transports more than 2,000 critically ill and injured children each year
- *U.S. News & World Report* ranks our Neurology Department 12th in the nation.
Neurodevelopmental Disabilities (NDD) Clinic

- Multidisciplinary Service
  - medical, educational, OT, PT, Speech

- Research/Publications
  - NIH Autism Research
  - Clinical database for children with autism
  - Textbook/Clinical Guide for PCPs on Autism

- 9th NDD Residency in the country

- DISD Doctoral Program Supervisors
NDD Clinic Team

- **Multidisciplinary Team of Specialists**
  - Pediatric Neurologists/NDD Specialists
    - Patricia A. Evans, MD
    - Sailaja Golla, MD
  - Educational and Assessment Specialist
    - Mary Ann Morris, PhD, BCSE
  - Registered Nurse
  - Occupational and Physical Therapists
  - Speech Pathologists
  - Residents and Medical students
NDD Clinic Patients

- Cognitive delay/developmental disorders/chromosomal abnormalities
- Pervasive Developmental Disorders (PDD)
  - Autistic
  - Rett’s
  - Childhood Disintegrative
  - Asperger’s
  - PDD,NOS
- Traumatic Brain Injury (TBI)
- Fragile X
- Fetal Alcohol/Drug Exposure
Common Clinical Orders/Referrals
- Lab Work/Imaging
  - Blood/Urine
    - Genetic and metabolic testing
  - EEG/MRI
- Referrals to other Specialists
  - Vision/Hearing
  - Cardiology
  - Psychiatry
  - Genetics
  - OT/PT and/or Speech services
  - Dental Department
- Records Release Forms (e.g., school, medical)
Tommy’s family returned to school after his doctor’s appointment. They presented the diagnosis along with the services requested by Tommy’s physician. With the script in hand, they believed that the school would finally provide him with the services he needed to be successful. The school refused to recognize the diagnosis since Tommy did not demonstrate academic need (i.e., failing or near failing). A medical diagnosis doesn’t automatically entitle a student to special education services, rather eligibility is based on an educational determination of a disability.
Components of a Medical Diagnostic Evaluation

• Background information
  • Parent/caregiver interview
    o Health history: prenatal and perinatal histories; medical history; review of systems (e.g., hearing, vision, gastrointestinal)
  • Developmental and behavioral history
    o Aggression, fears, separation anxiety, fearless,
  • Family medical and mental health history
  • Assessment of family resources and needs
Components of a Medical Diagnostic Evaluation, cont.

- Direct Behavior Observation
  - Observe interaction with family and other familiar/unfamiliar adults
  - Speech, movement, eye contact, etc.
  - Stereotypic behaviors (e.g., hand-flapping, flicking, body rocking, head banging)
Components of a Medical Diagnostic Evaluation, cont.

- Medical evaluation
  - General physical and neurodevelopmental examination
  - Developmental neurological examination
  - Laboratory tests
  - Genetic testing
  - Sensory evaluation (vision and hearing)
Components of a Medical Diagnostic Evaluation, cont.

- Adaptive Functioning
  - Communication
    - Receptive and expressive language
    - Pragmatic language/social communication/reciprocal communication
    - Nonverbal communication (eye contact, use of gaze, gestures)
    - Echolalia
  - Socialization/social-emotional functioning
  - Fine and gross motor development, coordination, gait, motor planning
  - Daily living/self-help skills – hygiene, toileting, eating, dressing
Components of a Medical Diagnostic Evaluation, cont.

• Cognitive assessment (for differential diagnosis determination and intervention planning)

• Sensory Processing:
  • hyper- or hypo-sensitivities to foods, smells, textures, sounds, etc.

• Behavioral Functioning
  • Serious behavioral difficulties can impact the child’s safety, interfere with family functioning, and limit child’s and family’s participation with extended family and the community (e.g., church, restaurants).
Components of a Medical Diagnostic Evaluation, cont.

