

A Field Guide for Autism and Developmental Delays

Eric Flake MD

MAMC Developmental Behavioral Pediatrics

Program Director

Associate Professor USUHS

Eric.Flake@us.af.mil



DISCLOSURE STATEMENTS

I have no commercial or financial interest
to disclose.

*The views expressed in this presentation are those of the author(s)
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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



Der Wilde von Aveyron.

The Wild Boy of Aveyron

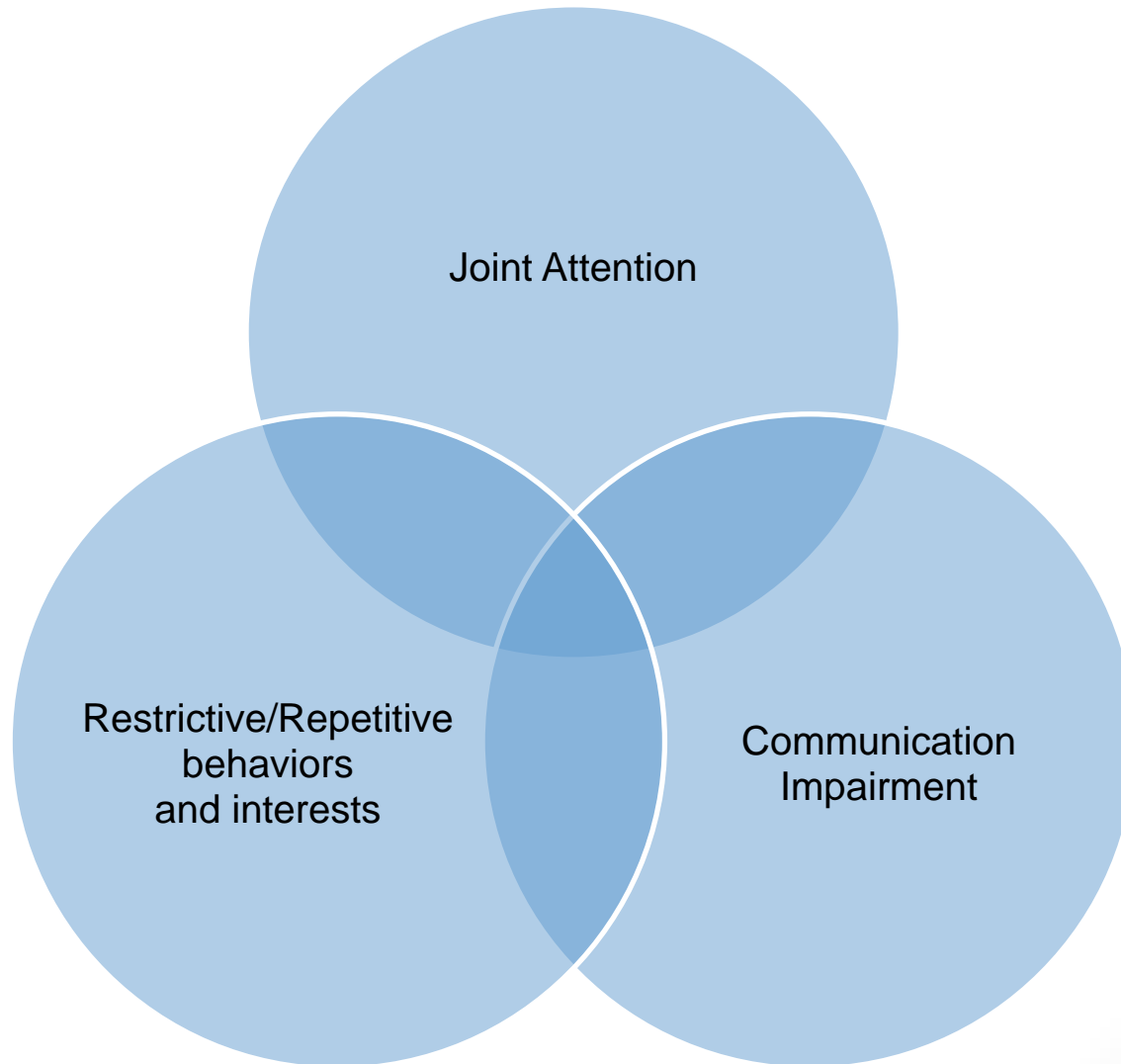
Leo Kanner 1896-1981

- **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.**



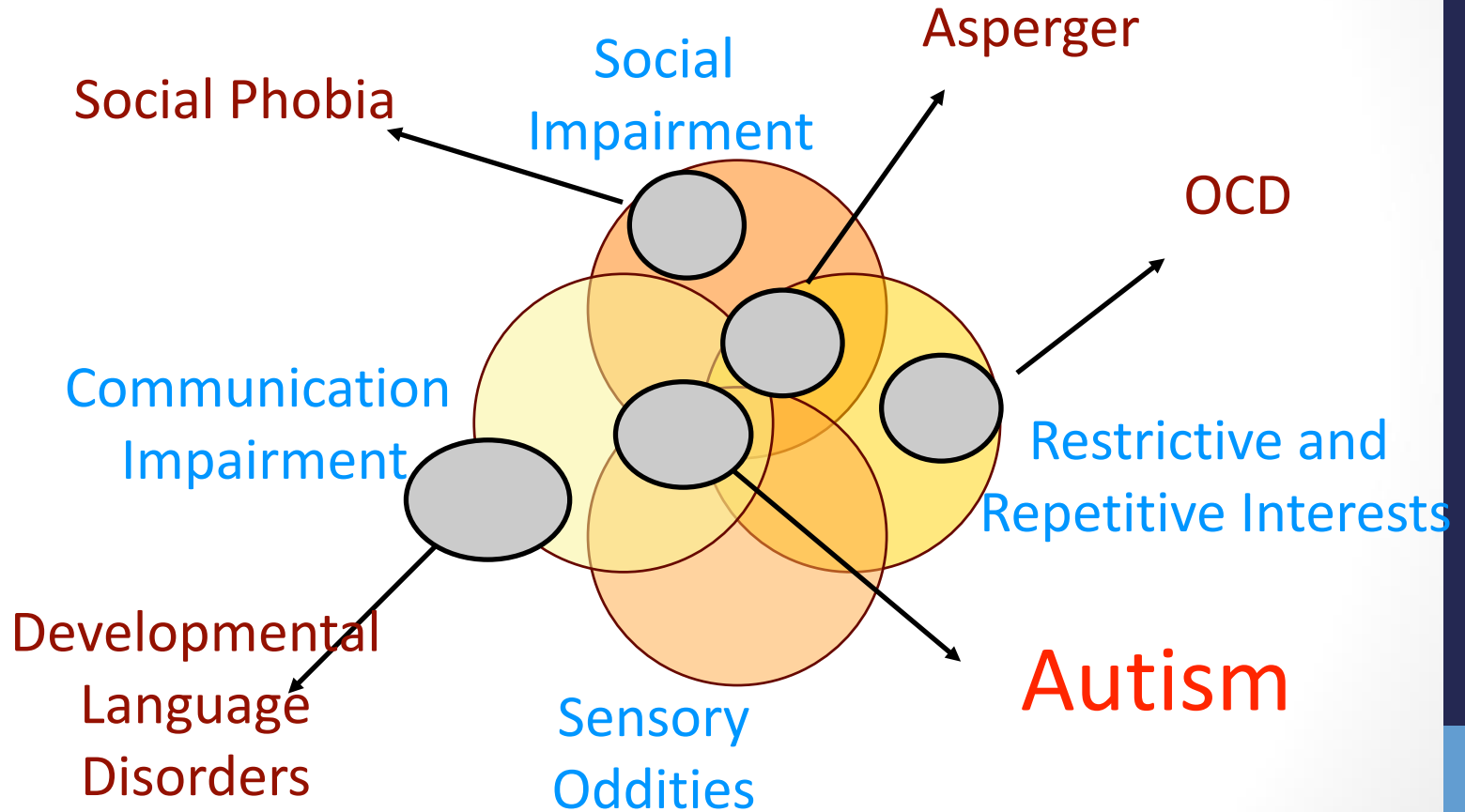
Autism Triad

Diagnostic and Statistical Manual - IV



Social > Cognitive

Autism Triad Plus



DSM-5:

