Autism
A Parent and School Nurse Perspective
Learning Objectives:

1. **Describe the current DSM V criteria for ASD**

2. **Look at the goals for successful independence and 'least restrictive environment’**

3. **Review how to navigate resources for school staff and family members**
ASD includes autism, childhood disintegrative disorder, Asperger disorder, and pervasive developmental disorder not otherwise specified.
Autism Spectrum Disorder

1. Deficits in communication and language skills
2. Difficulty engaging in appropriate reciprocal social interaction
3. Narrow, repetitive, and stereotypical patterns of behaviors, interests, and activities
Communication Deficits include at least one of the following:

- A delay in or lack of development of spoken language
- For those who speak, difficulty initiating or sustaining a conversation with others
- Echolalia
- Lack of spontaneous, age appropriate, make believe or social imitative play
Impaired social interaction includes at least two of the following:

- Non verbal behavior difficulties
- Failure to develop appropriate peer relationships
- Lack of spontaneous sharing of ideas or interests
- Lack of social or emotional reciprocity
Diagnosis: A Shifting Landscape

- Rare ➔ Common
- Rarely traceable to biological cause ➔ Often traceable to biological cause
- Narrow range of severity ➔ Wide range of severity
- Exclusive of other disorders ➔ "Co-morbidity"
- 3 Criterion Domains ➔ 2 Criterion Domains

Goals to work toward growth and independence depend on the severity of the 2 criteria domains.

Source: John Constantino MD. - Director of Department of Psychiatry and Pediatrics Best Practice in Autism Spectrum disorders (lecture October 2016)
LIFE HAPPENS IN CONTEXT and AFFECTS OUR GOALS

- **Family / Culture**
  - Observing for sensitivity to marital discord
  - Attending to “non-squeaky wheels”

- **Interests or “Bent”**

- **Co-Existing Diagnosis**

- **Severity Level of Deficits in Social Communication and Repetitive Behaviors**
CO-MORBIDITIES – CO-EXISTING

- Attention Disorders
- Anxiety/Depression
- IRRITABILITY – tantrums, aggression, self-injury
- Seizures
- GI Disorders
- Sleep Deficits
- Immune Dysfunction

Source: Kristin Sohl, MD, FAAP – Associate Professor, University of Missouri Thomson Center for Autism – School Nurse Webinar Series – Fall 2017
# Autism and Response to Stress

## Aspects of Autism Impairment

<table>
<thead>
<tr>
<th>Aspects of Autism Impairment</th>
<th>Response to Stressors</th>
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<tbody>
<tr>
<td>Social Awareness</td>
<td>Difficulty contextualizing incidents</td>
</tr>
<tr>
<td>Social Cognition (Interpretation)</td>
<td>Prone to misinterpretation</td>
</tr>
<tr>
<td>Social Communication (Response)</td>
<td>Difficulty seeking appropriate help</td>
</tr>
<tr>
<td>Social Motivation</td>
<td>Disinhibition</td>
</tr>
<tr>
<td>Rigidity/Stereotypy</td>
<td>Idiosyncratic; often misunderstood</td>
</tr>
</tbody>
</table>

Source: John Constantino MD. - Director of Department of Psychiatry and Pediatrics
- Navigating Adolescence in Autism - Identity, autonomy, Reciprocity, Contingency (lecture February 2017)
GOALS FOR SUCCESS AT SCHOOL AND BEYOND
Classroom Interventions for ASD

- Protection from predation

- 1:1 support

- Asocial is not antisocial

- IEP should address non-structured areas – bathroom, recess and PE

** Work toward getting same successful interventions at school to occur at home and vice-a-versa **
• Applying academic work to restricted interests

• Initiating vocational approach EARLY

• Group therapy when applicable

• Social Skills therapy when applicable

** Innovative psychiatric care and DIRECT (conference call) communication can be key to moving beyond ‘babysitting’.
Sense of competence
Learn to take responsibility
Encourage unique area of interest
Sense of being valued

**EQ (Emotional Quotient) versus IQ – real success occurs in ability to interact with others appropriately.**
Autism Spectrum Disorders (ASDs)

Screening and Diagnosis

Diagnosing autism spectrum disorders (ASDs) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child’s behavior and development to make a diagnosis.