- Behavior
  - mood, aggression, withdrawal
  - interests and activities
  - Restricted/narrowly defined interests
  - Ritualistic or compulsive behaviors
- Social competence and functioning
- Attention and concentration, impulsivity, regulation of activity level
Diagnosis and Statistical Manual of Mental Disorders (DSM)

- Published by the American Psychiatric Association
- Classification of mental disorders used in the US
- *Infantile autism* included for the first time in DSM-III
- Changed to *autism* in DSM-III-R
- DSM – IV published in 1994
- Text Revision in 2000
- DSM-V expected publication date 2013
Autistic Disorder
DSM-IV TR (2000)

- Qualitative impairment in social interaction
- Qualitative impairment in communication
- Restricted, repetitive and stereotyped patterns of behavior, interests, and activities
- Delay or abnormality in social interaction, language use for social communication, or symbolic or imaginative play with onset before age 3
DSM Criteria for an Autism Diagnosis (299.00)

- To receive a diagnosis of autism, a child must have at least 6 of the characteristics in the 3 areas (note minimums in each area)
  - In one of the areas, onset must be before age 3
DSM Criteria for an Autism Diagnosis: Social Interaction

Must meet 2 of the following:

- Marked impairment in multiple nonverbal behaviors (e.g., eye contact, facial expressions)
- Failure to develop peer relationships for age
- Lack of spontaneous seeking to share enjoyment, interests or achievement with others
- Lack of social or emotional reciprocity
DSM Criteria for an Autism Diagnosis: Communication

Must meet 1 of the following:

- Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication)
- Marked impairment in ability to initiate or sustain conversation with others
- Stereotyped and repetitive use of language
- Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
DSM Criteria for an Autism Diagnosis: Restricted Repetitive and Stereotyped Patterns of Behavior, Interests, and Activities

Must meet 1 of the following:
• Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that’s abnormal in intensity or focus
• Inflexible adherence to specific, non-functional routines or rituals
• Sterotyped and repetitive motor mannerisms (e.g., hand flapping, rocking)
• Persistent preoccupation with parts of objects
Autism Specialists under the Medical Model
Autism Specialists

Neurodevelopmental Disabilities Pediatric Neurologist:
• specializes in all aspects of abnormal neurologic aspects of children, with particular interest in developmental disabilities. Typically have particular interest in autism, cognitive disorders, and traumatic brain injury survivors

Pediatric Neurologist:
• specializes in all aspects of abnormal neurologic problems in children, including delay, regression, epilepsy, and syndromic disorders

Behavioral Developmental Pediatrician:
• pediatrician who is trained in abnormal behaviors, including ADHD, Learning Disabilities, and autism spectrum disorders; Are particularly adept at cognitively normal or near-normal children with abnormal behaviors
Autism Specialists, cont.

Pediatric Psychiatrist:
• may or may not have the interest or ability to admit to in-patient psychiatric services; however is instrumental in coordinating medications for rage, mood disorders, disorders of psychoses; and Tourette’s syndrome

Psychologist:
• is often involved in the process of diagnosing both children and adults with autism, as well as provide treatment for issues such as anxiety, behavior, and social issues

Autism Research Team:
• because there is such a drive to investigate causes and cures for autism, many excellent research teams exist all over the country
The American Academy of Pediatrics
Autism Screening

All children should be screened for autism spectrum disorders (ASD) at 18 months and 24 months.

• Level one screening for developmental deficits (e.g., delayed or no language, loss of language, lack of eye contact)

• Level two screening should be performed if a child is identified in the first level of screening with delays and/or concerns.
  • The second level of screening may include more formal diagnostic procedures or a referral to a specialist.
Education Model
Cathy’s mother requested and received a letter of diagnosis from her child’s physician that noted the child’s current diagnosis, date of diagnosis, and prescribed medications, as well as a request to the school to complete a comprehensive evaluation and provide Cathy with the support services that would appropriately address her needs as a child with autism. Cathy’s mom also provided the school with a well organized and comprehensive compilation of chronological data (medical history, interventions/therapies, evaluations, behaviors). She braced herself for a struggle with the school, but was very pleased that the school completed the evaluation and determined Cathy to be eligible for special education services.
## Disability Categories Under IDEA 2004