Autistic Disorder

Asperger's Disorder

PDD-NOS

CDD

Autism Spectrum Disorder

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graph TD; A[Autistic Disorder] --> D[Autism Spectrum Disorder]; B[Asperger's Disorder] --> D; C[PDD-NOS] --> D; E[CDD] --> D;
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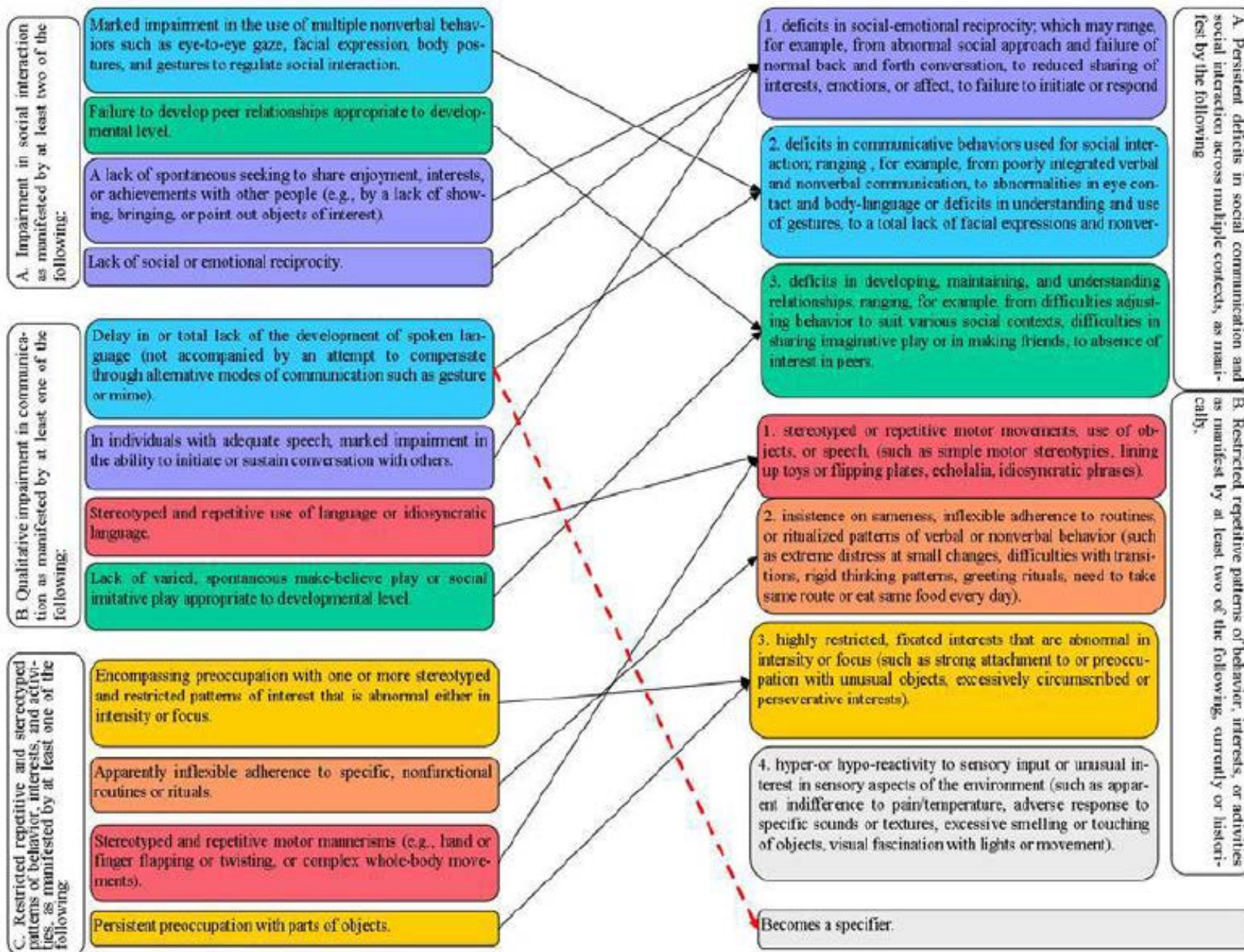
The diagram illustrates the change in DSM-5 classification. Four categories from the previous DSM editions—Autistic Disorder, Asperger's Disorder, PDD-NOS, and CDD—are shown in separate boxes at the top. Purple arrows from each of these boxes point downwards to a single, larger box at the bottom labeled 'Autism Spectrum Disorder', indicating that these four categories have been consolidated into one.

Autism Dyad

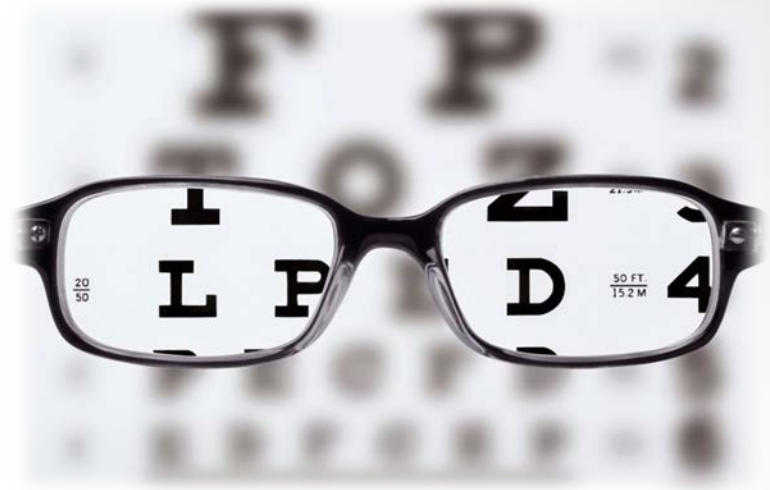
DSM - 5



THE CROSSWALK



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

Autism and Developmental Disabilities Monitoring Network

Surveillance year	Birth year	# of ADDM sites reporting	Prevalence per 1000	This is about 1 in X children
2000	1992	6	6.7	1 in 150
2002 (reported in 2007)	1994	14	6.6	1 in 150
2004	1996	8	8.0	1 in 125
2006	1998	11	9.0	1 in 110
2008	2000	14	11.3	1 in 88
2010 (reported in 2014)	2002	11	14.7	1 in 68
2012 (reported in 2016)	2004	11	14.6	1 in 68

