# Closing the Gap: Caring for Military Children with Special Healthcare Needs (M-CSHCN) and Neurodevelopmental Disabilities

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## 1020 – 1120 (ET)

# Presenter(s)

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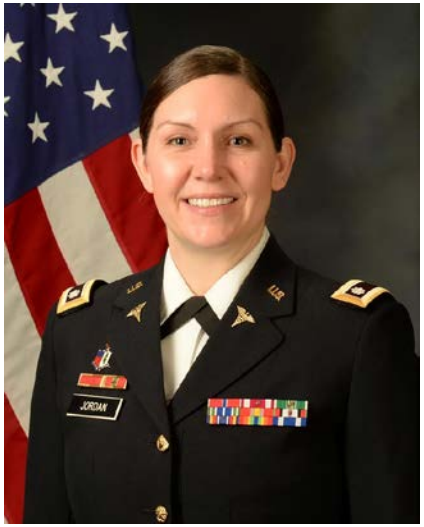


LTC Bonnie Jordan is a Developmental and Behavioral Pediatrician (DBP). LTC Jordan completed her residency training in General Pediatrics and her fellowship training in DBP at Madigan Army Medical Center in Tacoma WA. She is currently the Associate Program Director of the DBP fellowship program and the Chief of the Medical Exceptional Family Member Program at Madigan Army Medical Center. She is an Assistant Professor of Pediatrics for Uniformed Services University of the Health Sciences.

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# Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Identify and interpret the unique challenges affecting M-CSHCN.

2. Outline specific interventions for military children with Autism Spectrum Disorders.

3. Recognize the Readiness impact for Active Duty Service Members (ADSMs) when there is a gap between medical services needed versus those available for M-CSHCN.

# Children with Special Health Care Needs (CSHCN)

*"Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"* *(Child and Adolescent Health Measurement Initiative, 2012)*

Child and Adolescent Health Measurement Initiative (2012). "Who Are Children with Special Health Care Needs (CSHCN)." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 4/2/12.

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# Military children

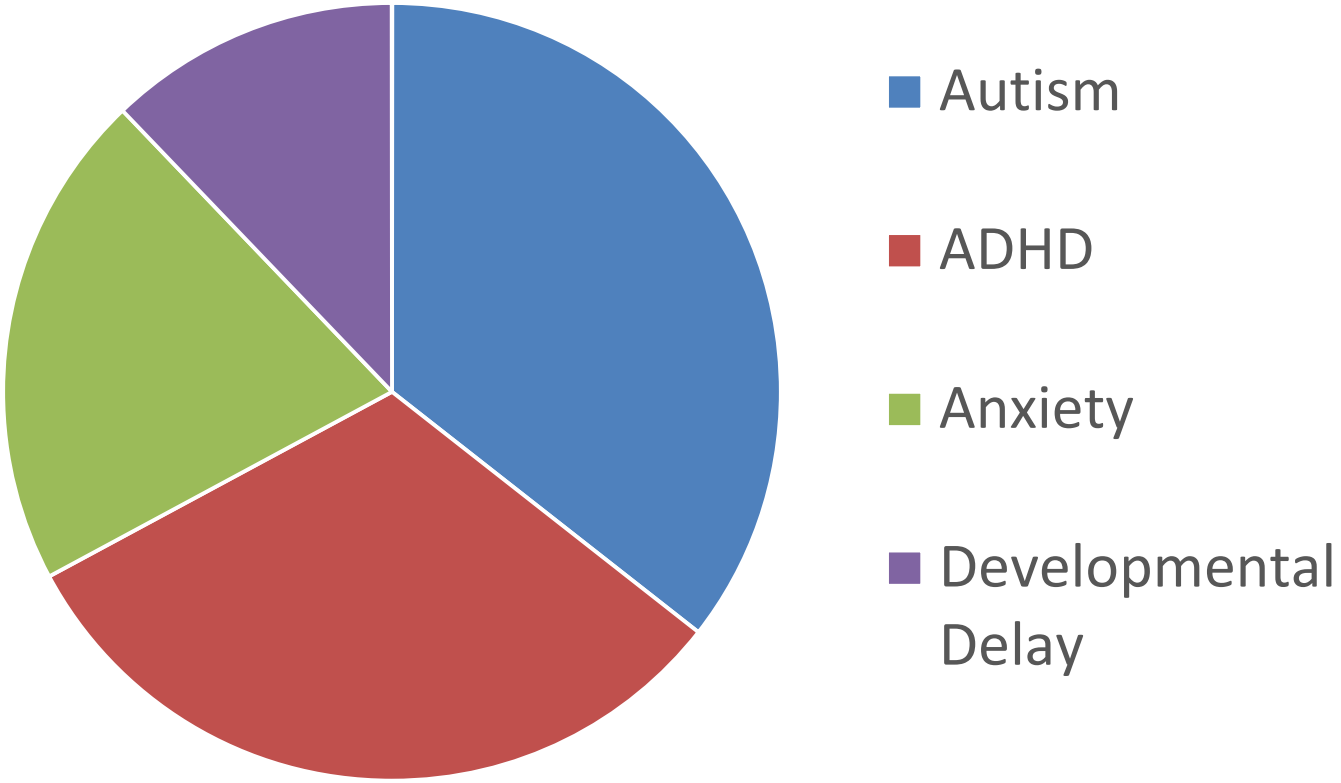
- Four million military connected children (AD, Guard, Reserve, Veterans) (Huebner, 2019)
- 1.7 million military children in Active Duty (AD) and reserve families (Huebner, 2019)
- 26,000 military children enrolled in medical EFMP (Exceptional Family Member Program) (EFMP, 2020)
- 12,800 military children are enrolled in the educational EFMP (EFMP, 2020)
- 15,200 military children enrolled for Autism Spectrum Disorders (ASD) (EFMP, 2020)

