NATIONAL CFRP
Center for Fatality Review & Prevention

Reviewing Deaths of

Children and Youth With Special Health Care Needs or Disabilities

Learning Together, Protecting Tomorrows



Key Funding Partner

Federal Acknowledgement

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The speakers have no financial relationships or interests to disclose.



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Agenda

What We'll Cover Today

Defining the Population

Who are children and youth with special health care needs and disabilities?

Searching Records

Looking beyond the traditional sources of information.

Understanding the Impact

Understanding how gaps in agency data affect review.

Improving Prevention

Strengthening reviews and prevention practice.

Questions and Answers

What questions do you have?

About the National Center

National Center for Fatality Review and Prevention





Defining the Population

Understanding Who Is Included and Why They Matter



Why This Population Matters

Considering Special Health Care Needs in Fatality Review

Stronger Prevention

Teams can identify contributing factors, system gaps, and opportunities for prevention when they understand a child's special health care needs.

Complex Health Needs

Chronic health conditions, disabilities, care coordination needs, and dependence on services may shape the circumstances surrounding a child's death.

Significant Population

Approximately 1 in 5 U.S. children has a special health care need, making this an important population for fatality review teams to understand.

Source: HRSA Maternal and Child Health Bureau, National Survey of Children's Health, "Children and Youth with Special Health Care Needs."

Understanding Disability and Special Health Care Needs Definitions

Same Children, Different Definitions

Children with Disabilities

Children with qualifying physical, intellectual, developmental, sensory, emotional, or other impairments who require special education and related services.[1]

Children and Youth with Special Health Care Needs

Children who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services beyond those required by children generally.[2]

[1] U.S. Department of Education, Individuals with Disabilities Education Act regulations, 34 C.F.R. § 300.8.

[2] McPherson, M., et al. (1998). "A New Definition of Children with Special Health Care Needs." *Pediatrics, 102*(1), 137–140. https://doi.org/10.1542/peds.102.1.137

Fatality Review

Understanding the Full Story



Understanding Circumstances

Fatality review is a multidisciplinary process designed to understand the circumstances surrounding a death.



Identifying Factors and Opportunities

Teams seek to identify contributing factors leading to the child's death and identify prevention opportunities.



Developing Prevention Recommendations

Fatality review strives to strengthen systems to help prevent future deaths.

Source: Warren, M. D., Pilkey, D., Joshi, D. S., & Collier, A. (2024). "Fetal, Infant, and Child Death Review: A Public Health Approach to Reducing Mortality and Morbidity." *Pediatrics, 154*(Supplement 3), e2024067043B.

Partners Engaged in CDR

Common Team Membership and Records Reviewed



MCH Public Health



Healthcare Providers



Schools



District Attorneys



Child Welfare Agencies



Medical Examiners/Coroners



Law Enforcement



Mental Health Professionals



Community Advocacy Organizations



Emergency Response Agencies

Partners Engaged in FIMR Review Team

Common Team Membership and Records Abstracted



MCH Public Health



OB-GYN



Doulas



NICU Providers



Child Welfare Agencies



Medical Examiners/Coroners



Law Enforcement



Mental Health Professionals



Community Advocacy Organizations



Emergency Response Agencies



Where to Look

Beyond Traditional Records

Where Teams Find Relevant Information

Important Information in Multiple Systems

- Medical and hospital records.
- Primary care records.
- School and special education records.
- Early intervention records.
- Social service provider records.
- Disability service provider records.
- Behavioral health records.
- Family or caregiver interviews.





What Might Teams Miss?

Missing Information Can Limit Understanding

Health and Development

Key health, developmental, behavioral, and caregiving needs may be overlooked.

Communication Needs

Communication challenges and technology dependence can limit understanding of a child's circumstances.

Functional Limitations

Mobility limitations may affect safety, daily activities, and care needs.

Services and Supports

Service involvement and care coordination provides context on supports and interventions received.

Prevention Opportunities

Barriers to care may identify unmet needs and missed prevention opportunities.