2018 – now 1/59

Epidemiology of Autism

- **Special education - ASD**

- 1980 20,000
- 2003 191,000
- **2012 455,000**
- **2014 538,000**

National Center for Education Statistics



- **Why an increase?**

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



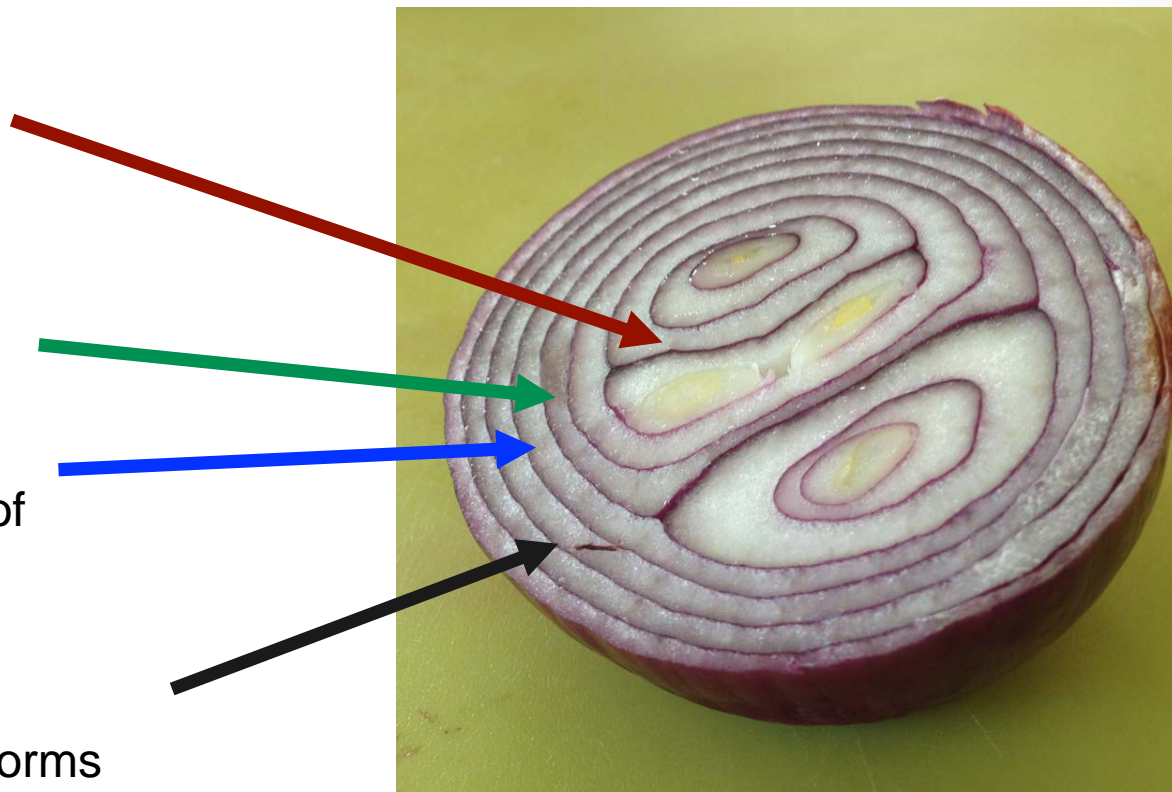
Layers of the ASD Onion

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)

Turn Taking -	Play	Rolls car back and forth
Doll Play -	Play	Simple functional play with doll or animal
Bubbles -	Requesting	Requests help opening bubbles or more bubbles
Food -	Requesting	Requests help opening food with eye contact and vocalization
Balloon -	Directing	Directs your attention to deflating balloon
Puppet -	Directing	Directs your attention to puppet
Bag of Toys -	Directing	Directs your attention to a toy in the bag
Noisemaker -	Directing	Directs your attention to noisemaker
Shake Rattle -	Imitation	Imitates your shake of rattle
Roll Car -	Imitation	Imitates your roll of car
Drum Hands -	Imitation	Imitates your drumming of hands
Hop Dog -	Imitation	Imitates your hopping of toy dog

