

A Field Guide for Autism and Developmental Delays

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DISCLOSURE STATEMENTS

I have no commercial or financial interest to disclose.

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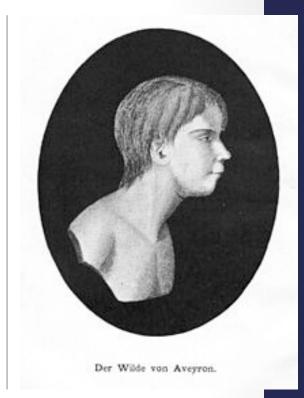
Learning Objectives

- 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

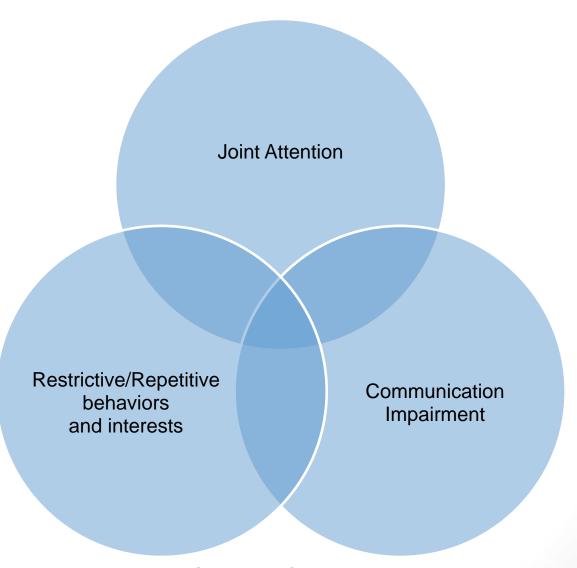
The Wild Boy of Aveyron

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.

