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

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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.


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.
“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)
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”  

1 Child and Adolescent Health Measurement Initiative, 2012

- Learning Disability
- Cerebral Palsy
- Behavioral Health
- Asthma
- Developmental Disability
- Autism Spectrum Disorder
- ADHD
- Epilepsy
- TBI
- Diabetes
- Hearing/Vision Problem

“Medically Ready Force...Ready Medical Force”
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)

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)

Top EFMP Diagnoses (Army)

- Autism
- ADHD
- Anxiety
- Developmental Delay

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


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

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Unique Challenges for M-CSHCN

- Gap in care & services
- Care availability & location
- Gaps in essential medication
- Lost or broken equipment
- Transition of IEP/SPED
- New Medical Home (new system of care)
- Home health nursing
- Sleep dysfunction
- Behavioral Crisis
- Medical forms for School
- Financial Hardship
- Housing Modifications
- Childcare


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

Josiah – 3.5 years old

- First 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

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


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
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“Medically Ready Force...Ready Medical Force”
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
  - Dyssmorphic features
  - Café au lait macules/Hypopigmentation
  - Hearing
- SNP microarray
- Fragile X
- MRI if Intellectual disability or abnormal CNS exam


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


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

“Medically Ready Force…Ready Medical Force”
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](http://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?

“Medically Ready Force...Ready Medical Force”
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

“Medically Ready Force...Ready Medical Force”
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!

“Medically Ready Force...Ready Medical Force”
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.
References


References


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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/
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