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



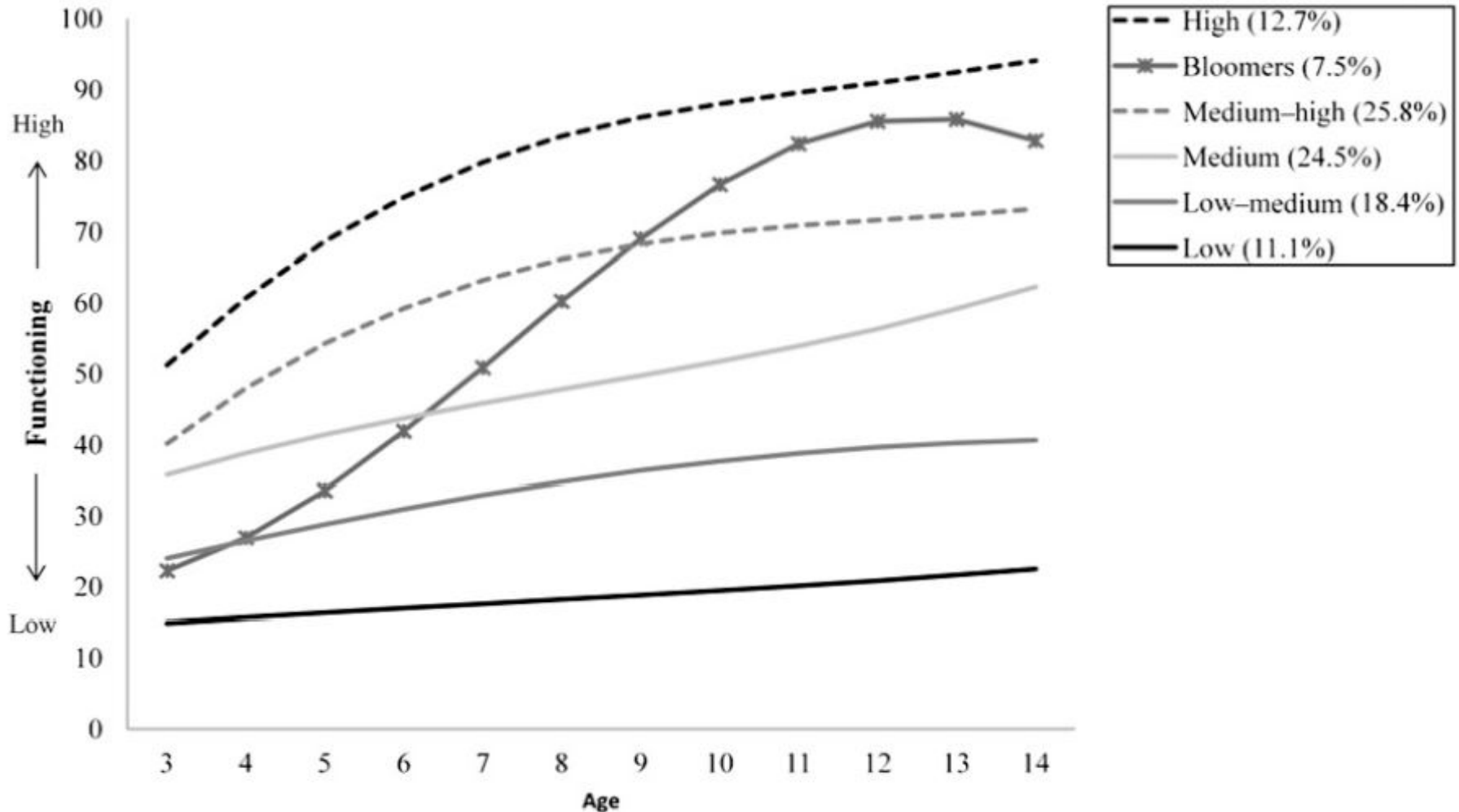
ABA: Applied Behavior Analysis

- 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.**

Trajectories

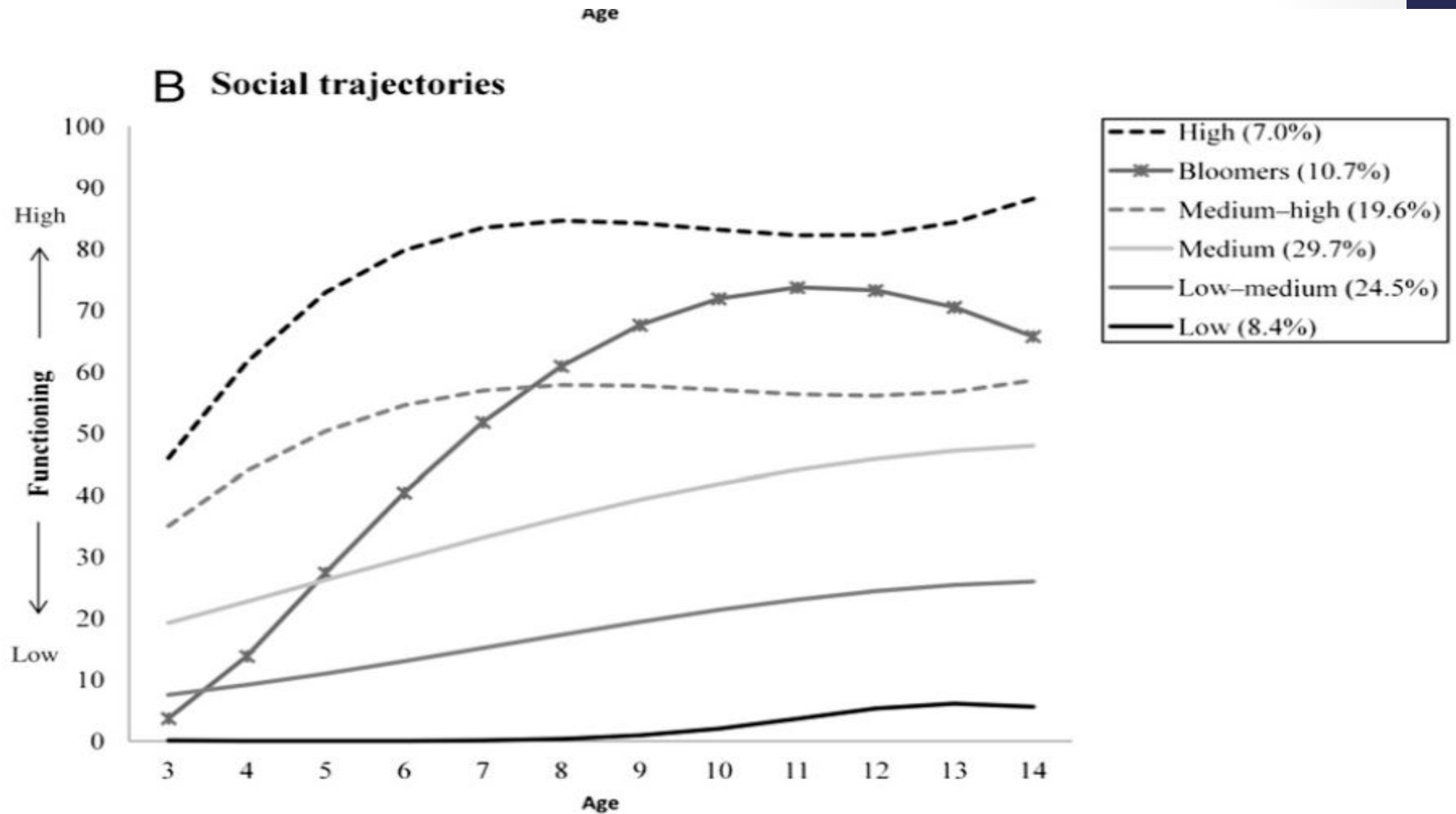
Pediatrics; April, 2012;
Christine Fountain, Alix S. Winter and Peter S. Bearman
**Six Developmental Trajectories Characterize
Children With Autism**