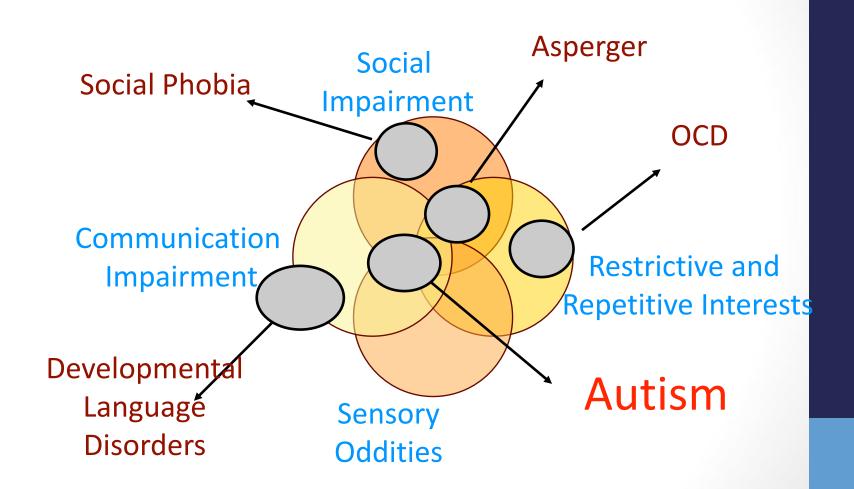


Autism Triad Diagnostic and Statistical Manual - IV

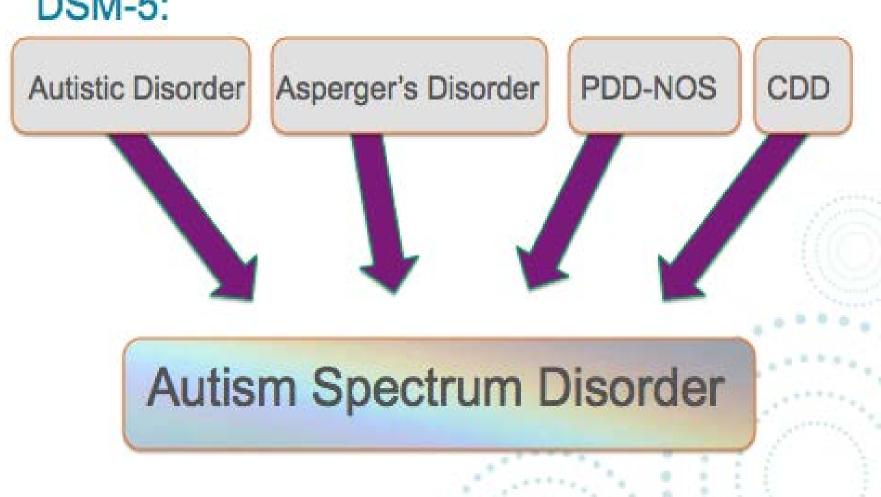


Social > Cognitive

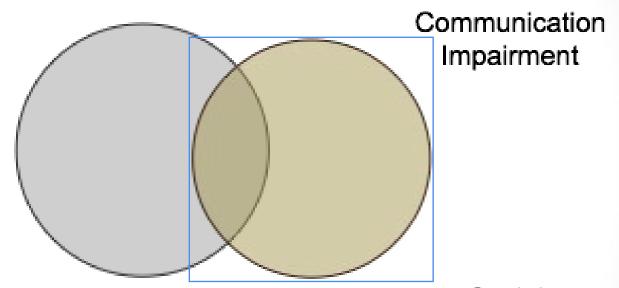
Autism Triad Plus



DSM-5:



Autism Dyad DSM - 5



Restrictive and Repetitive Interests Social Impairment

THE CROSSWALK

Marked impairment in the use of multiple nonverbal behavinteraction two of the iors such as eve-to-eve gaze, facial expression, body postures, and gestures to regulate social interaction. at least Impairment in social Failure to develop peer relationships appropriate to developmental level

A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or point out objects of interest).

Lack of social or emotional reciprocity.

Delay in or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).

In individuals with adequate speech, marked impairment in the ability to initiate or sustain conversation with others.

Stereotyped and repetitive use of language or idiosyncratic anguage.

Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).

Persistent preoccupation with parts of objects.

deficits in social-emotional reciprocity; which may range, for example, from abnormal social approach and failure of normal back and forth conversation, to reduced sharing of interests, emotions, or affect, to failure to initiate or respond

2. deficits in communicative behaviors used for social interaction; ranging, for example, from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body-language or deficits in understanding and use of gestures, to a total lack of facial expressions and nonver-

3. deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts, difficulties in sharing imaginative play or in making friends, to absence of interest in peers

1. stereotyped or repetitive motor movements, use of objects, or speech, (such as simple motor stereotypies, lining up toys or flipping plates, echolalia, idiosyncratic phrases).

2. insistence on sameness, inflexible adherence to routines. or ritualized patterns of verbal or nonverbal behavior (such as extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. highly restricted, fixated interests that are abnormal in intensity or focus (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (such as apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Becomes a specifier.

B 8 Restricted repetitive patterns of behavior, interests, or activities manifest by at least two of the following, currently or histori-

social interaction across multiple contexts, as mani-fest by the following

A. Persistent deficits

5

social communication and

as manifested by at least one of the B Qualitative impairment in communicafollowing:

tion

C. Restricted repetitive and sterectyped patterns of behavior, interests, and activities, as manifested by at least one of the following.

munifested by

following:

Apparently inflexible adherence to specific, nonfunctional routines or rituals.



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

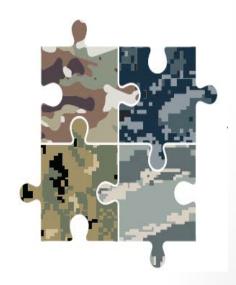
2018 - now 1/59

MMWR, CDC



Epidemiology of Autism

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



• 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

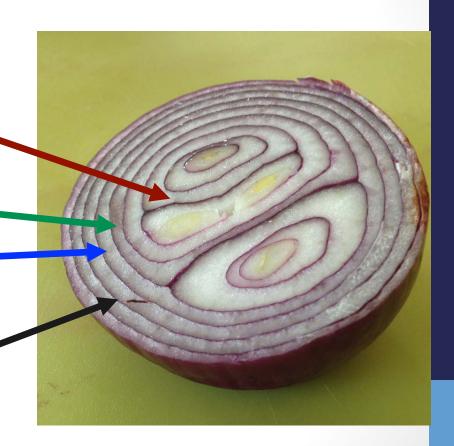
DNA 1000+ genes with various roles in ASD