- Estimate 31,000 military children with special healthcare or educational needs (MCSHCN) based on EFMP enrollments
  - ❑ Additional military connected children (reserve, guard, veteran)
- Estimate 5.6% of all military connected children with complex chronic needs (Huebner, 2019)

Huebner, CR, AAP Section on Uniformed Services, AAP Committee on Psychosocial Aspects of Child and Family Healht. Health and Mental Healt Needs of Children in US Military Families. Pediatrics. 2019; 143(10:E20183258

Exceptional Family Member Program. 2020. Office of the Surgeon General. Retrieved February 6, 2020.

# Top EFMP Diagnoses (Army)




Exceptional Family Member Program. 2020. Report 09. Analysis of Diagnosis Frequency. Department of the Army. Retrieved February 7, 2020.

# Challenges for Military Children

Relocation (every 1-3 years)
Geographic Isolation from Family/Friends
Limited School District options
Separation (ship duty, training)
Domestic Violence and Child Neglect Deployment
Mental health (Anxiety, depression, PTSD)
Limited Housing options
Limited Childcare options
Early PT hours (ADSM)
Poverty/Food Insecurity


Cramm, H., Smith, G., Samdup, D., Williams, A., & Ruhland, L. (2019). Navigating health care systems for military-connected children with autism spectrum disorder: A qualitative study of military families experiencing mandatory relocation. *Paediatrics & Child Health*, 478–484. doi: 10.1093/pcy/pxy179

Huebner, CR, AAP Section on Uniformed Services, AAP Committee on Psychosocial Aspects of Child and Family Health. Health and Mental Health needs of Children in US Military Families. Pediatrics. 2019; 143(1):e20183258

Wax SG, Stankorb SM. (2016). Prevalence of food insecurity among military households with children 5 years of age and younger. *Public Health Nutr*. 19(13):2458–2466