ASDs can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until much older. This delay means that children with an ASD might not get the help they need.

Diagnosing an ASD takes two steps:

Developmental Screening

Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem.

All children should be screened for developmental delays and disabilities during regular well-child doctor visits at:
- 9 months
- 18 months
Introduction

Welcome to the Autism Case Training (ACT) Web-based CE course. This introductory course contains three modules designed to help you better:

- identify autism spectrum disorders,
- assist a family through the diagnostic process,
- and care for patients with autism spectrum disorders.

Users will gain knowledge and skills to improve early identification of children with ASDs and ensure timely and appropriate care.

You can select the modules most relevant to you – or take all three! Each module is eligible for CME, CNE, and CEU.

Each module contains two or three case studies based on real-life situations. You may complete all cases within a module at once or at different times.
Autism Spectrum Disorders: Guide to Evidence-based Interventions

A 2012 CONSENSUS PUBLICATION
Autism Spectrum Disorders:
Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment

A 2010 CONSENSUS PUBLICATION
Navigating Resources for School Staff and Family Members
Eligibility

Who is eligible to receive services from the Division of DD? Eligibility is determined by what's known as a functional assessment as opposed to linking eligibility to a specific diagnosis. A developmental disability is a disability which is attributable to mental retardation, cerebral palsy, epilepsy, head injury, autism, or a learning disability related to a brain dysfunction, or any other mental or physical or mental impairment which occurs before the age 22. It must be determined that this disability is likely to continue indefinitely and that it results in a substantial functional limitation in two or more of the following six areas of major life activities: self care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self sufficiency and mobility.

Who should I contact if I believe I am eligible or a member in my family is eligible for services? There are 11 regional offices located throughout the state in the following cities: Central Mo. Regional Office (Columbia, MO), Albany, Hannibal, Joplin, Kansas City, Kirksville, Poplar Bluff, Rolla, St. Louis, Sikeston, and Springfield. Find addresses and phone numbers of these regional offices.

If I'm eligible for services, is there an age requirement? No. The Division of DD provides services to persons of any age. The only age requirement in determining eligibility is that the disability must have occurred prior to
Regional Offices

- Regional Office Map
- Regional Office Restructure Chart
- Regional Office Restructure (Powerpoint explaining the functions and positions at the Regional Offices)
- Look Up Your Legislator

The Division operates 17 entities that provide or purchase specialized services. Eleven (11) are regional offices that provide support coordination and work with individuals, families and providers. The regional offices, the primary points of entry into the system, provide assessment and case management services, which include coordination of each Individual Support Plan.

- Albany Regional Office
- Central Missouri Regional Office
- Hannibal Regional Office
- Joplin Regional Office
- Kansas City Regional Office
- Poplar Bluff Regional Office
- Rolla Regional Office
- Sikeston Regional Office
- Springfield Regional Office
- St. Louis Regional Offices
Albany Regional Office - Atchison, Holt, Nodaway, Andrew, Buchanan, Worth, Gentry, DeKalb, Clinton, Harrison, Daviess, Caldwell

Hannibal Regional Office - Marion, Monroe, Audrain, Ralls, Pike, Lincoln, Montgomery, Warren

St. Louis County Regional Office
St. Louis County

St. Louis Tri-County Regional Office
*St. Louis City, Jefferson County, and St. Charles County residents*

Kansas City Regional Office - Platte, Clay, Ray, Lafayette, Jackson, Cass, Johnson, Bates
Missouri’s Autism Projects

The Department of Mental Health’s Division of Developmental Disabilities funds five regional autism projects that serve individuals with autism and their families. Each Autism Project funds different services as decided by that region’s parent advisory council. These programs and services assist individuals with autism in developing skills and provide needed training and support for families. To enroll in your local Autism Project, talk to your service coordinator through your Regional Office or your local Senate Bill 40 Board.

