

Using Telehealth to Meet the Needs of Military Families with Children with Autism Spectrum Disorder



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Learning Objectives

- An increased understanding of characteristics of children with Autism Spectrum Disorders (ASD)
- A basic understanding of effective approaches to treatment including Applied Behavior Analysis
- A better understanding of the use of telehealth to meet the needs of families of children with ASD
- A better understanding of how ASD impacts military families
- A best case presentation of a multidisciplinary approach to working with a family of a school-aged child with ASD via telehealth

Meet Cora

- Cora is 6 years old. She loves the color pink and she loves pancakes. Cora enjoys jumping and going to the park.
- Cora has a diagnosis of autism spectrum disorder. She was diagnosed at age 3 years old by an interdisciplinary assessment team at an autism diagnostic center.



So what is autism?





The Diagnosis

- The Diagnostic and Statistical Manual (DSM-5) includes a single diagnosis, **Autism Spectrum Disorder**, for all of autism.
- This diagnosis emphasizes “deficits in social communication and social interaction” and “restricted, repetitive patterns of behavior, interests, or activities.”
- Autism Spectrum Disorder replaces the DSM-IV category of Pervasive Developmental Disorders and the specific diagnoses of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.



Autism Spectrum Disorder

- Autism was first identified in 1943 by Dr. Leo Kanner of Johns Hopkins. At the same time, a German scientist, Dr. Hans Asperger, described a milder form of the disorder now known as Asperger Syndrome
- All of these disorders are characterized by varying degrees of impairment in communication skills and social abilities, and also by repetitive behaviors.
- Scientific evidence available to us today points toward a potential for various combinations of factors causing autism – multiple genetic components that may cause autism on their own or possibly when combined with exposure to as yet undetermined environmental factors.

What it is not.....



We know that the once common belief that poor parenting causes ASD is not true....The Centers for Disease Control and Prevention

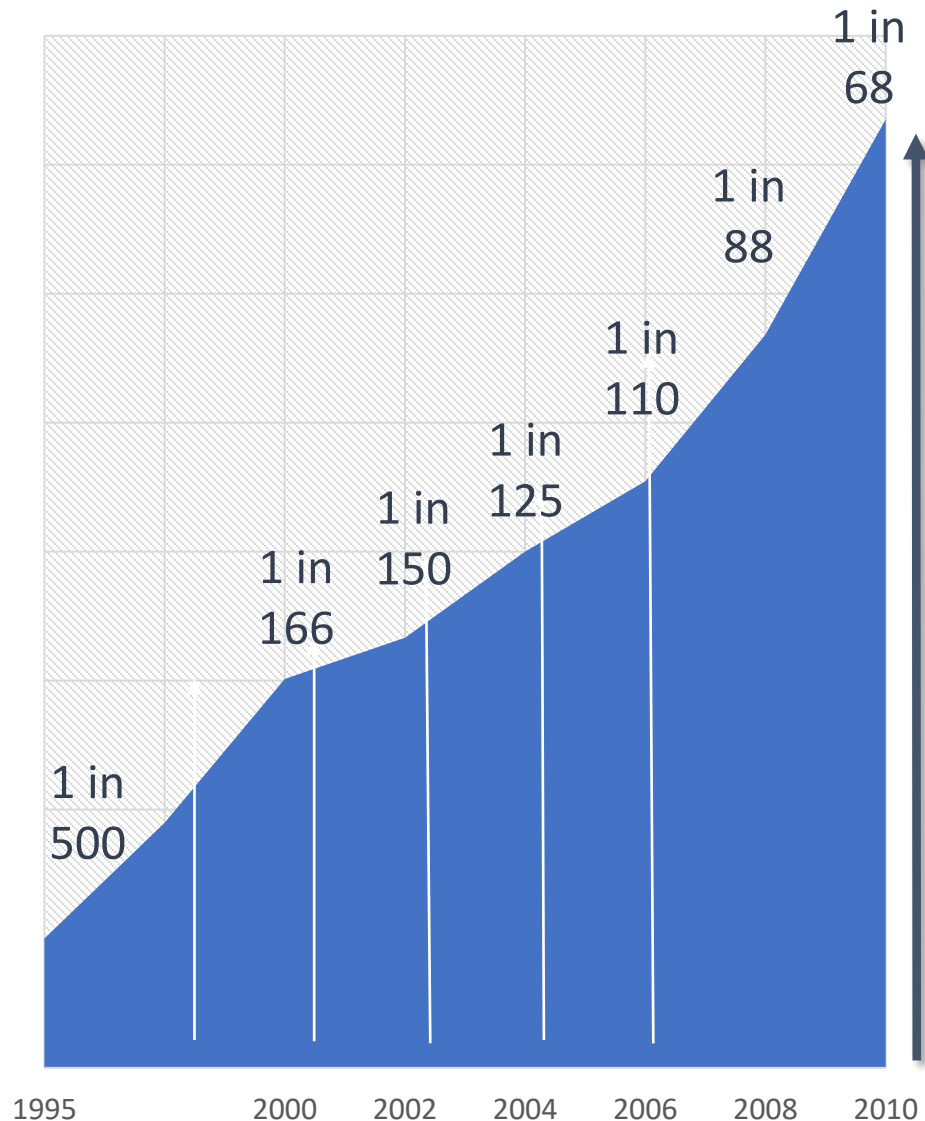
Growing Rate of Autism Center for Disease Control