<table>
<thead>
<tr>
<th>Categories</th>
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<tbody>
<tr>
<td>Autism</td>
<td>Orthopedic Impairment</td>
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<tr>
<td>Deaf-Blindness</td>
<td>Specific Learning Disabilities</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>Speech and Language Impairment</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>Hearing Impairment (including deafness)</td>
<td>Visual Impairment (including blindness)</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>Other Health Impairment</td>
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<td>Multiple Disabilities</td>
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Dallas, Texas   07/28/12
Privileged and Confidential
Non-Categorical Early Childhood (NCEC)

- Younger students (ages 3 to 5) may be served under the category of Non-Categorical Early Childhood (NCEC) due to delays in:
  - Physical
  - Cognitive
  - Communication
  - Social
  - Emotional
  - Adaptive Development
Autism definition by IDEA

- A developmental disability that significantly affects verbal and nonverbal communication and social interaction; generally evident before age 3, that adversely affects a child's educational performance.

- Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

- The term does not apply if a child's educational performance is adversely affected primarily because the child has a serious emotional disturbance.

Note: Autism was added as a separate category of disability in 1990 under P.L. 101-476. This was not a change in the law so much as it is a clarification. Students with autism were covered by the law previously, but now the law identifies them as a separate and distinct class entitled to the law's benefits.
Educational Determination

- An educational determination for services is based on the impact of the condition on the student’s learning.

- Assessments will differ due to the age, ability level, and needs of the child and will include the assessment of:
  - pre-academic and academic skills
  - self-help and adaptive skills
  - communication
  - socialization
  - sensory regulation
  - motivation and reinforcement, behavior,
  - fine and gross motor
  - play and leisure
  - cognition
Decision Making in the Assessment Process

- Assessment in special education is a process that involves collecting information about a student for the purpose of making decisions about an individual.

- Assessment plays a critical role in the determination of SIX important decisions
1. **Evaluation Decisions:** Information collected in the assessment process can provide detailed information of a student’s strengths, weaknesses, and overall progress.

2. **Diagnostic Decisions:** Information collected in the assessment process can provide detailed information of the specific nature of the student’s problems or disability.

3. **Eligibility Decisions:** Information collected in the assessment process can provide detailed information of whether a child is eligible for special education services.
4. **IEP (IEP Development) Decisions:** Information collected in the assessment process can provide detailed information so that an Individualized Education Program (IEP) may be developed.

5. **Educational Placement Decisions** Information collected in the assessment process can provide detailed information so that appropriate decisions may be made about the child’s educational placement.

6. **Instructional Planning Decisions** Information collected in the assessment process is critical in planning instruction appropriate to the child’s special social, academic, physical, and management needs.
Parents/guardians should keep records about their child, including:

- Professionals seen (date, time, reason for contact, result, contact information)
- Letters, emails, faxes from the school and other professionals/service providers
- Evaluations and progress notes from the school and outside professionals (e.g., therapists)
- School documents (e.g., IEPs, samples of school work, report cards, school conferences, disciplinary notices)
- Parents/guardians should also create a document that includes developmental history, personal observations about difficulties and strengths, illnesses, behaviors, family medical histories, etc.
• Use neutral language and not angry or accusatory statements in their letter.

• The letter can be hand delivered, but a copy of the letter should be stamped with the date and signed by the school personnel that received the letter (e.g., secretary).

• It is preferable to send the letter by certified mail with a return confirmation receipt. If the letter has been mailed and no response has been received in 10 days, the parent should contact the administrator to determine the delay in a response.

• The family should receive a written response that includes a consent or denial of an evaluation plan. If it is denied, then a rationale must be provided.

• Once the consent form for assessment is signed by the parent/guardian and returned to the school, the school has 60 days to evaluate the child.
Sample School Letter from Parent/Guardian

Date
Name of Special Education Director
Director of Special Education
School System Name
Street Address
City, State, Zip Code

Dear Ms./Mr. (Name of Special Education Director):

I am requesting a Full Individual Evaluation for my child, (Child's Name), to determine if he/she is eligible for special education services. He/She is in (Grade Level) at (School Name). His/Her date of birth is (Birth Date). (Child’s name) has been struggling with _______ (reading, writing, math, attention, social skills, and/or behavior) since _____(e.g., grade, age). He/She has been identified as having (name of disability) by (name of professional). I’ve enclosed a copy of the report(s).
I would like to meet with the special education chairperson for my child's school before testing begins so that I might share information and discuss the evaluation procedures, as well as sign the written permission document to allow the assessment of my child. I would like a copy of the written report from each evaluator so that I can review them before meeting to discuss the evaluation results.

