Child Maltreatment Involving Children with Disabilities and Medical Complexity

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WI-CAN, September 2025

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Disclosure Information for: Mallory McPhee, MD, FAAP

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Objectives

01

Understand how children with medical complexity are similar AND different from the broader population of children considered disabled.

02

Understand what is currently known about how children in these two categories interact with the child welfare system.

03

Identify how we can support families of children in these categories to prevent maltreatment from occurring and in response when concern for maltreatment does arise.

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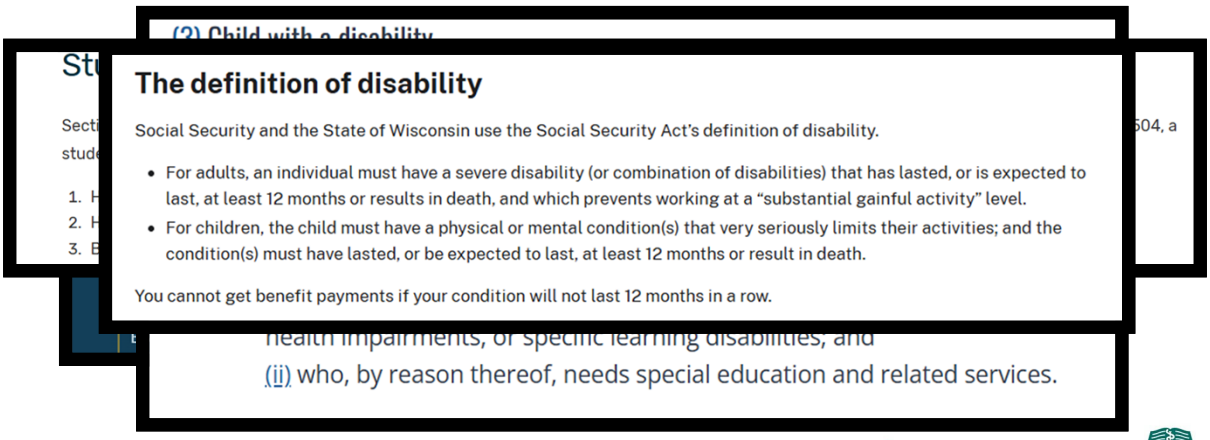
Definition of Disabled/Disability?



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Children with Disability

- Need additional support from their caregivers/other adults to accomplish activities of daily living and participate in typical for age activities.

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Definition of Children with Medical Complexity?

- Per the AAP: Children who have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need/utilization and often the need for or use of medical technology[1].

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Disabled

- Medical Care
- Rehabilitative Services
- Community Services
- Accommodations at school/work/public places

Medically Complex

- Primary Care Provider
- Multiple medical/surgical subspecialists
- Durable medical equipment
- Special feeding plan/equipment
- +/- Home nursing
- Rehabilitative services
- Community services
- Accommodations at school/public places

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8yo with Congenital Limb Difference

- 1x yearly PCP visit for well child check
- 1-2x yearly orthopedic appointment for monitoring
- 1-2x yearly orthotic/prosthetic appointment
- Possibly occupational and/or physical therapy
- 504 Plan at school +/- extra communication with school to meet needs throughout the year

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8yo with Type 1 Diabetes

- 1x yearly PCP visit for well check
- 3-4x yearly to endocrinology
- Possibly diabetes specific mental health care
- 504 plan at school and lots of communication with school RN
- Need for 24/7 caregiver who can respond to Type 1 emergencies
  - Intense planning for social activities, extra curriculars etc.
- Conversations with insurance to obtain insulin and devices for management

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8yo with Cerebral Palsy, Tracheostomy, G-Tube Dependence and Seizure Disorder

- 2+ primary care appointments annually for care coordination and well checks
- 1-2+ appointments each with physical medicine & rehabilitation, pulmonology, gastroenterology, and neurology.
  - Potential need for surgery or ENT visits for medical technology management
- Commonly require at least some period of hospitalization
- 24/7 **trained** caregiver to manage tracheostomy and other needs
- Coordination of DME and supply delivery
  - Back up trach, g-tube replacements, suction, feeding supplies
- Occupational and/or physical therapy services
- Scheduled medication administration, breathing treatments, daily care of technology
- Frequent need for conversations with insurance/providers to acquire meds and supplies

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Key Points

All of these children require increased support

The level of support needed can vary widely

We must also consider the additional strain on caregivers for these children

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Child Maltreatment in Children with Disabilities

- Discussion of current studies
- In general, still relatively under researched
- Some limitations:
  - Definition of disability?
  - How is disability status determined?