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

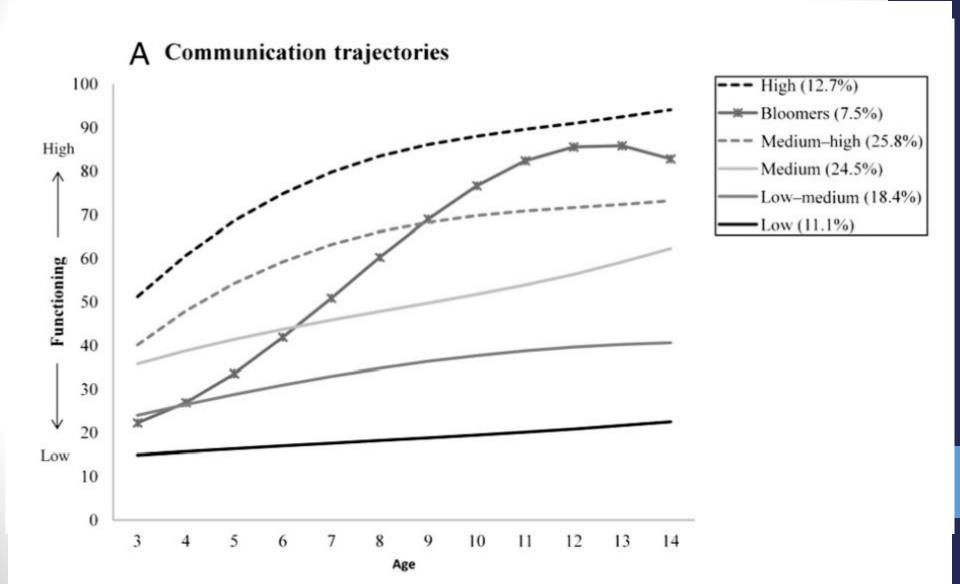
 ABA rooted in Skinner principles: the science of learning.

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

Behavioral interventions make a difference.

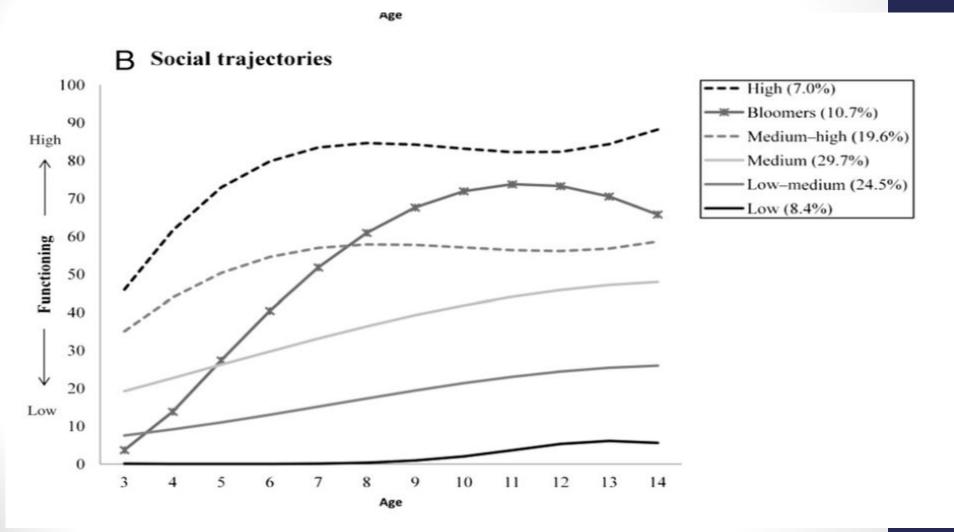
Trajectories

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



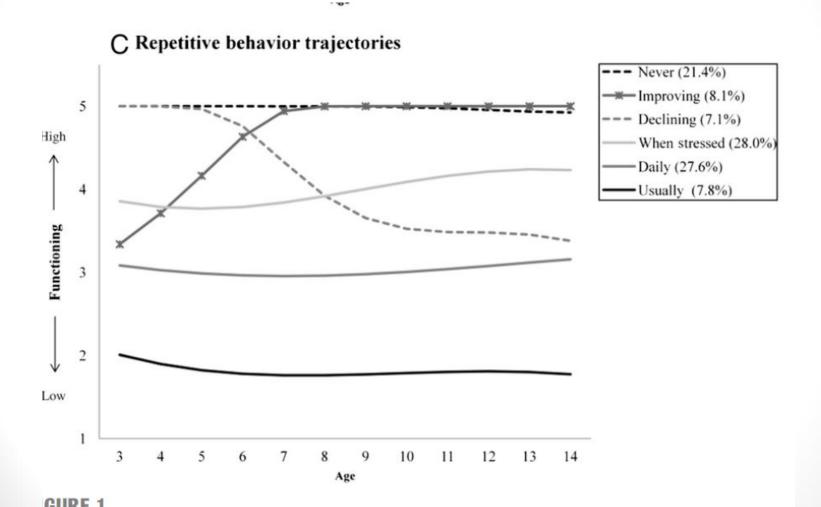
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Challenges to care for children with autism

