



All Under One Roof

Caring for Children with Medical Complexity Across Settings

Session #3 : Educational and Medical Supports

3/31/2021

All Under One Roof: Caring for Children with Medical Complexity Across Settings

Session #3

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- ▶ Don't forget to fill out the pre-evaluation survey. Link is in the chat.

Faculty & Presenters

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Agenda

- ▶ Introduction & disclosures
- ▶ Didactic presentation
- ▶ Case Presentation
- ▶ Group discussion

Project Disclosure Statement

- ▶ We have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider of commercial services discussed in this activity
- ▶ We do not intend to discuss an unapproved/investigative use of a commercial product/device in our presentation.

Mitigating Potential Bias

- ▶ The information and recommendations involving clinical medicine are based on evidence that is currently accepted within the profession and are not medical advice.

Assessment

- ▶ Surveys: please complete any survey assessments emailed to you related this ECHO series. We appreciate your feedback!
- ▶ Presentation materials: the slides and chat log will be emailed to you.

Caring for Children with Medical Complexity Across Settings

Session #3: Educational and Medical Supports

Dana Bakula, PhD

3/31/2021



Objectives

1. Identify common educational and medical needs for CMCs.
2. Understand the use of IEPs and 504 plans, and describe common components involved in their development and implementation.
3. Recognize the educational needs of older CMCs including transition and graduation.



Common Educational Needs


- ▶ **Developmental Disability**
 - ▶ “A disability that occurs before the person reaches 22 years of age, substantially impacts the person’s daily life, is caused by an intellectual disability or related condition.”



Common Educational Needs



DDRCCO.com



Our Mission: Create Opportunities for People with Intellectual Disabilities and their Families to Participate in the Community