Autism Project information: http://dmh.mo.gov/dd/autism/AutismProjects.htm

The Statewide Missouri Advisory Committee on Autism has parent representatives from each of the regional Autism Projects below:

Central Missouri Autism Project
150 Vandiver Dr., Columbia, MO 65202
573-882-9835 • 888-671-1041

Eastern Missouri Autism Project
St. Louis Regional Office
111 N. 7th St., 6th Floor, St. Louis, MO 63101
314-244-8800 • 314-244-8805 • 800-358-7665

Southeast Missouri Autism Project
2351 Kanell Blvd, Poplar Bluff, MO 63901
573-840-9300 • 800-497-4214

Northwest Missouri Autism Project
Kansas City Regional Office
821 E. Admiral Blvd., P.O. Box 412557
Kansas City, MO 64141
816-889-3400 • 800-454-2331

Southwest Missouri Autism Project
1515 E. Pythian, P.O. box 5030
Springfield, MO 65801
417-895-7400 • 888-549-6635
WELCOME TO THE INTERACTIVE AUTISM NETWORK (IAN) PROJECT

The Interactive Autism Network (IAN) is an innovative online project bringing together tens of thousands of people affected by autism spectrum disorder (ASD) and hundreds of researchers in a search for answers. Individuals with an ASD and their families can share information in a secure setting to become part of the largest online autism research effort. The data collected by IAN both facilitates scientific research and empowers autism community leaders to advocate for improved services and resources. In addition, anyone impacted by ASD can become part of IAN's online community to stay informed about autism research and make their voices heard.
Tool Kits

100 Day Kit

For Newly Diagnosed Families of Young Children
BE
REDY
TO FIND A MISSING CHILD WITH AUTISM.
Transition to adulthood
Items Needed for Transition to Secondary Education or Vocational Rehabilitation Services

✓ Current psych-cognitive evaluation
✓ Most recent IEP or 504 Plan
✓ HS transcript
✓ Managing physician letter of diagnostic criteria
LET’S GET REAL
OR
NUGGETS TO TAKE AWAY

• Reality – Will probably make judgements and decisions based on psychological age
  • ‘Terminal middle school’ – may have IQ content but make decisions and react emotionally to change like school age or middle schooler.
  • Adolescence – Identity should be good balance of intimacy and autonomy – good relationships have both!

• Working with differing viewpoints on what success looks like
  • age 21 – State is not longer ‘obligated’ to provide educational setting.

• Take risks
  • try a new environment, meet new people, encourage new life skills – Driving? Different living environment from home?
CONTINUE TAKE AWAY NUGGETS

How can you plan to put in some support strategies for the future?

• Talk with family and friends regarding support of aging adult

• Letter of Intent
  • Walks ‘support family’ through the myriad of needs and individual idiosyncracies – banking, bills, transport, medical, apartment/living arrangements, job support contacts, social group support (friends/people they trust), lawyer

• Special Needs Trust – puts into place some financial support that cannot be ‘spent down’ by Medicaid for custodial care – 2 co-trustees
Resources:

Janice Selekman, DNSc,RN,NCSN,FNASN, School Nursing A Comprehensive Text Second Edition 2013, pages 959-963

John Constantino MD. - Director of Department of Psychiatry and Pediatrics
• Autism Classroom Interventions (lecture January 2012)
• Best Practice in Autism Spectrum disorders (lecture October 2016)
• Navigating Adolescence in Autism - Identity, autonomy, Reciprocity, Contingency (lecture February 2017)

Kristin Sohl, MD, FAAP – Associate Professor, University of Missouri Thomson Center for Autism – School Nurse Webinar Series – Fall 2017


Website Resources:


http://www.cdc.gov/ncbddd/autism/facts.html

http://www.cdc.gov/ncbddd/actearly/act/class.html


http://dmh.mo.gov/dd/facilities/eligibility.htm

http://www.ianproject.org/
Website Resources continued

Show Me ECHO – Thompson Center -
https://thompsoncenter.missouri.edu/autism-training/echo-autism/.../show-me-echo/

Big Red Safety Toolkits
http://nationalautismassociation.org/docs/BigRedSafetyToolkit.pdf

http://nationalautismassociation.org/docs/BigRedSafetyToolkit-FR.pdf

Autism Speaks at: http://www.autismspeaks.org/
https://www.autismspeaks.org/family-services/tool-kits


MO Families for Effective Autism Treatment

The Tailor Institute -- http://www.thetailorinstitute.org/

MPACT at: http://ptimpact.org/