- 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







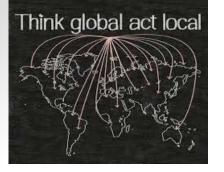


Mission Perspective – Levels of action for "at risk"

- Strategic Big Picture Large and Multiple Systems
- Operational Think Global Act Local Local Systems, Partnerships

Tactical – On the ground, Day to Day operations





Strategic – Mission Connections and Coping

 Embedded Care Coordination in the Medical Home Healthy Steps



- Pediatric Developmental Autism Extenders
 - Eval children < 5 for Autism</p>



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



NeurodevelopmentalCenter 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

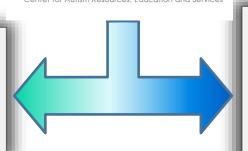




- Physician and Therapist oversight of CARES center
- 100% oversight of community Autism care for military beneficiaries
- Training and research



40% remain in CARES for long term therapy



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

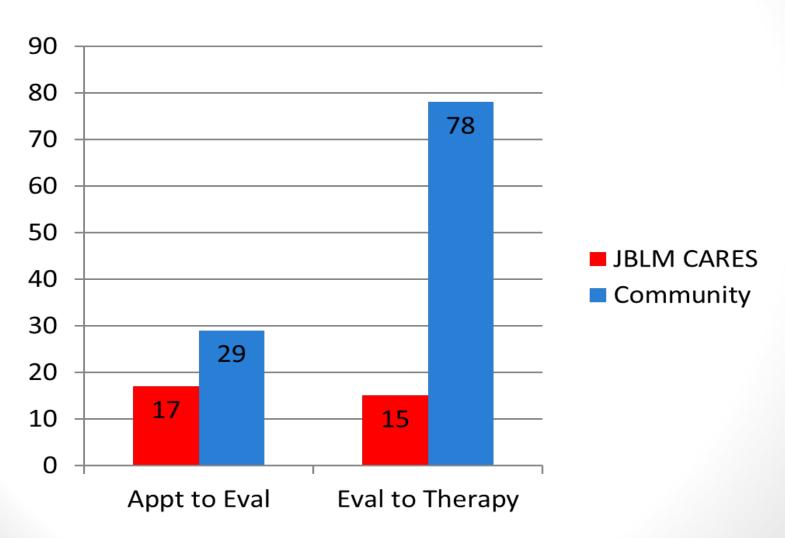








Average number of days to services



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.

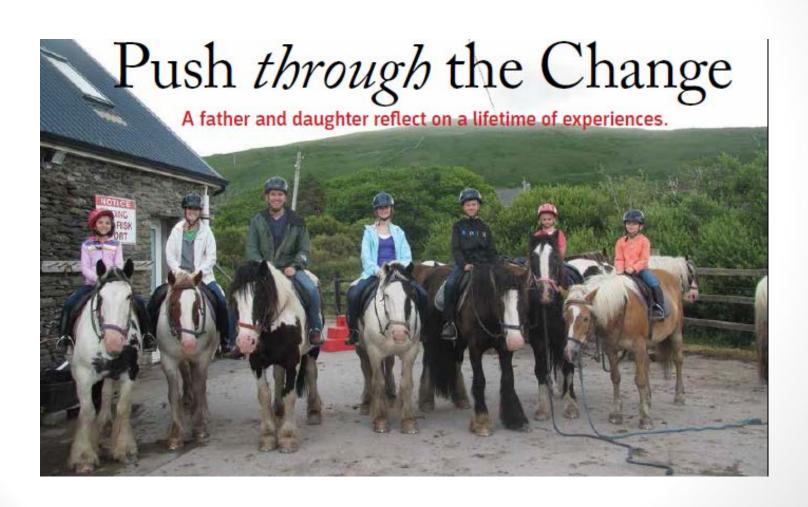


Major Racine believes it make a big difference for her family.





Questions? / Comments!







- AAP Understanding Autism Spectrum Disorder (2015 version) pamphlet
- Autism Speaks Tool Kits for Families www.autismspeaks.org

TOOLS

Autism Treatment
 Network Toolkits for
 Providers
 <u>www.autismspeaks.org/at</u>
 n/tool-kits

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