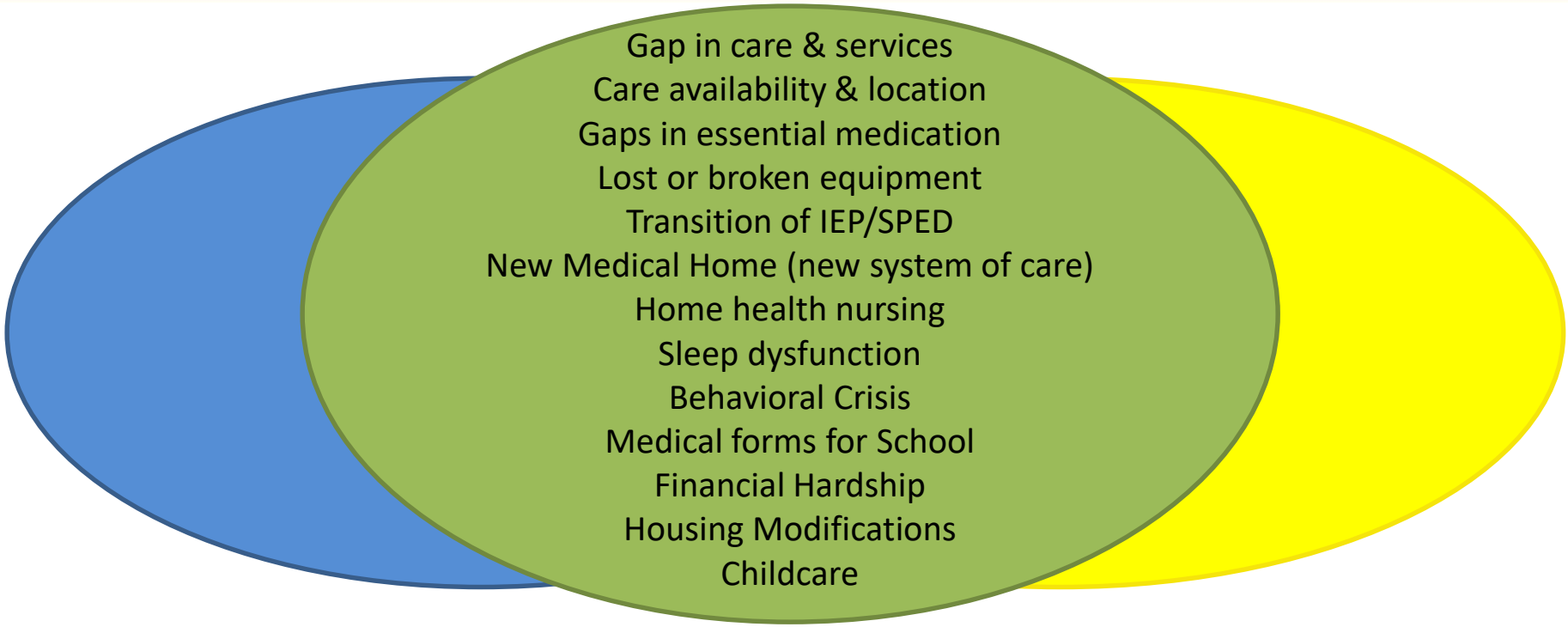
# Challenges for CSHCN

Increased medical care needs
Increased therapy needs
Chronic pain
Social impairment
Behavioral problems
Communication impairment
Limitations in Childcare
Need for stability/routine
Reliance for activities of daily living
Care Coordination needs
Cost of care
Mobility

Child and Adolescent Health Measurement Initiative (2012). "Who Are Children with Special Health Care Needs (CSHCN)." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 4/2/12.

Li Huang PhD , Gary L. Freed MD, MPH , Kim Dalziel PhD. (2020). Children with special health care needs: how special are their health care needs?, Academic Pediatrics (2020), doi: https://doi.org/10.1016/j.acap.2020.01.007

# Unique Challenges for M-CSHCN

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# Educational Challenges for M-CSHCN

- Transition from school to school
- Different resources in different districts

- Current education law, IDEA, and its amendments over time, have evolved to included educational supports for children with disabilities
  - Part B: children age three and older
  - Part C: birth to 3rd birthday

Federal Law 20 U.S.C. 1412. https://sites.ed.gov/idea/statuteregulations/#slip_law. Retrieved February 7, 2020.

# Josiah – 3.5 years old

- 1st PCMH visit after relocation
- Doesn't talk – grunts a lot and has giant meltdowns when he doesn't get his way
- Kicked out of daycare for aggression
- Bangs his head and runs off
- Difficult sleeper
- Very picky eater
- Diagnosed with Autism shortly before moving here

*names have been changed for privacy; **permission to use pictures

# Autism Spectrum Disorders (ASD)

- Neurodevelopmental disorder (1/59) characterized by social impairments and restricted, repetitive patterns of behavior (Baio, 2014)
- Male to female ratio of 4:1 (Baio, 2014)
- Clinical diagnosis per Diagnostic and Statistical Manual (DSM) 5 criteria
- Spectrum: diverse function, communication, cognitive abilities
- Comorbidities that affect the entire family include:
  - ❑ severe/dangerous behaviors (this can be a crisis)
  - ❑ severe sleep dysfunction
  - ❑ restricted or aversive eating
  - ❑ school problems
  - ❑ intense need for routine/predictability

Baio J, Wiggins L, Christensen DL, et al. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. MMWR Surveillance Summaries. 67(No. SS-6):1–23. DOI: http://dx.doi.org/10.15585/mmwr.ss6706a1external icon.