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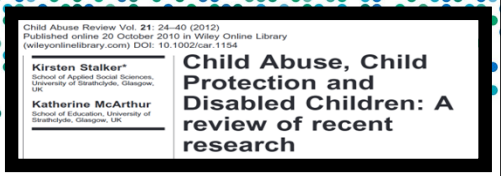
Child Abuse Review Vol. 21: 24–40 (2012)
Published online 20 October 2010 in Wiley Online Library
(wileyonlinelibrary.com) DOI: 10.1002/car.1154

Kirsten Stalker*
School of Applied Social Sciences, University of Strathclyde, Glasgow, UK

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School of Education, University of Strathclyde, Glasgow, UK

Child Abuse, Child Protection and Disabled Children: A review of recent research

Available Research

- Stalker & McArthur[2]
  - Scoping study analyzing research between 1996-2009
    - 38 papers analyzed
  - Key Points
    - Apparent association between disability and abuse
    - Concerns about directionality and under reporting
    - Apparent increased vulnerability for particular types of disabilities:
      - Communication impairment
      - Behavioral disorders
      - Learning disability
      - Sensory impairments

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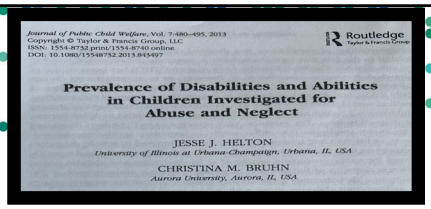
Journal of Public Child Welfare, Vol. 7:480–495, 2013
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Prevalence of Disabilities and Abilities in Children Investigated for Abuse and Neglect

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Available Research

- Helton & Bruhn[3]
  - Retrospective study analyzing National Survey of Child and Adolescent Well- Being (NSCAW II) results.
    - Assessed kids ages 3-10 to use standardized measures of functionality
      - Behavior, Cognition, Daily-Living Skills, Social Skills
    - Categorized based on results in each domain from severe impairment to superior functioning
  - Key Points
    - Between 38-60% of children had severe, serious or moderate impairments
    - More than half with severe or serious impairment in 1 domain had impairment in another domain as well

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Available Research

- Sullivan & Knutson[4]
  - Merged school system records with Department of Social Services, foster care and law enforcement records/databases.
- Key Points
  - Disability status = educationally mandated disability
  - ~3x the rate of maltreatment in group with disability

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Summary

- Children with disabilities are at increased risk of child maltreatment compared to their typically developing peers.
- Some types of disabilities may increase risk further.

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Child Maltreatment in Children with Medical Complexity

- Increasing population in pediatric healthcare[5]
  - Children's hospital systems dedicating resources to this group
- Limitations of research in this population in general
  - Lack of consensus defining the group
  - Complex children often excluded
  - Optimal outcome in this population may differ
- Limitations of research relating to child maltreatment in this population
  - Identifying children considered in this group
  - Issues with temporality

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Available Research

PEDIATRICS

Pediatrics. 2013 Mar;131(3):455–462. doi: 10.1542/peds.2012-1774

Chronic Conditions Among Children Investigated by Child Welfare: A National Sample

Ruth E.K. Stein, Michael S. Hurlburt, Amy M. Heneghan, Jinjin Zhang, Jennifer Rolls-Reutz, Ellen J. Silver, Emily Fisher, John Landsverk, Sarah McCue Horwitz

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PMCID: PMC4074665 PMID: 23420907

- Stein, et al.[6]
  - Retrospective study analyzing NSCAW II data to assess for chronic health conditions (CHC)
  - CHC identified based on caregiver interviews and questionnaires
- Key Points
  - 30.6-49.0% of children investigated by CPS had a CHC
  - Prevalence of CHC in children investigated was more than 1.5x the general population
  - How they determined CHC status was complicated

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Available Research

Sage Choice

Child Maltreat. 2021 Jul 5;27(2):257-266. doi: 10.1177/10775595211029713

Child Welfare System Involvement Among Children With Medical Complexity

Corry Azzopardi [1,✉], Eyal Cohen [2], Karine Pépin [3], Kathy Netten [4], Catherine Birken [5], Sheri Madigan [6]