We have tried the following to help (child's name) …

Parents should include in this section strategies employed at home, tutors (it should be noted if these services have been paid out of pocket), as well as accommodations/modifications reported by teachers (documentation such as parent/teacher conference notes or emails are important). District or state assessment results that indicate below grade level performance or a failure to meet criteria, report cards, progress reports or samples of work that document the child’s struggles should also be included.
In keeping with *Individuals with Disabilities Education Act* (IDEA) requirement, I understand that I should receive communication from you within 10 days of receipt of this letter. I look forward to working with you, for the benefit of my child's education.

Sincerely,
Name  
Address  
Phone number

cc: the child’s principal (if letter is addressed to another administrator) and the child’s teacher
Medical Diagnosis vs. Educational Determination
A Review of the Differences
# Classification Comparisons

<table>
<thead>
<tr>
<th>Guided by</th>
<th>Educational</th>
<th>DSM-IV TR</th>
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<tbody>
<tr>
<td></td>
<td>Individual Disabilities Education Act IDEA)</td>
<td>Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition Text Revision (DSM-IV TR)</td>
</tr>
<tr>
<td>Symptoms are adversely impacting</td>
<td>Academic Functioning (Ages 3 and above)</td>
<td>Adaptive Functioning</td>
</tr>
<tr>
<td>Performed by</td>
<td>Team Membership defined in rule</td>
<td>Professional Diagnostic training</td>
</tr>
<tr>
<td>Age</td>
<td>Birth – 21</td>
<td>Children and Adults</td>
</tr>
</tbody>
</table>
## Classification Comparisons

<table>
<thead>
<tr>
<th>Process and Method</th>
<th>Educational</th>
<th>DSM-IV TR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Specific evaluation process and procedures are required and methods are identified.</td>
<td>Not Specified: Process and procedures determined by referral concerns. Developmental or Cognitive testing for rule out of developmental delay</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Included</th>
<th>Educational</th>
<th>DSM-IV TR</th>
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</table>
|          | • Observation  
            • Testing  
            • Interview | • Observation  
                           • Testing  
                           • Interview |

<table>
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<th>Evaluation of</th>
<th>Educational</th>
<th>DSM-IV TR</th>
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<tbody>
<tr>
<td></td>
<td>Child as well as Family Concerns, Strengths and Resources</td>
<td>Child, Family Concerns, Stressors</td>
</tr>
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</table>
Research
Buspirone in the Treatment of 2-6 Year Old Children With Autistic Disorder (B-ACE)

- A Randomized, Placebo-controlled, Double-masked Clinical Trial of Buspirone in the Treatment of 2-6 Year Old Children With Autistic Disorder (NIH)

- To evaluate the effects of twice-daily oral buspirone on the ADOS Composite calibrated severity score, social behavior, repetitive behavior, language, sensory dysfunction and anxiety. [Time Frame: Baseline 1, Week 24 and Week 48]
SEROTONIN SYNTHESIS CAPACITY:

Chugani et al., 1999
The Autism Center of UT Southwestern (UTSW) Medical Center Research Opportunities

Drs. John Sweeney and Matt Mosconi are examining cognitive and sensorimotor functioning of Autism Spectrum Disorders.

**Eligibility:**
- Between ages 2 and 55
- Individuals with autism as well as non-affected biological parents and siblings
- Individuals who do not have autism are also needed to serve as controls

**Testing:**
- Eye Movement Studies
- Hand Movement Studies
- Tests of Cognitive Ability
- Brain Activity Testing
- Genetics Testing

For more information, call 214-648-5155 or email autism@utsouthwestern.edu
## How is Participating in Research Different from Seeing a Doctor?