Home About Us Services Resources Get Involved Careers

Resources / Terms And Definitions

Glossary of Developmental Disability Terms

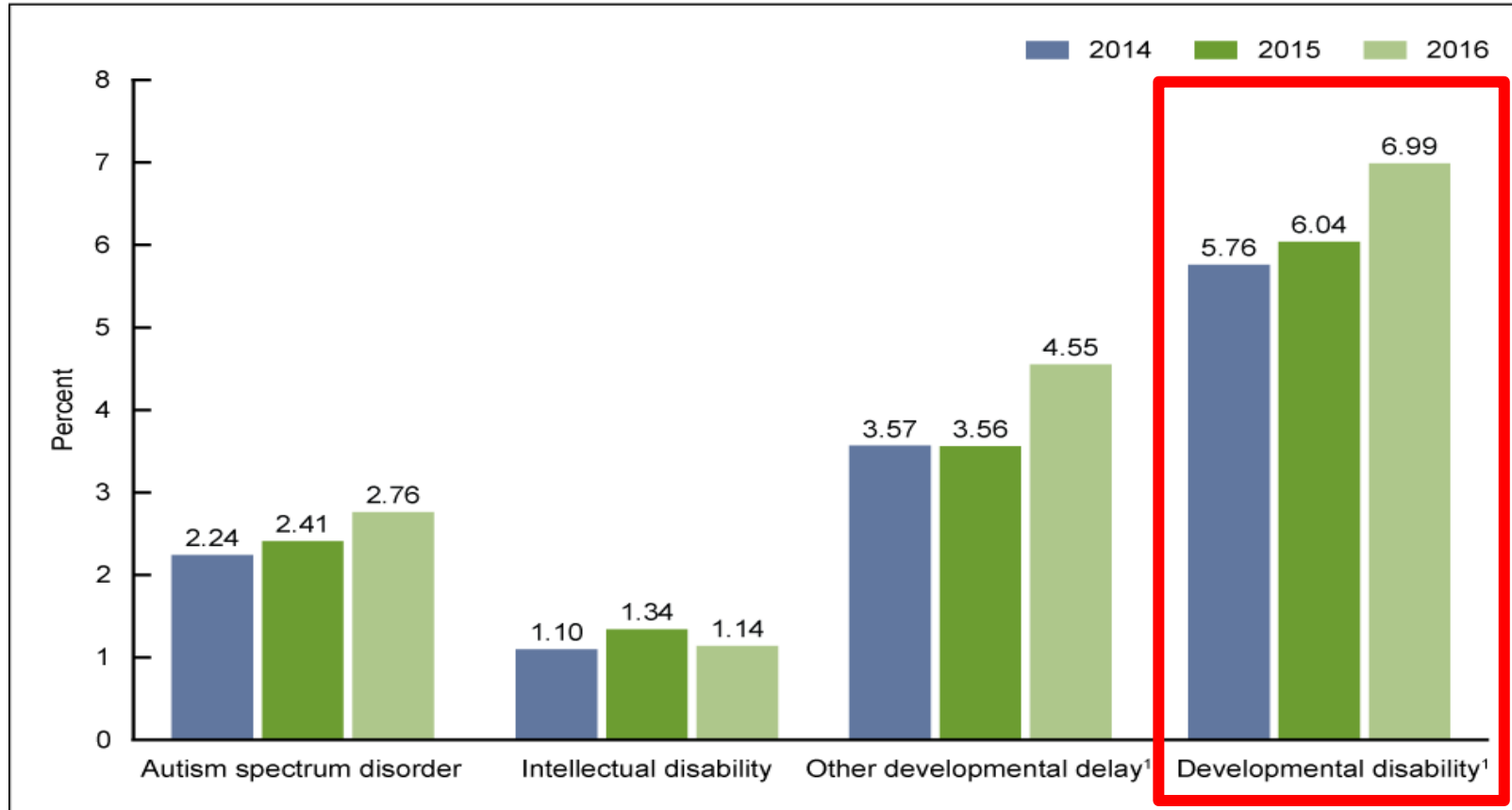
This resource has been compiled by the staff of Developmental Disabilities Resource Center. It is dedicated to Mike Boorn, for his many contributions to DDRRC and especially for his helpful reminders regarding the use of clear language. If you have any suggestions for this glossary can help you find the answers.

Term	Definition
AAIDD	American Association on Intellectual and Developmental Disabilities. The nation's oldest and most respected organization of professionals who support people with intellectual and developmental disabilities. www.aidd.org
ABA	Applied Behavior Analysis. A discipline devoted to the understanding and improvement of human behavior through the use of operant conditioning. Often used interchangeably with behavior analysis.



Common Educational Needs

Figure 1. Prevalence of children aged 3–17 years ever diagnosed with selected developmental disabilities, by year: United States, 2014–2016



¹Linear increase from 2014 to 2016 is statistically significant ($p < 0.05$).

NOTES: Developmental disability includes autism spectrum disorder, intellectual disability, and any other developmental delay. Access data table for Figure 1 at: https://www.cdc.gov/nchs/data/databriefs/db291_table.pdf#1.

SOURCE: NCHS, National Health Interview Survey, 2014–2016.



Common Educational Needs

- ▶ Intellectual Disability
- ▶ Learning Disorders
- ▶ ADHD & Executive Functioning Deficits



Common Educational Needs

- ▶ Intellectual Disability
 - ▶ Impairment in intellectual functioning and adaptive functioning
 - ▶ Below-average intelligence
 - ▶ Learn new skills more slowly
 - ▶ Range from mild to profound



Common Educational Needs

- ▶ **Learning Disorders (LD)**
 - ▶ Information-processing problem
 - ▶ Prevents children from learning skills and using them effectively
 - ▶ Lifetime prevalence in CMC: 27.8%
 - ▶ compared with 5.4% in children without medical complexity



Common Educational Needs

- ▶ ADHD & Executive Functioning Deficits
 - ▶ A child with ADHD or executive functioning deficits might...
 - ▶ daydream a lot
 - ▶ forget or lose things a lot
 - ▶ squirm or fidget
 - ▶ talk too much
 - ▶ make careless mistakes or take unnecessary risks
 - ▶ have a hard time resisting temptation
 - ▶ have trouble taking turns
 - ▶ have difficulty getting along with others
- ▶ ADHD: Inattentive, Hyperactive, Combined Type



Common Educational Needs

- ▶ ADHD & Executive Functioning Deficits
 - ▶ Executive function is a set of mental skills that include working memory, flexible thinking, and self-control.