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PMCID: PMC9003756 PMID: 34219484

- Azzopardi et al.[7]
  - Retrospective chart review at one pediatric tertiary care center
  - Identified patients under the care of Complex Care Program
  - Collected data about CPS involvement, sociodemographic information and clinical variables
- Key Points
  - 23.6% of reviewed patients had CPS involvement (most for neglect)
  - 9.1% had out of home placement of some kind
  - Caregiver mental health condition, history of trauma/violence or chronic medical condition associated with CPS involvement

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Not Yet Available Research

- McPhee, Rebbe, Huang, Laub
  - Retrospective Case Control Study
  - Examined Rady Children's Hospital medical records from 2016-2021
  - Identified children under 10yr with a Complex Chronic Condition (CCC) diagnosis
  - Use linked database to examine state birth and CPS records
  - Healthy controls matched to CCC children with available birth record information using 3:1 matching
  - Collected variables related to health status, demographics, CPS involvement

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Results

- Results related to CCC group
  - Identified 37,534 children with CCC who also had CA birth records
  - 25% of these children ever had a report to CPS
  - Percent of children with CPS report increased based on how many CCC categories of diagnosis they had.
  - Significantly higher percentage of CCC children who used public health insurance for birth were reported (32.6%) compared to private insurance (13.6%)

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Results Continued

CCC Group

- 25% reported to CPS
- 24% w/ at least 1 substantiation
- Higher percentage of physical abuse and severe neglect substantiation
- More likely to have higher number of reports
- Reports more frequently from medical providers

Control Group

- 20% reported to CPS
- 25.6% w/ at least 1 substantiation
- Higher percentage of general neglect and emotional abuse substantiations

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McPhee et al. Continued

- Key Points
  - Children with CCC received CPS reports more often than healthy peers
  - More medical complexity (higher number of CCC categories) increased reporting
  - Higher percentage of reports related to use of public insurance
  - Multiple limitations
    - Single center/geographical location
    - A child with 1 or 2 CCC may not adequately represent a medically complex child
    - Use of public insurance as a proxy for socioeconomic status
    - Lack of understanding of trajectory of CPS investigation/outcomes

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Summary

- This subset of children also appear to be at increased risk compared to typical peers
- Significant lack of research on this topic
  - Identification of the size of the issue
  - Identification of outcomes for these children
  - Understanding of how we can improve these outcomes

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Risk Factors

- Risk Factors for maltreatment
  - Caregiver mental health issues
  - Experiencing parental or economic stress
  - Families who are isolated from community
- Reports from caregivers of medically complex children
  - Feelings of isolation
  - Work/income loss
  - Financial hardship
  - Development of mental health conditions

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Prevention

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Prevention

- Assess family and caregiver well-being
  - Identify stressors and/or changes to the family structure
  - Assess risk/benefit of specific recommendations

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Prevention

- Know the resources in your community/health system
  - Financial resources
  - Qualify for Complex Care Program?
    - Other care coordination options
  - Caregiver support groups
    - Social media

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Prevention

- Time is short
  - Consider close follow up when needed
  - Utilize telehealth if available

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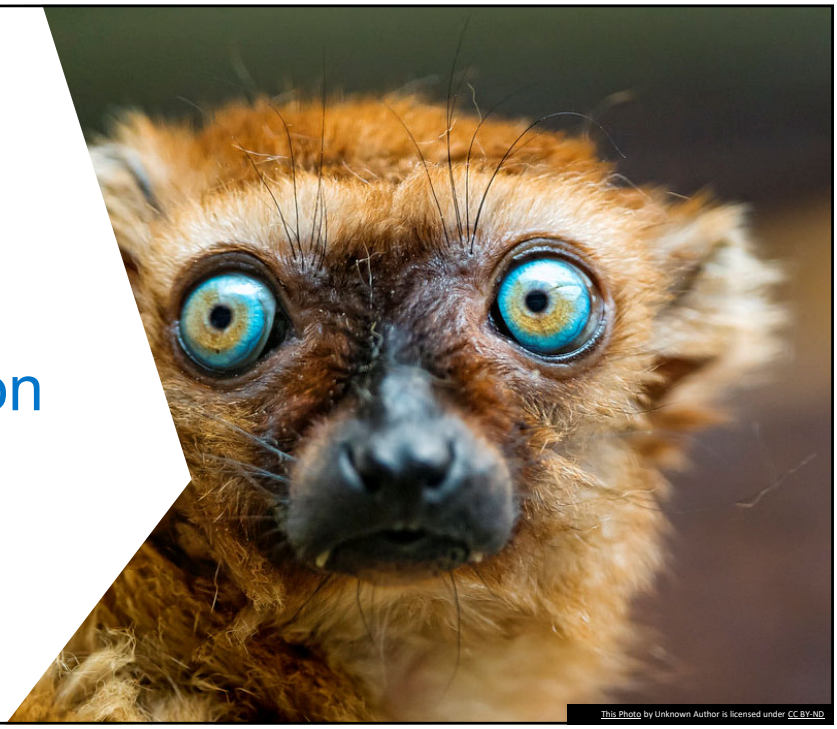
Identification