- Autism Speaks

<table>
<thead>
<tr>
<th>Key Differences</th>
<th>Participation in Clinical Research</th>
<th>Care from a Personal Physician</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Purpose</td>
<td>The researcher’s goal is to learn about your illness.</td>
<td>Your doctor’s goal is to treat your condition.</td>
</tr>
<tr>
<td>Treatment Flexibility</td>
<td>The researcher must use standardized procedures.</td>
<td>Your doctor will change/customize your treatment as needed.</td>
</tr>
<tr>
<td>Possibility of Dummy Treatment</td>
<td>You may be randomly assigned to a group taking a standard treatment or placebo (an inactive pill) versus the group taking the new treatment.</td>
<td>The patient always receives an active drug, typically the best standard treatment available.</td>
</tr>
</tbody>
</table>
### How is Participating in Research Different from Seeing a Doctor?, cont.

- Autism Speaks

<table>
<thead>
<tr>
<th>Key Differences</th>
<th>Participation in Clinical Research</th>
<th>Care from a Personal Physician</th>
</tr>
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<tbody>
<tr>
<td>Additional Procedures and Time Commitments</td>
<td>You may be asked to undergo procedures (blood tests, imaging scans, etc.) and complete questionnaires important for research but not necessary for your care.</td>
<td>Testing procedures and questionnaires are restricted to those necessary for your medical care.</td>
</tr>
<tr>
<td>Costs</td>
<td>Medical and other costs associated with participation may be partly or fully covered.</td>
<td>You are likely to be responsible for treatment costs and/or the cost of health insurance coverage/co-pays, etc.</td>
</tr>
<tr>
<td>Altruistic Benefits</td>
<td>Participating in research provides the opportunity to advance scientific understanding and help others.</td>
<td>Your treatment is focused on your needs, not that of others.</td>
</tr>
</tbody>
</table>
Fragile X

- The world’s leading cause of inherited mental impairment
- The most common known cause of autism
- About 30% of individuals with Fragile X Syndrome have autism
- 2-6% of individuals with autism have Fragile X Syndrome
- Can be accurately diagnosed with a simple blood test or DNA

http://www.fragilex.org/research/clinical-trials
Research Studies

- Participant's Guide to Autism Drug Research
  - http://www.autismspeaks.org/science/participate-research/participants-guide-drug-research

- National Institutes of Health (NIH)
  - http://www.nih.gov/

- Clinical Trials.gov
  - http://www.clinicaltrials.gov/

- National Institute of Neurological Disorders and Stroke
  - http://www.ninds.nih.gov/disorders/clinical_trials/index_all.htm

- Autism Speaks
  - http://www.autismspeaks.org/
National Resources

Autism Society of America
The website for the Autism Society of America (ASA) provides information, education, and support.

National Dissemination Center for Children with Disabilities (NICHCY)
NICHCY is a national information center which provides information on disabilities and disability related issues, focusing on children and youth.

National Institute of Mental Health (NIMH)
Autism information from the National Institute of Mental Health.

Autism Information Center at Centers for Disease Control and Prevention (CDC)
Publications, research, and information.

Yale Developmental Disabilities Clinic
Headed by Fred Volkmar, M.D., and Ami Klin, Ph.D., two respected experts in the field of autism, Asperger's Syndrome, and other pervasive developmental disorders, this website includes information, resources, and publications.
School Resources

Parent Handout for Attending a Child’s ARD/IEP Meeting
Using the ARD/IEP Agenda to Understand the Special Education Process
  - http://www.texasprojectfirst.org/ARDIEP.html
  - How to Survive an ARD Meeting
  - Admission, Review and Dismissal Committee Meetings (ARDs)
    - http://www.atpe.org/protection/YourStudentsAndParents/ards.asp
  - IEP Meeting Preparation

Parent Questionnaire for School
  - Six Questions Parents Should Ask at an ARD Meeting
  - IEP Meeting Preparation Checklist for Parents
Family Education Network
www.familyeducation.com
This site provides a great expanse of information to parents generally, and includes a number of articles written by a special education attorney for parents of children with disabilities and their advocates regarding the special education system.

Special Education Advocate (WrightsLaw)
www.wrightslaw.com
This site provides legal information about special education law and advocacy for students with disabilities.

Special Education Law (Reed Martin)
www.reedmartin.com
This site provides informational resource for parents and school personnel advocating for children with special needs.
QUESTIONS?
Thank You!