

A View From The Bench: Advocating For Medically Fragile/Special Needs Children

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***This session is being recorded**

CASA GAL
Court Appointed Special Advocates
Guardians ad Litem
FOR CHILDREN

Panelists:

Honorable Joseph Fernandes, Judge
Court of Common Pleas, First Judicial District of
Pennsylvania Family Court, Philadelphia, Pennsylvania

Honorable Valeri Love, Judge
2nd Judicial District of Oregon, Eugene, Oregon

Honorable Samantha Wagner, Judge
Branch IV, Brown County Circuit Court, Green Bay, Wisconsin

Moderator:

Honorable Ernestine S. Gray, Judge (Ret.)
Orleans Parish Juvenile Court, New Orleans, Louisiana

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Description/Objectives

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Participants will gain a better understanding of the challenges faced by children with varying levels of educational and medical complexities. They will learn about strategies to use in their CASA/GAL advocacy, in order to effectively implement what judges would like them to do when gathering information to report and make recommendations to the court as to what is in the best interests of children and youth.

Framing the Discussion

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Framing the Discussion

- The Court Appointed Special Advocate and guardian ad litem (CASA/GAL) Core Model states that programs provide screened, trained, and qualified community volunteers to advocate for the best interests of children and youth who are before the court as a result of abuse or neglect as defined by the state child welfare laws, living at home or in out-of-home care.

- Children with special needs, including educational, medically complex conditions, and medical fragility all require unique forms of advocacy and support.

- This session will explore the specialized services, medical technology, and care coordination that may be required across the spectrum of need.

Different Definitions for Special Needs, Medically Complex and Medically Fragile Children

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Different Definitions
Special Needs, Medically Complex, Medically Fragile Children

- While often used interchangeably by the general public, these terms describe different levels of medical fragility and functional impairment.
- In pediatric care, they represent a spectrum ranging from broad developmental or physical needs to severe, life-sustaining medical dependencies.

Different Definitions
Special Needs, Medically Complex, Medically Fragile Children

Special Needs Child

This is the broadest umbrella term. It encompasses any child who requires medical, behavioral, emotional, or educational support that goes beyond what is typically required for children.

Scope: Includes physical disabilities (e.g., cerebral palsy), developmental delays (e.g., autism), chronic illnesses (e.g., asthma, diabetes), and learning or behavioral challenges.

Support: Requires accommodations such as special education programs, speech/occupational therapy, or behavioral support, but not necessarily continuous nursing care or medical technology.

Different Definitions
Special Needs, Medically Complex, Medically Fragile Children

Medically Complex Child

This term describes children with **multiple, chronic health conditions** that affect multiple organ systems and require intensive coordination among various medical specialists.

Scope: A child generally qualifies as medically complex if they face several major concurrent conditions (e.g., a severe neurological condition coupled with respiratory issues and feeding difficulties).

Support: Requires constant medical attention, complex medication schedules, and relies heavily on medical technology (like feeding tubes or ventilators) for basic activities. Their condition often poses a high risk for life-threatening events and requires frequent hospitalizations.

Different Definitions
Special Needs, Medically Complex, Medically Fragile Children

Medically Fragile Child

This is the most acute category. It typically refers to a child with **one or more severe, chronic health conditions** that are so critical that their health is highly vulnerable to rapid decompensation.

Scope: While a medically complex child always has multiple conditions, a medically fragile child may have just one extremely severe, life-threatening condition (such as extreme prematurity complications, muscular dystrophy, or congenital heart disease).

Support: Depends heavily on medical devices (e.g., ventilators, tracheostomies) or life-sustaining treatments to survive, and require 24-hour skilled nursing care. Missing a single treatment or medication can immediately threaten their life.

Different Definitions
Special Needs, Medically Complex, Medically Fragile Children

In Summary,

Special Needs is a life condition needing accommodations (like school modifications or therapies).

Medically Complex means managing multiple chronic illnesses that require intense specialist management.

Medically Fragile means technology dependence and a vulnerability to rapid, life-threatening health changes.

Children and Youth with Special Educational Needs

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Children and Youth with Special Educational Needs

The Individuals with Disabilities Education Act (IDEA) is a federal law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children.

The IDEA governs how states and public agencies provide early intervention, special education, and related services to eligible infants, toddlers, children, and youth with disabilities.

Individualized Education Program (IEP)

- Under the IDEA, each public school child who receives special education and related services must have an Individualized Education Program (IEP).

- Each IEP must be designed for one student and must be a truly individualized document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability.

Panel Discussion and Questions

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Panel Discussion and Questions

Generally, what information does a judge want from the CASA/GAL volunteer regarding special needs, medically complex, and medically fragile children?

Panel Discussion and Questions

What information does a judge want from the CASA/GAL volunteer if a child/youth has a condition needing accommodations (like school modifications or therapies).

If a child/youth has special educational needs, what information does a judge want from the CASA/GAL volunteer about the need or implementation of an Individualized Education Program (IEP).

Panel Discussion and Questions

What information does a judge want from the CASA/GAL volunteer if a child/youth has a medically complex condition that requires managing multiple chronic illnesses with intense specialist management?

Panel Discussion and Questions

What information does a judge want from the CASA/GAL volunteer if a child/youth has a medically fragile condition that requires technology dependence and a vulnerability to rapid, life-threatening health changes?

Panel Discussion and Questions

How does the CASA/GAL program/volunteer learn what information the judge wants included in their reports?

Summary and Wrap-up

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