# ASD - Intervention

- Medications are limited to symptomatic relief (aggression, executive functioning, anxiety, etc.)
  - Risperidone and Aripiprazole are FDA approved for irritability in ASD
- Intensive model of supportive therapy can improve outcomes
  - Up to 40 hours per week of Applied Behavior Analysis (ABA)
  - Speech Therapy
  - Occupational Therapy
  - Special Education supports
  - Social Skills groups
  - Nutrition / Feeding Therapy
  - Routine health care
- Kids do best with routines, decreased transitions and a reliable form of communication

Medavarapu, S., Marella, L., Sangem, A., Kairam, R. (2019). Where is the Evidence? A Narrative Literature Review of the Treatment Modalities for Autism Spectrum Disorders. Cureus. V 11(1): doi: 10.7759/cureus.3901. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6424545/#REF35. Retrieved February 5, 2020.

Ortega JV. (2010). Applied behavior analytic interventions for autism in early childhood: meta-analysis, meta-regression and dose- response meta-analysis of multiple outcomes.. Clin Psychol Review. 30:387–399. doi: 10.1016/j.cpr.2010.01.008

# Problem List for Josiah

- Nonverbal – no functional communication
- Routine is disrupted
- Gap in care (seven months delay)
- Access to care
  - ❑ wait list for therapies
- Impaired sleep
  - ❑ Parents and siblings affected
- Nutritional concerns
  - ❑ Disruptive to whole family routine

# Caring for Josiah

- EFMP enrollment/connect with EFMP Family Services
- Referral for ABA Therapy
- Referral for Speech Therapy
- Assist in enrollment for Developmental Preschool
- Assist in connecting mother with Child and Youth Services on post for additional childcare options
- Connect mother with Military and Family Life Consultant (MFLC) or clinic Social Work support
- ASD education for mother
- Developmental Behavioral Pediatrics referral
- www.militaryonesource.mil & www.operationautismonline.org

# Bridging the Readiness Gap - ASD

- Immediate and intensive therapy
  - Minimize gaps
  - Aggression, sleep, Activities of Daily Living (ADL)s and communication can all improve with therapy
- Support the entire family, not just the child
- Education and advocacy with the command
- Parent education
- Empower parents (Care Notebook, proactive planning)
- Know your community therapy options