The Center for Disease Control surveillance study in 2014 identified **1 in 68 children** (1 in 42 boys and 1 in 189 girls) as having autism spectrum disorder (ASD).

This makes autism more common than childhood cancer, juvenile diabetes and pediatric AIDS combined.

An estimated **1.5 million individuals** in the U.S. are affected by autism.

Government statistics suggest the prevalence rate of autism is **increasing 10-17 percent annually**.



Challenges Faced by Families with Children with ASD

- Major communication issues in receptive and expressive language
- Complex behavioral excesses and deficits including tantrums, social withdrawal, unpredictable behavior and perseverations
- Severe impact on family routines
- Disrupted sleep patterns
- The need for respite from constant demands
- Lack of control relating to caring for their child
- Bullying and abuse of children in schools by peers
- Negative reactions to ASD in the community
- Isolation, depression, financial distress

How ASD Impacts Military Families

- More than 23,000 United States military dependents, the majority of them children, have a diagnosed autism spectrum disorder (ASD) (TRICARE Management Activity, 2012).
- Active duty military families face such ongoing challenges as frequent geographic mobility, family separations and risk of injury or death (Segal, 1986).



The Story of Fort Lee

How ASD Impacts Military Families



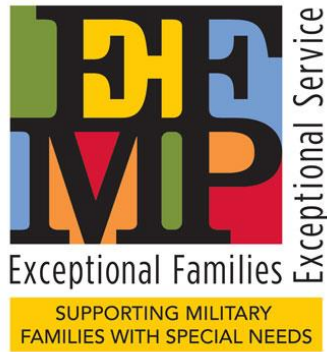
- Frequent moves impacting a timely diagnosis and consistent, ongoing care
- Deployments leading to single parent care of a child
- Frequent changes in health care providers
- Lack of access to extended family support
- Tenuous relationships with varied school systems
- A cumbersome and complex access to services

Military Child Education Coalition, 2012; Fisher, 2014.



Military Families: Needs & Opportunity for Telehealth

- Continuity of care during relocations
- Easing the stress of new settings
- Supporting spouse when service member is deployed (e.g., temporary one parent household makes clinic visits difficult)
- Providing a valuable resource to local school systems
- Instruction in Applied Behavior Analysis
- Learning skills for schedule making
- Supporting the changing routines of families



Resources for Military Families

- Military families with children with special needs, including ASD, may be eligible for additional insurance benefits under the extended health care option (ECHO) through the military insurance, Tricare.
- Military families who have a family member with any special need are required to enroll in the exceptional family member program (EFMP) which helps ensure families are relocated to an installation that can accommodate the needs of the dependent with a disability.
- Operation Autism



Aging Out of Early Intervention: What happens to family focused goals?

- School-based services must support goals that are educationally relevant.
- Families of school aged children with ASD continue to require support at home. The interdisciplinary team supports activities of daily living for children in their homes, such as toilet training, mealtime/eating, and sleeping.
- Telehealth allows for families to receive intervention in authentic contexts as well as promotes continuity of care.



More about Cora

- Cora is in an inclusive kindergarten room with a para for some of her day, but spends most of her time in a self-contained classroom. Cora's dad is currently deployed.

Cora's mother has identified the following goals:

- Morning Routine & Transition to School
- Bathing Routine
- Bowel movement training





Interdisciplinary Team Support in ASD: What's best practice?

- Family Centered Care means providing intervention that is based on the family's priorities and the family's goals.
- Spouses of deployed service members have markedly high stress levels; family centered care has been shown to decrease parent stress.
- All professionals must collaborate to support the family

Medway et al. (1995); Saltzman et al. (2011)

