Diagnosis and Treatment of Autism in South Dakota

Daisha Seyfer, MD, FAAP
Developmental-Behavioral Pediatrician
Disclosure

• Behavior Care Specialists, Inc. provides ABA services in South Dakota
Autism

- Leo Kanner first described Autism in 1943 in his paper *Autistic Disturbance of Affective Contact* in which he described the behavior of 11 children.
- “Autism” from the Greek word “auto” meaning self. Autism had also been used to mean “escape from reality.”
Demographics

- Occurs in all racial, ethnic, and socioeconomic groups
- Almost 5 times more common among boys (1 in 42) than girls (1 in 189)
- Prevalence in Asia, Europe, and North America - 1%

Centers for Disease Control website, Accessed 1/7/16.
http://www.cdc.gov/ncbddd/autism/data.html
# Identified Prevalence of Autism Spectrum Disorder

**ADDM Network 2000-2010**

Combining Data from All Sites

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of ADDM Sites Reporting</th>
<th>Prevalence per 1,000 Children (Range)</th>
<th>This is about 1 in X children...</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>6.7 (4.5 – 9.9)</td>
<td>1 in 150</td>
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<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6 (3.3 – 10.6)</td>
<td>1 in 150</td>
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<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0 (4.6 – 9.8)</td>
<td>1 in 125</td>
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<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0 (4.2 – 12.1)</td>
<td>1 in 110</td>
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<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3 (4.8 – 21.2)</td>
<td>1 in 88</td>
</tr>
<tr>
<td>2010</td>
<td>2002</td>
<td>11</td>
<td>14.7 (5.7 – 21.9)</td>
<td>1 in 68</td>
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</tbody>
</table>

DSM-V Criteria

1. Deficits in social communication and social interaction across multiple contexts, currently or by history
   - Deficits in social/emotional approach. Abnormal social approach, conversational difficulties, reduced sharing of interests/emotions/affect, decreased response to social interaction
   - Deficits in nonverbal communicative behaviors (eye contact, body language, gestures), lack of facial expressions/nonverbal communication
   - Deficits in developing/maintaining/understanding relationships. Difficulty adjusting behavior to social context. Difficulties in imaginative play or in making friends. Possible absence of interest in peers.
2. Restricted, repetitive patterns of behavior/interests/activities, as manifested by at least two of the following:

- **Stereotyped or repetitive motor movements**, use of objects, speech (e.g., simple motor stereotypies, lining up objects, echolalia, idiosyncratic phrases).

- Insistence on **sameness, inflexible adherence to routines, ritualized patterns of behavior** (e.g., difficulty with transitions, rigid thinking, etc.).

- Restricted, **fixed interests** abnormal in intensity or focus.

- Hyper- or hypo **reactivity to sensory input** or unusual sensory interests.
DSM-V criteria continued

- 3. Symptoms must be **present in the early developmental period** (but may not become manifest until social demands exceed limited capacities, or may be masked by learned strategies later in life.

- 4. Symptoms must cause **clinically significant impairment** in social, occupational, or other important areas of current functioning.

- 5. These disturbances are **not better explained by intellectual disability or global developmental delay**. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.
DSM-V criteria continued

• Specify if:
  - With/without intellectual impairment
  - With/without language impairment
  - Associated with a known medical or genetic condition or environmental factor
  - Associated with another neurodevelopmental, mental, or behavioral disorder
  - With catatonia
DSM-V autism severity levels

- Level 3 - Requiring very substantial support
  - Severe deficits in verbal/nonverbal social communication, limited initiation of social interaction
  - Inflexible behavior, extreme difficulty coping with change, restricted/repetitive behaviors markedly interfere with functioning
DSM-V autism severity levels

• Level 2- Requiring substantial support
  – Marked deficits in verbal/nonverbal social communication, social impairments apparent even with supports in place, reduced or abnormal responses to social overtures.
  – Inflexible behavior, difficulty coping with change, restricted/repetitive behaviors appear frequently enough to be apparent to the casual observer.
DSM-V autism severity levels

- Level 1- Requiring support
  - With supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions.
  - Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities.
In a Nutshell

• Some people with autism need a lot of help in their daily lives
• Others need less
Autism Spectrum Disorder

• DSM-V Includes:
  • Autistic Disorder
  • Pervasive Developmental Disorder, NOS
  • Asperger syndrome

• These are now all called Autism Spectrum Disorder
Causes of Autism

• There may be many different factors that make a child more likely to develop an ASD

• Environmental, biologic, and genetic factors
Risk Factors

• Genes are one of the risk factors
  – Children who have a sibling with ASD are at higher risk of having an ASD themselves
  – Identical twins: if one ASD, other has a 36-95% chance
  – Fraternal twins: if one ASD, other has a 0-31% chance

• More common in certain genetic conditions like Fragile X, tuberous sclerosis, Down syndrome
Risk Factors continued

- Valproic acid and thalidomide during pregnancy have been linked to a higher risk of ASD
- Children born to older parents at higher risk
- Prematurity and low birth weight may be higher risk for ASD
Other Characteristics