Challenges Identifying Relevant Information

Why Information May Be Missing



Child and Family Context

- Not Yet Identified.
- Barriers to Evaluation or Services.



Records and Systems

- Difficult to Access.
- Information Across Systems.



Review Process

- Inconsistent Documentation.
- Unclear Sources.



The Complete Picture

Understanding the whole child often requires gathering, connecting, and interpreting records from multiple sources across different systems, making it challenging to develop a complete understanding of the child’s circumstances.



Understanding the Impact

Better Information Leads to Informed Reviews



Missing Information

Potential Impact During Reviews

Risk Identification

Identify disability-specific risks.

Service Access

Understand service gaps.

Pattern Recognition

Recognize patterns across deaths.

System Analysis

Identify system barriers.

Prevention Planning

Develop targeted prevention recommendations.

Mock Scenario

Drowning of a Child with Mobility Limitations

A school-aged child drowned while visiting a community recreation area with family members. The incident occurred near a body of water that was accessible to the public. Emergency responders were called, but lifesaving efforts were unsuccessful.



Note: This is a fictional scenario developed for educational purposes; it is not based on an individual case.

Mock Scenario: Comparison of Review Findings

Drowning of a Child with Mobility Limitations

Initial Review

A review team examines the drowning death of a child and identifies common environmental risk factors, including access to water and supervision concerns. Based on the available information, recommendations focused on water safety education and barriers to prevent unsupervised access to water.

Additional Information

As more records are reviewed, the team learns the child had significant mobility limitations and relied on adaptive equipment to move safely. Information from therapy providers and caregivers reveals that environmental barriers limited the child's ability to navigate safely and that existing safety plans did not adequately consider the child's functional needs.

Note: This is a fictional scenario developed for educational purposes; it is not based on an individual case.



Mock Scenario

What Additional Information Revealed

Mobility Limitations

The child required assistance navigating environments.

Adaptive Equipment Use

Daily activities depended on specialized equipment and supports.

Environmental Barriers

Physical surroundings created additional safety challenges.

Individualized Safety Needs

Existing safety measures did not fully account for the child's functional abilities.

Expanded Prevention Opportunities

Prevention strategies extend beyond supervision alone.

Note: This is a fictional scenario developed for educational purposes; it is not based on an individual case.



Mock Scenario: Prevention

How the Review Enriches Recommendations

- The team expands its understanding beyond general drowning prevention. Recommendations now include consideration of adaptive safety planning, environmental accessibility assessments, caregiver support, and safety guidance tailored to children with mobility limitations.
- The review shifts from a focus on supervision alone to a broader examination of how functional needs and environmental design interacted to increase risk.

Note: This is a fictional scenario developed for educational purposes; it is not based on an individual case.



Impact to Prevention

What proves most informative is not the diagnosis itself, but how a child's health requirements, functional needs, and services played a role in the death.