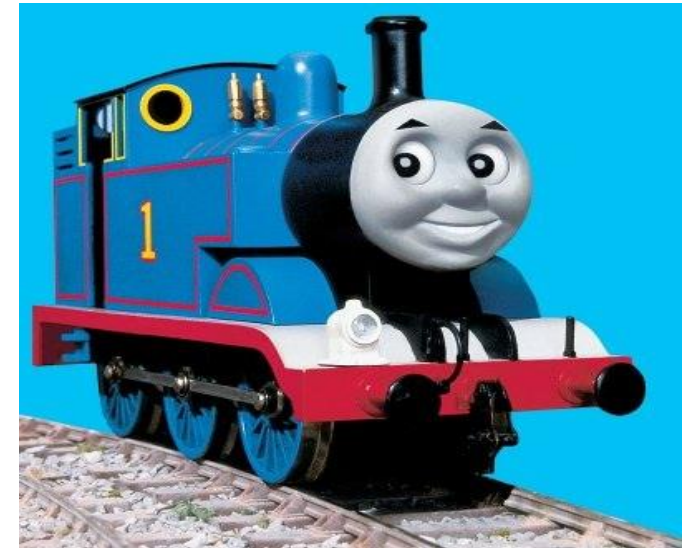
Effective Treatments

getting on the right track

“Right now, the most effective treatment for Autism Spectrum Disorders is intensive structured teaching of skills, often called behavioral intervention.”

“It is VERY important to begin this team-based intervention as early as possible in order to help your child reach his or her full potential.”

CDC (2017)



Best Outcomes

- Educational interventions should be based on principles of operant conditioning (ABA)
- Interventions should be comprehensive, focusing on as many problems as possible
- Interventions should involve all significant persons in life of autistic individual
- Intervention should begin as soon as possible
- Access to underserved through telehealth

Lovaas & Smith (1998)



Cora's Team

- Cora has the following providers:
 - ABA Therapist
 - School-based Occupational Therapist
 - School-based Speech Therapist
 - Clinic-based Speech Therapist
 - Occupational Therapy services via telehealth
 - Paraprofessional @ school
 - Special Education services
- All providers collaborate to provide family-centered care, which is recommended as a best practice for families children with ASD.



An example of Cora's Intervention Process: Bathing Routine

The client picks goals because this makes goals meaningful
& clients are motivated



The focus is on problem solving/ identifying solutions



Intervention is situated in authentic contexts to foster
generalization

Interdisciplinary Team
of Professionals
Supports Families
Throughout this
Process

The client picks goals because this makes goals meaningful & clients are motivated



Ask WHAT the client needs/ wants to do and this becomes the goal structure

The focus is on problem solving/ identifying solutions



OT uses reflective questioning and guided discovery

How the Interdisciplinary Team Impacts Identified Parent Solutions



Intervention is situated in authentic contexts
to foster generalization



Ask WHERE the
activities occur in
the client's life

Policy Barriers / Challenges to Telehealth

- Reimbursement-Specialists, SLP, OT, ABA
- Licensure Portability
- Telehealth Training for Teachers/Parents/Community
- Access to Broadband
- Medicaid Waivers
- Connection to schools and homes
- Racial, Economic, Geographic and Social Disparities

The Costs of Autism

- Individuals with an ASD had average medical expenditures that exceeded those without an ASD by **\$4,110–\$6,200** per year.
- On average, medical expenditures for individuals with an ASD were 4.1– 6.2 times greater than for those without an ASD.
- Differences in median expenditures ranged from \$2,240 to \$3,360 per year with median expenditures 8.4 – 9.5 times greater.
- In 2005, the average annual medical costs for Medicaid-enrolled children with an **ASD were \$10,709 per child**, which was about **six times higher** than costs for children without an ASD (\$1,812).
- In addition to medical costs, intensive behavioral interventions for children with ASDs cost **\$40,000 to \$60,000** per child per year.
- The costs of institutionalization can exceed **\$100,000** per year

CDC (2016)

Telehealth Saves Time & Money



- Compared clinic v. telehealth OT sessions among rural families of children with ASD
- Clinic based model is **2.64x** more expensive than telehealth
- On average, parents traveled 66 miles to OT sessions
- Families lost an average **11.31%** of their annual salary due to lost wages driving and attending therapy sessions
- Telehealth OT sessions have the potential to save \$3722.84 per family/year
- Yes, but is it acceptable to parents?

“It was nice because she was ‘in’ my home. She got to see how home life really is”

Telehealth Saves Time & Money

February 2016

Iowa Telehealth ASD Study

- The group studied 107 children ages 21 months to 6 years old with ASD or other developmental disabilities and who were treated between 1996 and 2014.
- This research demonstrated that parents can use ABA procedures to successfully treat behavior problems associated with autism spectrum disorders regardless of whether treatment is directed by behavior consultants in person or via remote video coaching. Because ABA telehealth can achieve similar outcomes at lower cost compared with in-home therapy, geographic barriers to providing access to ABA for treating problem behavior can be minimized.
- These findings support the potential for using telehealth to provide research-based behavioral treatment to any family that has access to the Internet. Researchers found that not only are specialists able to successfully train parents to use ABA procedures using telehealth, and at a fraction of the cost, but they are also able to provide the training to families in outlying rural areas who might otherwise not have access to care.



APRIL IS
Autism Awareness
Month

