A Field Guide for Autism and Developmental Delays

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DISCLOSURE STATEMENTS

I have no commercial or financial interest to disclose.

The views expressed in this presentation are those of the author(s) and do not reflect the official policy of Madigan Army Medical Center, the Department of the Air Force, the Department of Defense or the U.S. Government.
Learning Objectives

• Illustrate the new age of caring for children with Autism and other developmental disabilities

• Describe best practices to identify, evaluate and treat children with developmental disabilities/autism.

• Recognize the type of individualized treatment methods required for a military child with an Autism Spectrum Disorder and or developmental disability

• Discuss specific challenges military families who have a child with Autism or other special needs encounter.
Brother Juniper

Martin Luther and Victor

The Wild Boy of Aveyron
Leo Kanner 1896-1981

• 1943 wrote “Autistic Disturbances of Affective Contact”

• Kanner was the first to suggest that genetic factors may be part of the cause of autism, but rejected the idea that there was a problem in the brain.

• Suggested “cold, detached, rigid, humorless parents” were part of the cause of autism.
Autism Triad
Diagnostic and Statistical Manual - IV

Joint Attention

Restrictive/Repetitive behaviors and interests

Communication Impairment

Social > Cognitive
DSM-5:

- Autistic Disorder
- Asperger’s Disorder
- PDD-NOS
- CDD

Autism Spectrum Disorder
Autism Dyad

DSM - 5

Restrictive and Repetitive Interests

Communication Impairment

Social Impairment
DSM-5

• **SEVERITY**
  • “1, 2, 3” based on **degree of support** required for each of the core areas

• **SPECIFIERS**
  • Intellectual disability
  • Language Impairment
  • Other diagnosis, such as Fragile X or Down Syndrome
<table>
<thead>
<tr>
<th>Surveillance year</th>
<th>Birth year</th>
<th># of ADDM sites reporting</th>
<th>Prevalence per 1000</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</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0</td>
<td>1 in 125</td>
</tr>
<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0</td>
<td>1 in 110</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3</td>
<td>1 in 88</td>
</tr>
<tr>
<td>2010</td>
<td>2002</td>
<td>11</td>
<td>14.7</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2012</td>
<td>2004</td>
<td>11</td>
<td>14.6</td>
<td>1 in 68</td>
</tr>
</tbody>
</table>

2018 – now 1/59

MMWR, CDC
Epidemiology of Autism

- Special education - ASD
  - 1980  20,000
  - 2003  191,000
  - 2012  455,000
  - 2014  538,000

- Why an increase?

National Center for Education Statistics
Epidemiology of Autism

- Prevalence of Autism
  - 1 / 59

- Why an increase?
  - Broader diagnostic criteria
  - Increased provider recognition
  - Diagnostic substitution
  - Co-morbidity
  - Possibly a true increase in incidence?
  - Earlier Diagnosis to get services (age 6 ↓ to age 2)
“The New Spectrum”

- Sensory Processing Disorder (B criteria)
- Semantic/Pragmatic Communication Disorder (A criteria)
  - Use of language poor/socialization fair
- Non-Verbal Learning Disabilities
  - Poor at (language gestalt, spatial perception, and motor co-ordination)
- Hyperlexia = incredible rote reading skills from a young age
- Rigid and Restricted Interests impacting development
Layers of the ASD Onion

DNA 1000+ genes with various roles in ASD

Brain: abnormal brain growth

Mind: Abnormal Theory of Mind

Community: Societal Norms
See Temple Grandin video at
https://youtu.be/1qPFAT4p8Lc
Early Recognition of Autism
Joint Attention

• No big smiles or warm happy expressions by or after 6 months

• No back and forth sharing of sounds or facial expressions by 9 months

• No back and forth gestures like pointing, showing, reaching, or waving by 12 months

• Includes (PDP) protodeclarative pointing: Calling another person’s attention to an object or event.