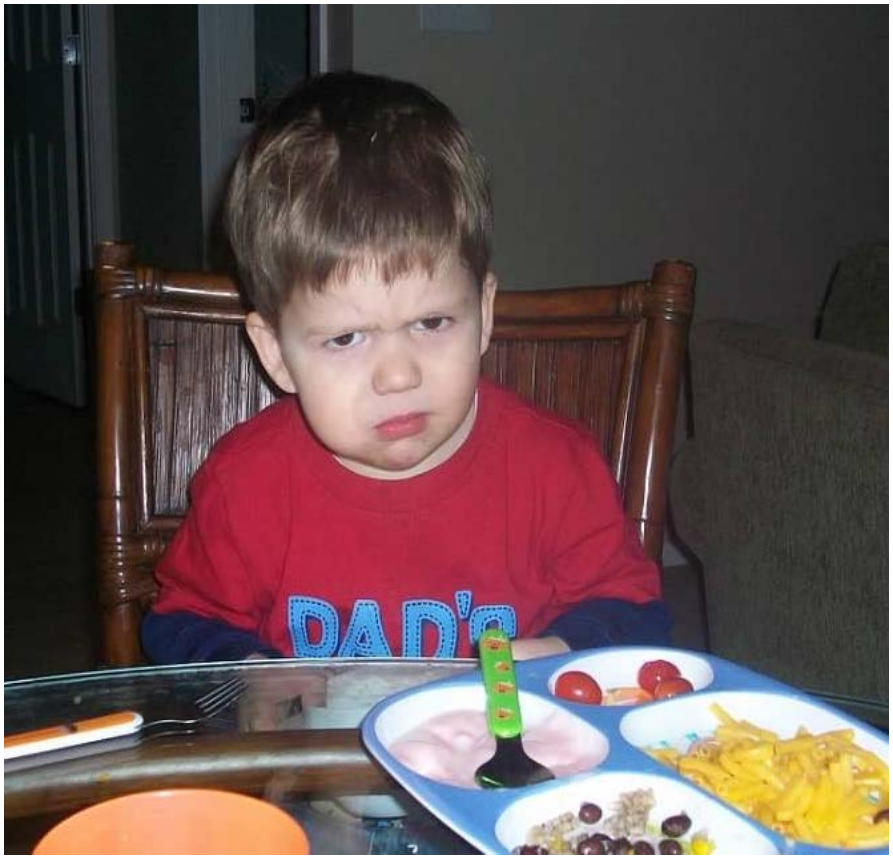
# Bridging the Readiness Gap - ASD

- Imm
  - ❑ M
  - ❑ A
- Sup
- Edu
- Par
- Emp
- Kno

improve

anning)

# Josiah's younger brother – 26months



- Johnny is not babbling
- No words, only grunts
- Poor eater, chipmunks his food
- Extreme meltdowns
- Also very aggressive
- Self-injurious behaviors
- Is he mimicking Josiah?

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# ASD – Etiology and Medical Evaluation

- Multifactorial (not vaccines)
- Red flags
  - ❑ Prematurity, AMA
- High genetic association
  - ❑ Syndromic
    - Fragile X, 22q11del/dup, T21, Tuberous Sclerosis, NF-1
  - ❑ Non-Syndromic
- Recurrence Risk for siblings
  - ❑ 2-18 % (Ozonoff 2011 & Sumi 2006)

- Comprehensive history/exam
  - ❑ Head circumference
  - ❑ Dysmorphic features
  - ❑ Café au lait macules/Hypopigmentation
  - ❑ Hearing
- SNP microarray
- Fragile X
- MRI if Intellectual disability or abnormal CNS exam


Ozonoff S, Young GS, Carter A, Messinger D, Yirmiya N, Zwaigenbaum L, Bryson S, Carver LJ, Constantino JN, Dobkins K, Hutman T, Iverson JM, Landa R, Rogers SJ, Sigman M, Stone WL. (2011) Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study. Pediatrics. 128: e488-e495.

Sumi S, Taniai H, Miyachi T, Tanemura M. (2006). Sibling risk of pervasive developmental disorder estimated by means of an epidemiologic survey in Nagoya, Japan. J Hum Genet. 51: 518-522.

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# Johnny – Evaluation?

- ✓ Complete MCHAT
- ❑ YOU suspect ASD
- ✓ Audiology evaluation
- ✓ Early Intervention Services
  - ✓ Speech Therapy
  - ✓ Feeding Therapy
- ✓ Referral to Developmental Behavioral Pediatrics
  - ❑ 12-18 month waitlist!!!

- ■ But you want to start ABA
- ■ Asynchronous telehealth
  - ✓ Call a specialist and review the case together
- ■ Perform a STAT (Screening Tool for Autism in Toddlers)
- ■ Developmental Extender Training
- ■ Healthy Steps

Handleman, J.S., Harris, S., eds. (2000). Preschool Education Programs for Children with Autism (2nd ed). Austin, TX: Pro-Ed. Retrieved February 6, 2020.
National Research Council. (2001). Educating Children with Autism. Washington, DC: National Academy Press. Retrieved February 6, 2020/.