A Communication trajectories



Trajectories

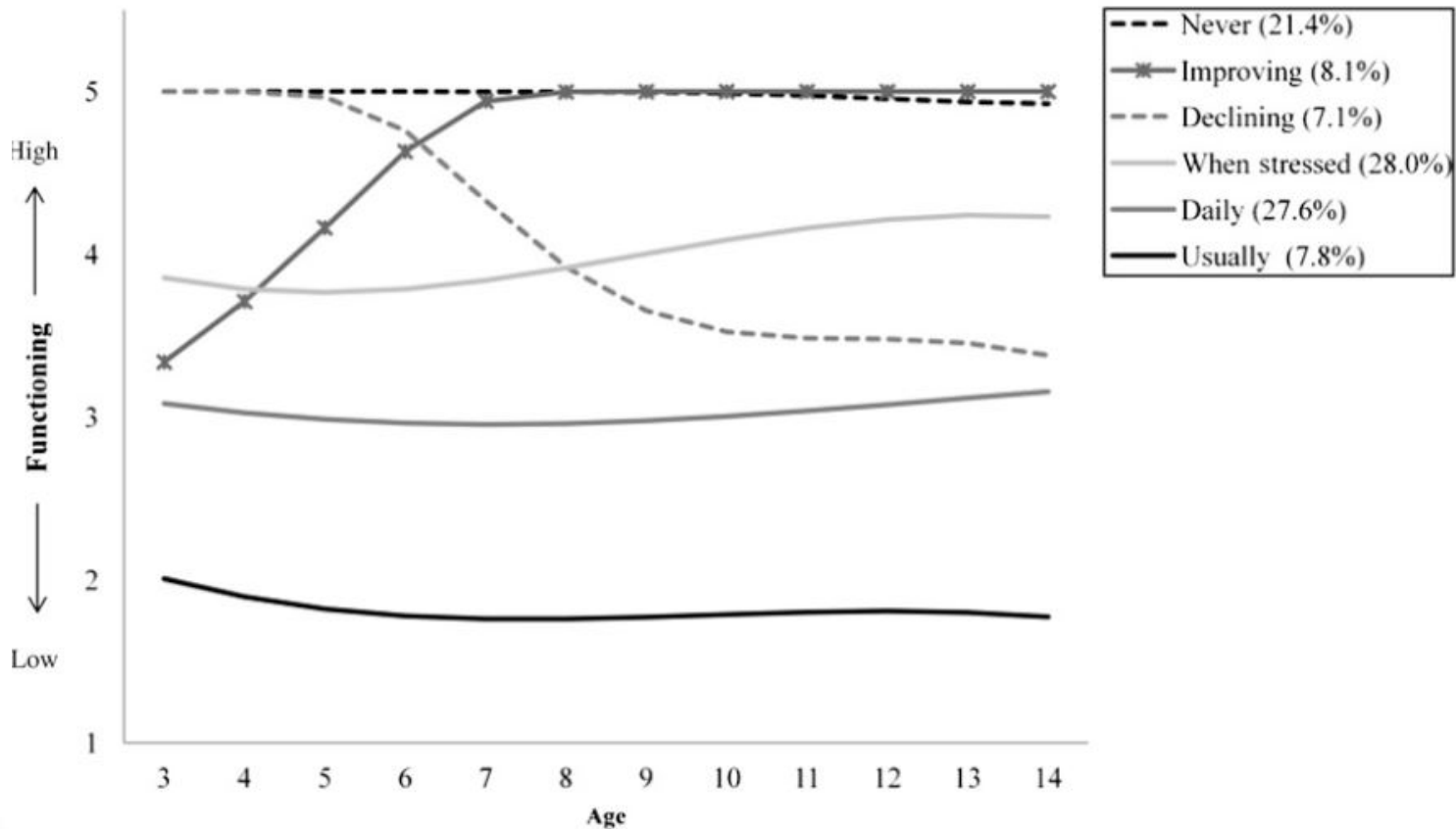
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Trajectories

Pediatrics; April, 2012;
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**Six Developmental Trajectories Characterize
Children With Autism**

C Repetitive behavior trajectories





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





A child with special needs will inspire you to be a special kind of person.

- 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



STRATEGY

The expert in battle seeks his victory from strategic advantage. - Sun Tzu

fineart
america

Think global act local



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

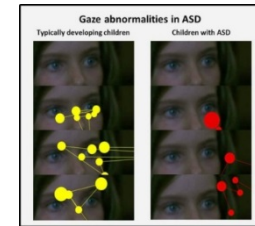
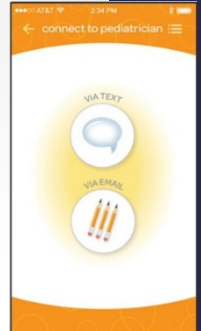
Operational-CONNECTIONS

- **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.