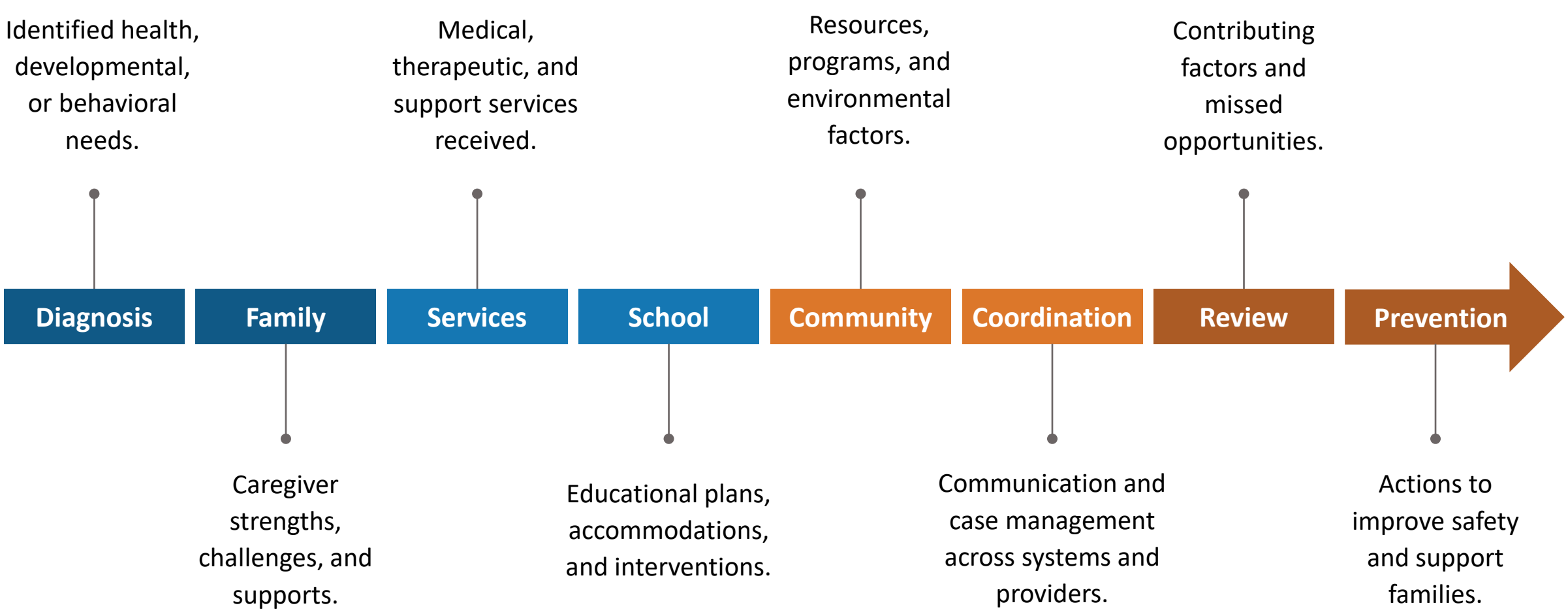


Opportunities for Improvement

Strengthening Reviews for Children with Special Health Care Needs

A Child's Journey Beyond the Diagnosis

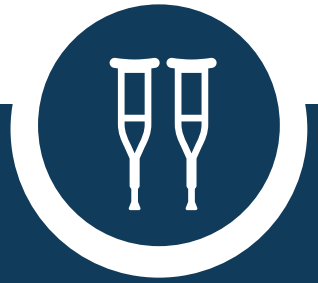
Prevention Pathway



Practice considerations developed for this presentation; informed by HRSA's CYSHCN systems-of-care framework.

What Review Teams Should Look For

Strengths Beyond Diagnosis



Function

Can the child:

Communicate

Move independently

Perform self-care



Supports

Did the child rely on:

Assistive devices

Daily medications

Specialty/advanced care

School services



Systems

Were there barriers to:

Healthcare

Transportation

Education

Language

Respite care



What Teams Can Do

Strengthening Disability-Informed Reviews

Strengthen Participation

Include organizations serving children and youth with disabilities and their families, including family-led organizations like Family-to-Family Health Information Centers.[1]

Improve Review Information

Identify information sources. Improve record access. Develop consistent review questions. Complete the Pediatric NFR-CRS questions regarding disabilities and chronic illnesses (A13).[2]

Advance Prevention

Share review findings with community partners to increase awareness and develop prevention initiatives.

[1] HRSA Maternal and Child Health Bureau. "Family-to-Family Health Information Centers."

[2] National Center for Fatality Review and Prevention. *National Fatality Review Case Reporting System Data Dictionary*, Version 6.0.



The Whole Story

A diagnosis is only one part of a child's story. Considering functional needs, supports, services, environments, and lived experiences helps review teams better understand risk, identify system gaps, and strengthen prevention efforts for children and families.



Questions

What Questions Do You Have?

Office Hours

2026 Sessions from the National Center

Date	Topic
11/17/2026	Working with Small Numbers to Catalyze Prevention
12/15/2026	Celebrating Success: Highlights of Prevention Successes

Visit https://ncfrp.org/news/ to register (each session requires individual registration).

References and Resources

Children and Youth With Special Health Care Needs or Disabilities

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Thank You for Your Time!

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