• IQ at age 8 years among children with ASD- Autism and Developmental Disabilities Monitoring Network, 2010

Developmental Screening
- Per AAP guidelines, M-CHAT should be done at 18 and 24 month visits
Red Flags

• No babbling, pointing, or other gestures by 12 months
• No single words by 16 months
• No 2-word spontaneous (not echolalic) phrases by 24 months
• Loss of language or social skills at any age
Diagnosis of Autism

• Signs and symptoms may begin to show before age 18 months
• By age 2, a diagnosis by an experienced professional can be considered reliable
• Many children are not diagnosed until age 4 years or later
• Parents may notice a developmental problem before first birthday
• Differences in social, communication, and fine motor skills may be evident from 6 months
Diagnosing Autism in South Dakota

• Places to get an autism diagnostic evaluation in South Dakota:
  – Behavior Care Specialists
  – LifeScape
  – Center for Disabilities
  – Black Hills Special Services, Sturgis

• Often school district is a good place to start
• Schools may do their own diagnostics or may contract out
Autism evaluation includes:

- Observation of play and child-caregiver interactions
- Detailed history and physical exam
- Review of records
- Developmental assessment of all skills
- Language evaluation
- Hearing test
Evaluation of Autism

- Autism specific tests:
  - ADOS: Autism Diagnostic Observation Schedule
  - GARS: Gilliam Autism Rating Scale
  - CARS: Childhood Autism Rating Scale
Medical Evaluation of a Child with Autism

- Developmental History
  - Gross motor skills
  - Fine motor skills
  - Speech and language skills
  - Social skills
  - Adaptive skills
Medical Evaluation of a Child with Autism

• History
  – Prenatal history, exposure to illicit drugs, alcohol, toxins, prenatal infections
  – Prematurity
  – Chronic medical conditions
  – Seizures
Medical Evaluation of a Child with Autism

• Physical examination

• Look for features that may be part of a genetic syndrome
  – Fragile X
  – FAS
  – Tuberous sclerosis
  – Rett syndrome
Medical Evaluation of a Child with Autism

- Formal Hearing Assessment - by an audiologist
- Vision assessment
- Testing for Fragile X
- Chromosomal microarray
- Other genetic testing as indicated
- Consider referrals to genetics or pediatric neurology if indicated
- EEG, MRI, metabolic testing may be indicated
Treatment of Autism in SD

- Early intervention
- Supportive therapies
- Behavior therapy
- Social supports
- Family supports
- Medications
Treatment of Autism

• No cure
• Early intervention is key
• Referral to Birth to Three
• Can also ask for an autism evaluation through Birth to Three
• The earlier therapies and treatments are started the better the outcome
Early Intervention

• Part C of the Individuals with Disabilities Education Act (IDEA)
• Children ages 0-3
• ANYONE can refer a child for Early Intervention Services (parents, grandparents, pediatricians, etc..)
• No diagnosis needed
• South Dakota Birth to Three program
Therapies

• If speech delay/abnormality- Speech Therapy
• If fine motor or sensory- Occupational Therapy
• If gross motor delays- Physical Therapy

• Schools may provide these services
• Can also do privately

• Don’t necessarily need an autism diagnosis to access these therapies
Behavior Therapy

• Behavioral Interventions are the first line of strategy in managing behavior problems!
• Behavior therapy is best evidence-based therapy for ASD
• Goal of behavior therapy:
  – Address problem behavior (aggression, self-injury, etc.)
  – Teach communication
  – Teach social behavior
  – Teach self-help skills (including toileting and feeding)
  – Teach basic academic skills
Applied Behavior Analysis (ABA)

- Considered the evidence-based best practice treatment for autism spectrum disorder
- Most effective method to teach children with ASD
- Scientific discipline founded in 1938
- Lovaas, 1987
- Substantial research base to support use
- Endorsed by US Surgeon General, National Institutes of Health (NIH), and American Academy of Pediatrics (AAP)
- 44 states require insurers to cover ABA to some extent, including SD

Behavior Therapy

• Behavior modification techniques include:
  – Positive reinforcement
  – Repetition
  – Prompting
  – Shaping
  – Differential reinforcement of other behaviors
Applied Behavior Analysis (ABA)
Applied Behavior Analysis (ABA)
Applied Behavior Analysis (ABA)

- Uses reinforcement to motivate and shape desired behavior
- Facilitate the development of language, positive skills, and social behavior
- Helps reduce social and behavioral problems
Benefits of ABA

• Studies have shown that kids with ASD who receive ABA may make **significant and sustained gains** in:
  - IQ
  - Language
  - Academic performance
  - Self-care behaviors
  - Social skills

Problems ABA can address

• Functional Living Skills
• Language
• Reading
• Social Skills
• Peer Interactions
• Academic Engagement
• Decreasing Inappropriate Behaviors
Address disruptive behaviors