- 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**

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

CARES Vision



Family with new diagnosis or PCS to JBLM

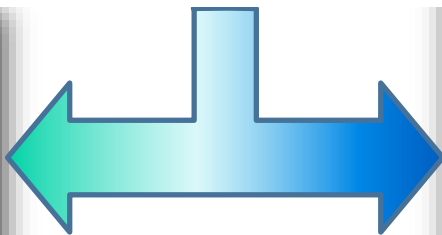


- Direct therapy for 100-150 children
- Eliminate referral wait time
- Recapture some cost
- Reduce EFMP denials
- Increase readiness

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



40% remain in CARES for long term therapy

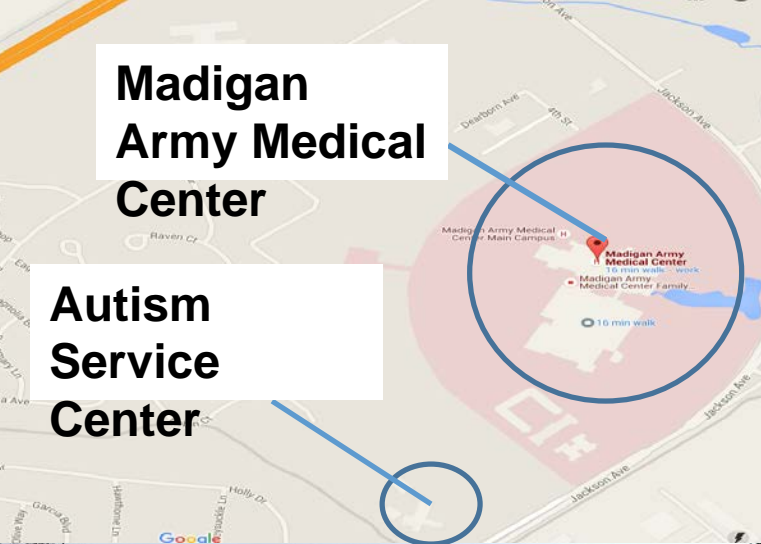


60% Case load turnover every 3-9 months to community partners or PCS/ETS