EXECUTIVE SKILLS



FOCUS &
ATTENTION



PLANNING &
ORGANIZATION



WORKING
MEMORY &
METACOGNITION



INITIATIVE &
PERSISTENCE



FLEXIBILITY &
PROBLEM
SOLVING



INHIBITION &
EMOTIONAL
CONTROL



Common Educational Needs by Medical Condition

Condition	Common Deficits
Epilepsy	Attention, executive functioning, behavioral
Premature infants	Cognitive, language, and behavioral impairments
Down syndrome	Memory, attention, executive functioning, language learning, working memory, and emotional responses
Acquired brain injuries	Attention, memory, executive functioning, emotion/behavior, specific deficits by injury
Spina bifida	Attention, executive functioning



Common Interventions to Address Education Needs at School

- ▶ Supporting educational needs
 - ▶ Modified curriculum
 - ▶ Communication Devices
 - ▶ Assistive technology
 - ▶ Extra time/breaks
 - ▶ Therapeutic services/pull out services
 - ▶ General education classroom vs. special education classroom
 - ▶ Use of paraprofessionals*

Should be individualized to the child

What do you most commonly see with your students?



Who Should Evaluate?

	School Psychologists	Clinical/ Developmental Psychologists (Community)	Neuropsychologists
Training background	Doctorate in psychology & development with focus on school	Doctorate in psychology & development	Doctorate in psychology & development + training in brain development
Areas of expertise/specialty	Learning and educational problems	Developmental and learning problems	Specialize in children with medical complexity
What they can offer for children with medical complexity	Understanding: the child's performance relative to expectations Recommendations: based on what is helpful for the specific deficits	Understanding: the specific deficits seen Recommendations: based on what is helpful for the specific deficits	Understanding: interaction between brain development & current functioning Recommendations: very detailed & tailored




Common Medical Needs at School

- ▶ Medications
- ▶ Safety
- ▶ Healthy habits (e.g., staying hydrated)
- ▶ Reduced stamina or fatigue
- ▶ Symptoms during school (e.g., seizures)
- ▶ Toileting (e.g., catheterization, bowel management, delayed toilet training)
- ▶ Tube feedings



Common Interventions to Address Medical Needs at School

- ▶ Accommodating physical health needs
 - ▶ Extra time
 - ▶ Water bottles
 - ▶ Toileting accommodations (catheterization, bowel management, diaper/pull-up changes, permanent bathroom pass)
 - ▶ Extra breaks (pacing)
 - ▶ Administering medications
 - ▶ Signs/signals to communicate medical needs
 - ▶ Paraprofessionals



Should be individualized to the child



IEPs/504s Historical Context

- ▶ **Individuals with Disabilities Education Act (IDEA):**
 - ▶ Federal law
 - ▶ Authorizes special education for children with disabilities
 - ▶ Authorizes early intervention services
 - ▶ Originally passed in 1975

- ▶ **Section 504 of the Rehabilitation Act of 1973:**
 - ▶ Civil rights law
 - ▶ Prohibits discriminating based on disabilities in both private and public programs



IEPs/504s Explained

IEP (Individualized Education Plan)	504 Plan
A plan for special education experiences	A plan to remove barriers for children with disabilities
Individualized education and related service plans	Modifications to the learning environment
To qualify: have a disability specified by IDEA act that impacts educational performance or abilities and requires special instruction	To qualify: any disability that interferes with a child's ability to learn in the classroom
Goal focused	Accommodation focused
Educational law	Civil rights law



Common Components of an IEP Meeting

- ▶ Present level of performance
- ▶ Goals
 - ▶ SMART goals: Specific, Measurable, Attainable, Results-oriented, Time-bound
- ▶ Special Education and Related Services
- ▶ Supplementary aids, services, modification, supports
 - ▶ Don't be afraid to ask for training!