• ABA can address:
  – Tantrums
  – Noncompliance
  – Feeding problems
  – Aggression
  – Self-injury
  – Compliance with special activities such as medical appointments
AAP Autism Recommendations

• Intervention as soon as an ASD diagnosis is considered
• Intensive behavioral intervention at least 25 hours per week
• Inclusion of a family component
• Curricula that address:
  – Functional, spontaneous communication
  – Social & adaptive skills
  – Cognitive skills
  – Reducing problem behaviors

AAP Recommendations Cont’d

• Speech Therapy
• Social skills instruction
• Occupational therapy and/or sensory integration therapy
• Medical management of:
  – Seizures
  – GI problems
  – Sleep disturbance
Medications

• Medications are not the first line of therapy
• **Stimulants:** Target symptoms of hyperactivity, impulsivity, and distractibility
• **SSRI’s:** Target anxiety, OCD, and depression
• **Alpha agonists:** Target symptoms of impulse control, hyperactivity, tics, emotional outbursts, aggression
• **Atypical Antipsychotics:** Target symptoms of irritability, aggression, repetitive behaviors
  – Risperidone
  – Aripiprazole
Social supports

• Social skills groups
  – Autism Behavioral Consulting, Sioux Falls
  – At your child’s school
  – LifeScape

• Social Thinking groups

• Opportunities to interact with typically-developing peers

• Recruit teachers and others to help promote child’s social skills
Family supports

• Providing education and resources
• Emotional support
• Assisting parents in advocating for their child’s needs
• Sometimes parental referral for counseling or mental health services is needed
• Encouragement to seek support from friends, relatives, other families
• Autism Support Network- http://www.autismsupportnetwork.com/
Prognosis

• Difficult to predict
• Early identification leads to better outcome
• Cognitive functioning is the most important predictor of outcome
• Those with average intelligence more likely to achieve independent functioning as adults
Economic costs of autism

- Total costs for children in the US estimated $11.5 billion - $60.9 billion (2011)
- Includes direct and indirect costs
  - Medical care
  - Special education
  - Lost parental productivity
Economic costs continued

- 2005 average annual medical costs for Medicaid-enrolled kids with ASD: $10,709 per child
- Six times higher than that for kids without ASD ($1812)
- Intensive behavioral interventions (ABA) can cost in excess of $40,000 to $60,000 per child per year

Centers for Disease Control website, Accessed 1/7/16.
ABA Accessibility in SD

• Not every child in SD can access ABA due to insurance coverage
• Avera is only large group plan that covers
• TriCare covers
• Some self-funded insurance companies will cover
  – Starbucks
  – Schwan’s
  – Wal-Mart
  – Wells Fargo
Autism Advocacy in SD

• 2014- Parent and provider group initiated bill to begin to get ABA coverage after SD Wellmark announced they were dropping coverage
• Bill killed in senate
• State agreed to fund a study of the issue- to be readdressed once results were in
Autism Advocacy in SD

• Initial bill for 2015 was actually presented via the governors office after bringing key stakeholders (mainly insurance companies) to the table.

• Bill offered very little benefit/coverage to kids and families.

• Families lobbied hard to get a stronger version of the bill passed and it was passed in the House but defeated in the Senate (much like the previous year).
SD Autism Law

• Passed in 2015
• Severe restrictions limit utility to South Dakota families
  – Tiered service model not covered
  – Restrictive dollar caps
• Only ONE South Dakota family has benefitted from this law (as far as I am aware), and ONLY because family appealed and appealed
SD Autism Law

• In a Nutshell:
  – We have lot more work to do!
Family and Provider

RESOURCES
Resources for Families

Resources for Families

• Autism Speaks First 100 Days Kits
  • https://www.autismspeaks.org/family-services/tool-kits/100-day-kit
Resources for Families

• Autism Speaks Sleep Toolkit
  • https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit
Resources for Families

• Autism Speaks Parent’s Guide to Applied Behavior Analysis
  • https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/avn-air-p-applied-behavior-analysis
Resources for Families

• Autism Speaks Parent’s Guide to Toilet Training
  • https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-toilet-training
Resources for Families

• Autism Speaks Dental Toolkit
  • https://www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
Resources for Families

• Autism Speaks
Haircutting
Training Guide
• https://www.autismspeaks.org/family-services/tool-kits/tips-successful-haircuts
Resources for Families

- Other Toolkits/Resources available for **free download** on Autism Speaks website
- Advocacy Toolkit
- Blood Draw Toolkit
- Dental Professional’s Toolkit
- Guide for Managing Constipation
- Guide to Feeding Behavior
- Guide to EEGs
- Guide to Pica
- Guide to Puberty & Adolescence
- Tools for Successful Vision Exams
- Challenging Behaviors Toolkit
- IEP Guide & Resources
- And more!
There is no Ham in Hamburgers

Resources for Providers

• CDC’s Learn the Signs. Act Early.
• http://www.cdc.gov/ncbddd/actearly/index.html
Resources for Providers

  - Dozens of handouts in English and Spanish on a variety of ASD-related topics


References cont’d