• Tunes other children and adults out
confused

joking

sad

serious
The Assessment

- **Level One**
  - **Surveillance** to identify any child at risk for delays
    - Ages and Stages
  - Specific **screen** for autism
    - MCHAT R/F 2014, CARS, or STAT
  - Referral to intervention program

- **Level Two**
  - In depth developmental assessment
  - Identifies the individual need for services
### Screening Test for Autism in Toddlers (STAT)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Action</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Turn Taking</td>
<td>Play</td>
<td>Rolls car back and forth</td>
</tr>
<tr>
<td>Doll Play</td>
<td>Play</td>
<td>Simple functional play with doll or animal</td>
</tr>
<tr>
<td>Bubbles</td>
<td>Requesting</td>
<td>Requests help opening bubbles or more bubbles</td>
</tr>
<tr>
<td>Food</td>
<td>Requesting</td>
<td>Requests help opening food with eye contact and vocalization</td>
</tr>
<tr>
<td>Balloon</td>
<td>Directing</td>
<td>Directs your attention to deflating balloon</td>
</tr>
<tr>
<td>Puppet</td>
<td>Directing</td>
<td>Directs your attention to puppet</td>
</tr>
<tr>
<td>Bag of Toys</td>
<td>Directing</td>
<td>Directs your attention to a toy in the bag</td>
</tr>
<tr>
<td>Noisemaker</td>
<td>Directing</td>
<td>Directs your attention to noisemaker</td>
</tr>
<tr>
<td>Shake Rattle</td>
<td>Imitation</td>
<td>Imitates your shake of rattle</td>
</tr>
<tr>
<td>Roll Car</td>
<td>Imitation</td>
<td>Imitates your roll of car</td>
</tr>
<tr>
<td>Drum Hands</td>
<td>Imitation</td>
<td>Imitates your drumming of hands</td>
</tr>
<tr>
<td>Hop Dog</td>
<td>Imitation</td>
<td>Imitates your hopping of toy dog</td>
</tr>
</tbody>
</table>
What Co-Morbid Problems do we need to look for or assess in a child/adolescent with ASD

- ADHD
- Sleep problems
- Seizures
- GI problems/Allergy
- Anxiety
- Depression
- OCD
- Outburst/Control
Accessing Services

- Early Intervention < age 3 - Federal
- Childhood Preschool Special Education (3-5)
  - School District
- Childhood Special Education (5-21)
  - Elementary
  - Middle School
  - High School
  - Vocational
  - Life Skills
- Transition to Adult (21 and beyond)
Intervention Strategies Used:

• Behavior Modification: Applied Behavior Analysis (ABA- Lovas)
• Developmental Strategies: Floortime (Greenspan)
• TEACCH (North Carolina-Duke)
• Play Project (Ohio)
• Picture Exchange Communication Systems (PECS)
• Social Skills/Social Scripts
• Integrated - Music, Pet, and Homeopathic
What should the parents expect!

- **Begin ASAP** and monitor frequently
- ****Intense
  - **20-30 hours or more per week
  - Summer programs
- **Parental involvement** (both if available)
- Good **communication** (parent, teacher, medical home and therapists)
- Program should
  - Encourage child to initiate, communicate, and **socially engage**.
  - Address **generalization**, working towards inclusion and independence
ABA: Applied Behavior Analysis

• ABA rooted in Skinner principles: the *science of learning*.

• Behaviors are targeted to diminish or increase depending on the situation.

• Behavioral interventions make a difference.
Six Developmental Trajectories Characterize Children With Autism

Pediatrics; April, 2012;
Christine Fountain, Alix S. Winter and Peter S. Bearman

A Communication trajectories

- High (12.7%)
- Bloomers (7.5%)
- Medium-high (25.8%)
- Medium (24.5%)
- Low-medium (18.4%)
- Low (11.1%)
Six Developmental Trajectories Characterize Children With Autism

*Pediatrics*; April, 2012;
Christine Fountain, Alix S. Winter and Peter S. Bearman

**B Social trajectories**

- **High (7.0%)**
- **Bloomers (10.7%)**
- **Medium–high (19.6%)**
- **Medium (29.7%)**
- **Low–medium (24.5%)**
- **Low (8.4%)**
Six Developmental Trajectories Characterize Children With Autism

*Pediatrics; April, 2012; Christine Fountain, Alix S. Winter and Peter S. Bearman*

**C** Repetitive behavior trajectories

- Never (21.4%)
- Improving (8.1%)
- Declining (7.1%)
- When stressed (28.0%)
- Daily (27.6%)
- Usually (7.8%)
Challenges to care for children with autism

• Comprehensive
• Continuous
• Coordinated
• Family centered
BLUF: Communication is Key