Common Components of a 504 Meeting

- ▶ Areas that are preventing the child from fully accessing the school program
 - ▶ E.g., child in a wheelchair and cannot get up to the lab table in chemistry
- ▶ Supplementary aids, accommodations, supports
 - ▶ Don't be afraid to ask for training!



Quick Tips for Successful IEP/504 Plan Meetings

- ▶ Ask for the most recent medical records and evaluations with recommendations
- ▶ Consider how you might meet the child's needs using the least restrictive means/environment
- ▶ Communication is key
- ▶ Involve the family (AND child when appropriate)
 - ▶ Be sure to address transition services with children older than 14!
- ▶ Respect the family and child's knowledge and autonomy
- ▶ Talk with parents how they can use school strategies at home and vice versa
- ▶ Remember: you may not reach consensus in one meeting
 - ▶ More frequent meetings may also be needed to accommodate COVID-19 changes



Quick Tips for Successful IEP/504 Plan Meetings

- ▶ Building positive relationships with families...
 - ▶ Imagine yourself in their place
 - ▶ Begin with a positive interaction and keep it going
 - ▶ Think about what you want to communicate in advance
 - ▶ Use “I” statements
 - ▶ Set an agenda/expectations each time you talk
 - ▶ It’s okay to say you don’t know
 - ▶ Be a good “partner” in identifying solutions



Transition Planning

- ▶ Students with a disability often require assistance from schools/community partners in transition from high school to adulthood.
- ▶ Required service per IDEA
- ▶ Part of IEP at 14 y/o
- ▶ IEP Transition planning includes:
 - ▶ Transition assessments.
 - ▶ Child and family participation
 - ▶ Involvement from relevant local agencies (e.g., vocational rehabilitation)
 - ▶ Community experiences (e.g., job shadowing, visits to colleges).
 - ▶ Student's goals... employment, education, practicing self-advocacy, independent living after high school, etc.
- ▶ Consider updated psychological evaluations to help with transition planning



Delayed Graduation

- ▶ Students with disabilities may be eligible for special education until they are 21 years old OR receive a diploma (IDEA)
- ▶ Many students will continue to receive educational services through 21 years of age to meet transition goals

Key Takeaways

- ▶ CMC often have several medical and educational needs in school settings.
- ▶ Collaboration and communication are key when designing IEP and 504 plans.
- ▶ CMC benefit from early and proactive planning around transition to adulthood.

Key Resources

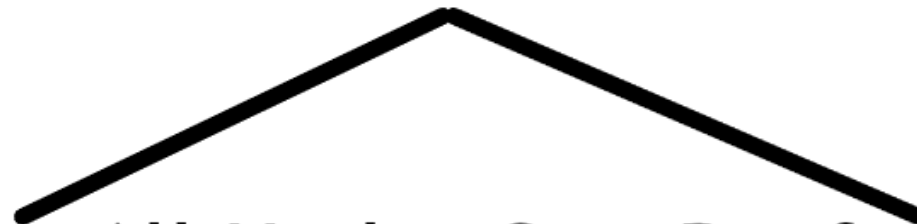
- ▶ CDC Resources on Developmental Disabilities: <https://www.cdc.gov/ncbddd/developmentaldisabilities/freematerials.html>
- ▶ Wrights Law (Special education law and advocacy center) <https://www.wrightslaw.com/>
- ▶ Understood (Non-profit informational resource) <https://www.understood.org/about>
- ▶ Got Transition <https://gottransition.org/>
- ▶ Kansas State Department of Education (Special Education Resources) <https://www.ksde.org/Agency/Division-of-Learning-Services/Special-Education-and-Title-Services/Special-Education>
- ▶ Don't Wait and See: A Neuropsychologist's Guide to Helping Children Who are Developing Differently (Book), By: Emily Papazoglou, PhD, ABPP-CN
- ▶ Families Together (advocacy) <https://famiestogetherinc.org/contact-us/>
- ▶ Glossary of Developmental Disability Terms <https://ddrcco.com/resources/terms-and-definitions>