# Molly – 15 years old

- Well visit: New diagnosis of Diabetes; Anxiety, Dyslexia, ADHD
- All are stable; ADHD is well controlled
- She sees a Behavioral Health (BH) therapist weekly
- Great school year (with extra tutoring AND an invested teacher)
- She is on the cheerleading squad
- Her family is moving this summer
- She is not enrolled in EFMP

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# Bridging the Readiness Gap – M-CSCHN

- Molly will need:
  - ❑ Access to medication
  - ❑ Equipment
  - ❑ Specialty care
  - ❑ BH therapy
  - ❑ School supports/IEP
- Routine care for age/gender
  - ❑ Vaccines
  - ❑ Anticipatory guidance
- EFMP enrollment to ensure her medical needs are accessible
- Proactive medical transition
  - ❑ Case coordinator?
  - ❑ Who will take over her specialty care?
    - Hard to know if you don't know where she is moving
- IEP or 504Plan for education and medical diagnoses
- www.militaryonesource.mil

# Proactive Care

- Medical Notebook
  - Records, images, IEP/504Plan/IFSP
  - Critical care/diagnosis information
- School District Recon (Special Education, Supports)
  - Education Directory for Children with Special Needs (www.militaryonesource.mil)
- Housing Recon (ADA accessible, safe)
- Proximity to ancillary care needs (PT, OT, ST, etc)
- Home health nursing
- Wait lists?  Call ahead?
- Childcare accommodations?

# DBP at Joint Base Lewis-McChord

- DBP Division
  - DBP, Psychology, Social Work, Genetics, Physical Therapy
- Educate
  - Second largest DBP training program in the nation (research focus)
  - Pediatric/Family Med Residents, Medical/PA/Nursing students
  - Autism Extender Training
- Healthy Steps Program in Pediatric Patient Centered Medical Home (PCMH)
- School based Behavioral Health collaboration
- Expansion of Reach
  - Itinerant care outreach (Alaska)
  - Video telehealth outreach

# JBLM CARES - Bridging Care Model

- Joint Base Lewis-McChord (JBLM) Center for Autism Resources, Education and Services (CARES)
  - ❑ Education and support for parents
  - ❑ Bridging therapy (OT, ST)
  - ❑ Feeding group
  - ❑ Social Skills groups
  - ❑ Integrated assessments
  - ❑ Diagnostic assessments
  - ❑ Events (holiday parties, sensory friendly events)
  - ❑ Advocacy
- Staff: Board Certified Behavior Analyst (BCBA), OT, Speech Language Pathology (SLP), MSA

# Importance of PCMH for M-CSHCN

- Identify M-CSHCN
  - ❑ Routine well visits, Surveillance and Screening, ACE Scores
  - ❑ Transition visits
- Utilize case coordinators/nurse case managers
- Ask about sleep and behavior
  - ❑ Improved sleep for the child means improved sleep for the parent
- Accurate and up to date EFMP enrollments
- Proactive care
- Don't contribute to gaps in care (delays in paperwork)
- Understand your local military resources (BH, EFMP Family Services, Military One Source, CYS)
- Asynchronous telehealth when needed – Phone a friend!

# Key Takeaways

- Military Children with Special Healthcare Needs face many unique barriers due to relocation and military lifestyle.
- PCMs have a critical role in early recognition and early intervention for children with ASD.
- Families and ADSMs can experience readiness impact (missed work, increased stress) due to their child's special healthcare needs and educational needs.

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Baio, J., Wiggins, L., Christensen, D.L., et al. (2018, April 27). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summary*. 67(SS-6), 1–23. http://dx.doi.org/10.15585/mmwr.ss6706a1.

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**To receive CE/CME credit, you must register by 0730 ET on 27 March 2020 to qualify for the receipt of CE/CME credit or certificate of attendance. You must complete the program posttest and evaluation before collecting your certificate. The posttest and evaluation will be available through 9 April 2020 at 2359 ET. Please complete the following steps to obtain CE/CME credit:**

1. Go to URL https://www.dhaj7-cepo.com/
2. In the search bar on the top left, copy and paste the activity name:. This will take you to the activity home page.
3. Click on the REGISTER/TAKE COURSE tab.
   a. If you have previously used the CEPO LMS, click login.
   b. If you have not previously used the CEPO LMS click register to create a new account.
4. Verify, correct, or add your profile information.
5. Follow the onscreen prompts to complete the post-activity assessments:
   a. Read the Accreditation Statement
   b. Complete the Evaluation
   c. Take the Posttest
6. After completing the posttest at 80% or above, your certificate will be available for print or download.
7. You can return to the site at any time in the future to print your certificate and transcripts at https://www.dhaj7-cepo.com/
8. If you require further support, please contact us at dha.ncr.j7.mbx.cepo-lms-support@mail.mil