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Identification

- Neglect Concerns
  - Are the items not being addressed truly “necessary”
  - Confirm understanding of medical concerns
  - Attempt to understand possible barriers
    - Follow through with trouble shooting
  - Provide resources when applicable to address gaps

- If still unable/unwilling to meet needs a report may be needed

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Identification

- Physical Abuse Concerns
  - If you're not looking for it, you probably won't see it!
  - Thorough physical exam every time
    - May require removing from mobility device
    - Evaluate areas covered by clothing/medical devices

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Identification

- Consider developmental status
  - Those who don't cruise, rarely bruise

- If you are concerned, seek help
  - CAPS consult
  - Report injury if necessary

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Response to Report

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Collaboration is Key

- Community Partners
- Medical providers
  - Primary care
  - Subspecialty
- Medical team support staff
- Ideally, caregivers

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Investigator Response

- Obtain as much information as possible about medical/developmental needs
  - Interview caregivers
    - Assess understanding
    - Understand daily routine
    - Assess support network
    - Identify perceived barriers/stressors

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Investigator Response

- Obtain as much information as possible about medical/developmental needs
  - Talk to primary care provider
    - Can often give best picture of overall health
    - May be able to bridge gap to subspecialists
    - Longer term relationship with family
    - Partner in getting health needs back on track

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Investigator Response

- Obtain as much information as possible about medical/developmental needs
  - Talk to medical subspecialists
    - Education regarding diagnosis and needs
      - Ask about prognosis if needs continue to be unmet
    - Understanding of resources/education given to family
    - Sometimes have social work or case management support available

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Medical Provider Response

- Ongoing reassessment of medical necessity
- Advocate for patient's best interest
- Make yourself available to investigators
  - Use non-medical jargon when able
  - Provide honest assessment

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Special Considerations

- Medically complex children may be at safety risk if removed from primary caregivers
  - Imperative that caregivers have appropriate training and understanding of medications, equipment, etc. to meet their needs.

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Take Home Points

Children with disabilities AND children with medical complexity are at increased risk of maltreatment

We are in unique positions to advocate for these children AND their families

Assessment of maltreatment concerns in this population requires collaboration

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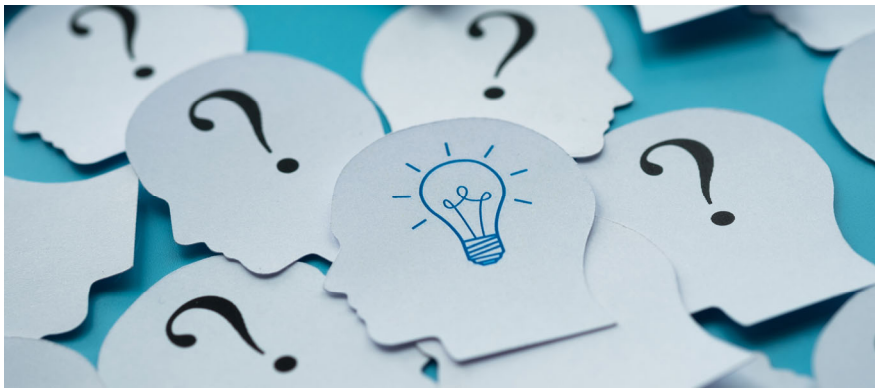

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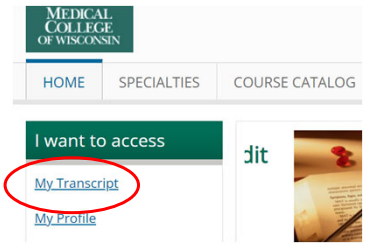

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