Key Resources: COVID-19 Specific

- ▶ **Individualized Education plan (IEP) and 504 plan Advocacy:**
 - Questions and Answers on Providing Services to Children with Disabilities During the Coronavirus Disease 2019 Outbreak. U.S. Department of Education. March 2020.
<https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-covid-19-03-12-2020.pdf>
 - Kansas: Families Together Inc <https://famielsttogetherinc.org/> and Kansas State Department of Education: <https://www.ksde.org/>
- ▶ **Children's Mercy:**
 - Protecting Children with Special Needs or Chronic Conditions: <https://www.childrensmrcy.org/health-and-safety-resources/information-about-covid-19-novel-coronavirus/protecting-children-with-special-needs-or-chronic-conditions-during-covid-19/>
 - Return to School and Community Safely: <https://www.childrensmrcy.org/health-and-safety-resources/information-about-covid-19-novel-coronavirus/returning-to-community-activities/> which includes guidebook and consultation for schools
 - CHILDREN'S MERCY COVID-19 HOTLINE (816) 302-8800 The hotline provides options for parents to ask questions regarding their child's health not answered on the website
- ▶ **American Academy of Pediatrics (AAP):**
 - American Academy of Pediatrics (AAP) HealthyChildren.org <https://www.healthychildren.org/English/health-issues/conditions/chest-lungs/Pages/COVID-19-Information-for-Families-of-Children-and-Youth-with-Special-Health-Care-Needs.aspx>
 - AAP Guidance for school re-entry: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/covid-19-planning-considerations-return-to-in-person-education-in-schools/>
 - AAP Caring for Children and Youth with Special Health Care Needs During COVID-19 Pandemic: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/caring-for-children-and-youth-with-special-health-care-needs-during-the-covid-19-pandemic/>
- ▶ **Centers for Disease Control (CDC):**
 - Those who need extra precautions: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/index.html>
 - Schools and Daycare: <https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/index.html>

Case Presentation Discussion

Guest Expert: Kathy Davis, PhD, MEd



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Case Presentation

Presented by Monique Gras, RN

7-year-old girl

- ▶ **Details:** Mom, Grandmother involved in care. Born at 27 weeks and in the NICU for 3.5 months. Global developmental and intellectual delays. Received early intervention services and attended head start.
- ▶ **Episodes:** The last 3 years, she has been experiencing "episodes" where her legs give out and she falls to the ground. She also has staring episodes. She was evaluated for seizures and no evidence was found for epileptic seizures. She was evaluated by psychiatry with no evidence of anxiety and psychiatric medication was not recommended.
- ▶ **Diagnoses:** She has bronchopulmonary dysplasia and mild pulmonary hypertension. Echocardiogram- right ventricular systolic pressure estimate mildly increased. Small left ventricle dimensions.
- ▶ **Concern:** She is severely behind in her learning and academics. She is regressing despite speech, occupational therapy and special education services. There is the feeling that nothing seems to help.
- ▶ **Goal:** To determine the next steps to help understand her learning needs.

Case presentation

Next steps:

- ▶ Clarifying questions
- ▶ Recommendations
- ▶ Summary

Participants: type any questions and recommendations you have in the chat

Questions?



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Thank you for participating!
Slides and materials will be sent to your email.

See you for Session #4 on
April 28 at noon

Please don't forget to complete survey assessments
related to this ECHO series. We value your feedback!