#1 Greatest identified need by parents

• Create Functional Goals
  • -purpose(s)
  • -schedule
  • -content
  • -form and function
• 1 out of 4 career Military Families are enrolled in EFMP

• 23% of Military Children have a Chronic Medical Condition
  • 5% with complex chronic care account for > 40% of child healthcare dollars

• Over 30,000 military children have been diagnosed with an Autism Spectrum Disorder (ASD)

• The average military child moves 3+ times before age 5
  • Attend 5-7 different schools prior to graduation
It takes a Village: Creating a Home, School, Medical and Community Collaboration
Mission Perspective – Levels of action for “at risk”

- **Strategic** – Big Picture – Large and Multiple Systems
- **Operational** – Think Global Act Local – Local Systems, Partnerships
- **Tactical** – On the ground, Day to Day operations
Strategic – Mission Connections and Coping

- Embedded Care Coordination in the Medical Home Healthy Steps

- Pediatric Developmental Autism Extenders – Eval children < 5 for Autism

- Empower Parent Councils

- Parent Mediated Intervention of Applied Behavioral Analysis for Autism
Operational-CONNECTIONS

• **JBLM CARES** – 1st DoD Autism Center

• Medical/Behavioral **integrated** school clinics

• Community **Bi-directional Outreach** – Multidisciplinary Teams

• Connected **Medical Homes**, Day Care/**Schools**, Libraries and Children’s museums

• **Parent Mediated Intervention** - Play Project – **positive** behavior

• **Screen for at-risk children** - Developmental/Mental Health
Tactical – COPING & SUPPORT

- **Smartphones**: Emails, Texts, Apps, and videos

- **Wearable devices** – camera’s / recording talking / step counters, Pressure sensors

- **Telehealth** – local and international

- Scheduled “**Team**” teleconferences
Military Kids with Special Needs

- Tricare for Kids
- NDAA 2017
- DHA

- Extended Care Health Option (ECHO) and the Autism Care Demonstration Updates:
  - Opened to Retirees
  - General Providers can assisted with ASD-DIAGNOSING
  - Ongoing monitoring of ABA the therapies CLARIFIED
  - TRICARE Overseas Program (TOP) has some limitations
    [www.tricare-overseas.com](http://www.tricare-overseas.com).

- The lifetime societal cost for one child with autism is $1.4 to $2.4 million
ABA in the Military

• **Almost ½ billion dollars** in Applied Behavior Analysis (ABA) Care

• Jan 2018 most recent in a series of policy updates of the **Autism Care Demonstration requires**:
  - 1. Outcomes Testing
  - 2. Confirmation of Diagnosis

*TOM chapter 18 section 18*
JBLM Story & Innovative Change:

• Caring for kids with Autism – a model for advocacy, change and improvement
• ABA and Therapy in the military
• Collaboration
Neurodevelopmental Center
On Joint Base Lewis McChord

Family with new diagnosis or PCS to JBLM

- 40% remain in CARES for long term therapy
- 60% Case load turnover every 3-9 months to community partners or PCS/ETS

CARES Vision

- Physician and Therapist oversight of CARES center
- 100% oversight of community Autism care for military beneficiaries
- Training and research

• Direct therapy for 100-150 children
• Eliminate referral wait time
• Recapture some cost
• Reduce EFMP denials
• Increase readiness
Average number of days to services

- Appt to Eval: JBLM CARES - 17, Community - 29
- Eval to Therapy: JBLM CARES - 15, Community - 78
YOUR MILITARY BASE

JBLM CARES

Center for Autism Resources, Education and Services

JBLM CARES STRATEGIC PILLARS

Pillar 1. Link children and families to existing RESOURCES.
Pillar 2. Provide comprehensive EDUCATION throughout the lifespan.
Pillar 3. Identify and facilitate appropriate SERVICES.
Pillar 4. Collect ongoing data to determine optimal therapeutic outcomes.
Major Racine believes it make a big difference for her family.

"tears came to my eyes immediately, because as a parent, this represents hope," she said.
Questions? / Comments!

Push through the Change
A father and daughter reflect on a lifetime of experiences.
• AAP Understanding Autism Spectrum Disorder (2015 version) pamphlet

• Autism Speaks Tool Kits for Families
  www.autismspeaks.org

• Autism Treatment Network Toolkits for Providers
  www.autismspeaks.org/atn/tool-kits

https://www.autismspeaks.org/family-services/tool-kits