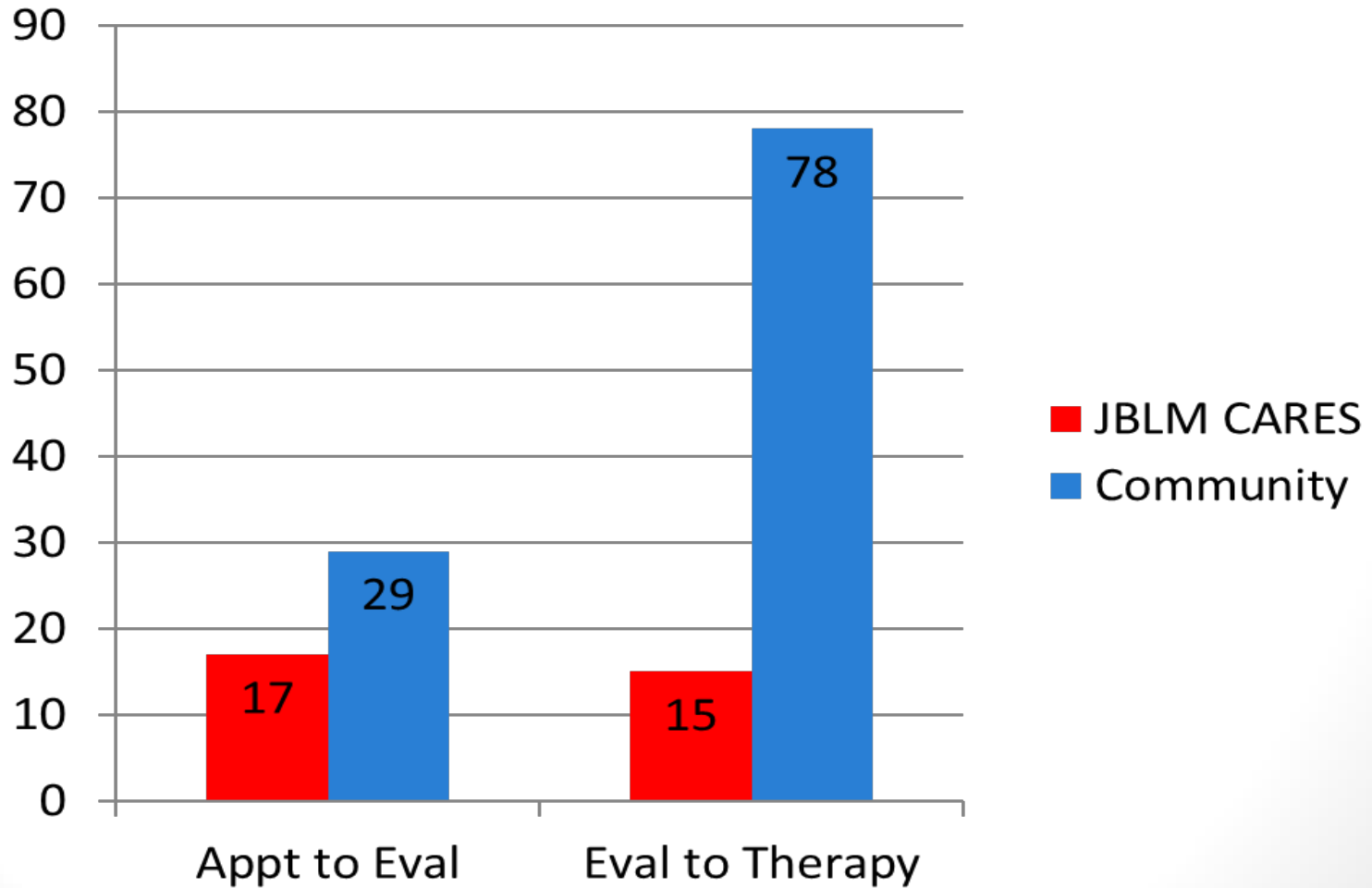
Madigan Army Medical Center

Autism Service Center





Average number of days to services



YOUR MILITARY BASE



JBLM

C·A·R·E·S

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.

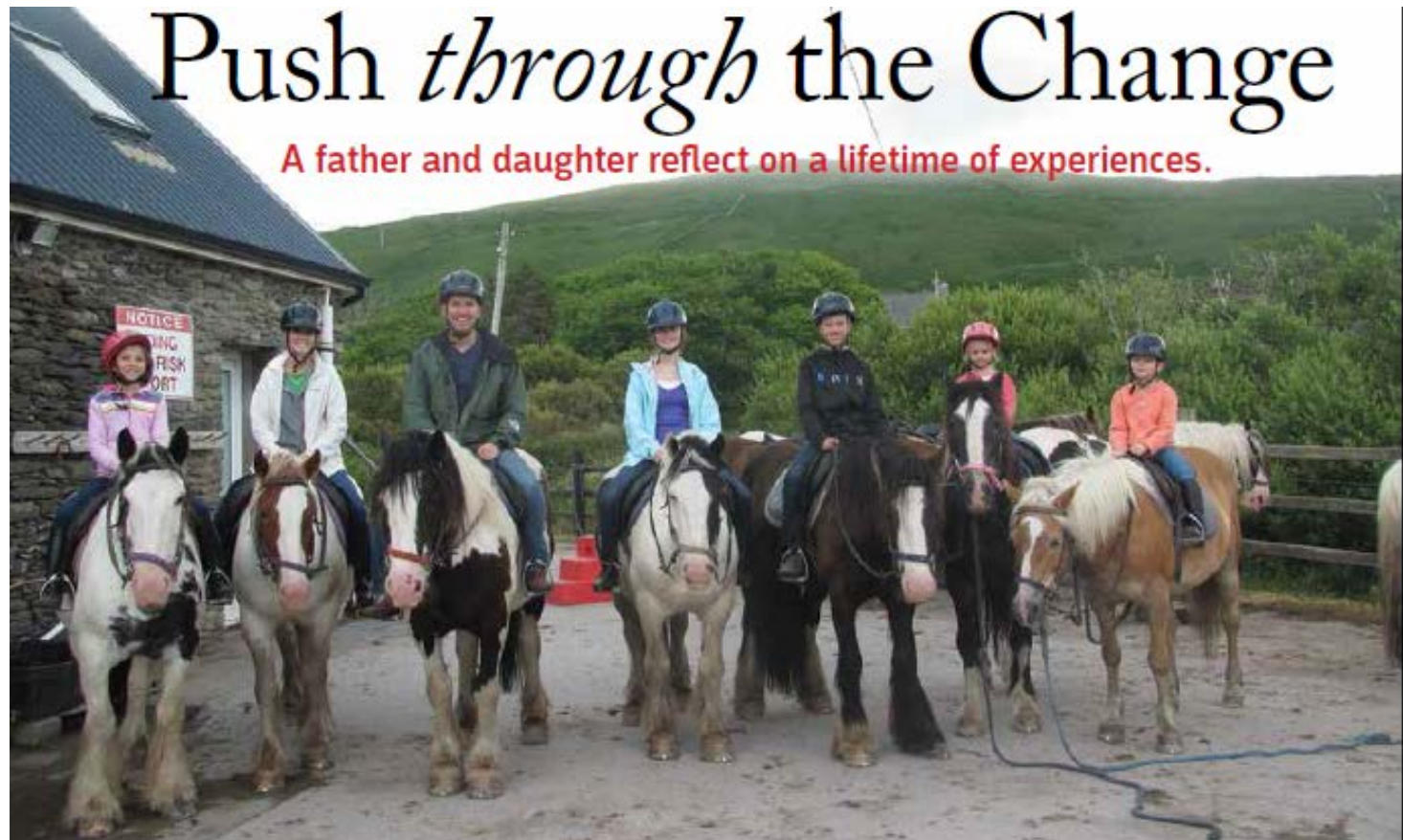
"tears came to my eyes immediately, because as a parent, this represents hope," she said.



JBLM
C·A·R·E·S

Center for Autism Resources, Education and Services

Questions? / Comments!





- 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

TOOLS

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