

Effective Review of the Deaths of Infants and Children with Disabilities and/or Special Health Care Needs



The National Center for Fatality Review and Prevention

February 8, 2017

About the National Center

The National Center for Fatality Review and Prevention is a resource and data center that supports child death review (CDR) and fetal and infant mortality review (FIMR) programs around the country.

It is funded in part by Cooperative Agreement Number UG7MC28482 from the U.S. Department of Health and Human Services (HHS), Health Resources Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).

Center aligns with MCHB priorities and performance and outcome measures such as:

- Healthy pregnancy
- Child and infant mortality
- Injury prevention
- Safe sleep

HRSA's overall vision for the Center

- Through delivery of data, training, and technical support, the Center will assist state and community programs in:
 - Understanding how CDR and FIMR reviews can be used to address issues related to adverse maternal, infant, child, and adolescent outcomes
 - improving the quality and effectiveness of CDR/FIMR processes
 - increasing the availability and use of data to inform prevention efforts and for national dissemination

Ultimate goal: improving systems of care and outcomes for mothers, infants, children, and families

Speaker Panel

Introduction: Diane Pilkey, RN, MPH

Senior Nurse Consultant

MCHB/Health Resources & Services Administration



Moderator: Faith Vos Winkel, MSW

Assistant Child Advocate

Connecticut Office of the Child Advocate
Coordinator, Connecticut CFR program.

Guest Speaker: Joan A. Scott, MS, CGC

Acting Director, Div'n of Children with Special Needs

MCHB/Health Resources & Services Administration.



Speaker: Linda Potter, JD

Associate Director

National Center for Fatality Review & Prevention

The National Center for Fatality Review and Prevention



Housekeeping

- Webinar is being recorded and will be available with slides in a few days on our website: www.ncfrp.org. We'll notify participants when it's posted
- All participants will be muted in listen only mode
- Questions can be typed into the Chat Window. Due to the number of participants, we may not be able to get to all questions in the time allotted. The Center will answer all questions and post the answers on the NCFRP web site: <https://www.ncfrp.org/>

Work group on Effective Review of Deaths of Children with Disabilities and Special Health Care Needs

Work group members

Child Death Review State/D.C. Coordinators

- Anne Pedrick, Delaware, Chair
- Faith Vos Winkel, Connecticut
- Arleymah Gray, Georgia
- Tracie Martin, District of Columbia
- Jenna Beebe, District of Columbia

National Center Staff

- Linda Potter

Products

- Written Guidance
 - Gathering information for the review
 - Inviting the right people
 - Background on risk factors for deaths of children and infants with disabilities and SHCN
 - Possible discussion questions for the review
 - Sample recommendations
 - Toolkit of resources
- Webinar

Webinar Goals

Participants will:

- Know what Children's Special Health Care Services (CSHCS) are and how to find them in your jurisdiction
- Understand that the infant/child's condition may or may not have played a role in the death, and how to figure it out
- Understand the risk factors for death of infants/children with disabilities and/or special health care needs
- Know how to prepare for review of the deaths
- Know where to look for sample recommendations and for additional resources

Children and Youth with Special Health Needs (CYSHCN): Considerations for Child Death Review Teams

Feb 8, 2017

Joan A. Scott, M.S., C.G.C.

**Acting Director, Division of Services for Children with Special
Health Needs**

Maternal and Child Health Bureau (MCHB)

Health Resources and Services Administration (HRSA)

Department of Health and Human Services



Health Resources and Services Administration (HRSA)

- America's healthcare safety net - HRSA is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable
- Maternal and Child Health Bureau (MCHB) - Provides leadership to improve the physical and mental health, safety and well-being of the maternal and child health population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and *children with special health care needs*.

<https://mchb.hrsa.gov/>



Division of Services for Children with Special Health Needs (DSCSHN)

Mission

To provide national leadership to expand and strengthen access to a system of services for children and youth with special health care needs and their families as they grow and transition through adulthood

Vision

Optimal health and quality of life for all children and youth with special health needs and their families

<https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs>



Children and Youth with Special Health Care Needs

- *Children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services or a type or amount beyond that required for children generally*
 - Nearly 20% of U.S. children under age 18 years
 - One in five U.S. families
 - Services needed from multiple systems – health care, public health, education, mental health, and social services
 - Increasing number of medically complex children



McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998; 102(1): 137-140



CYSHCN

- **Definition includes broad spectrum from being at risk, to having an identified physical, cognitive, or behavioral condition, to being medical complex**
- **Families of CYSHCN**
 - Significant financial and caregiving demands
 - Racial and ethnic disparities regarding prevalence, resource use, and survival rates
- **CYSHCN can have psychological or behavioral co-morbidities associated with the primary condition**
- **Child may come to the CDR team already known as a CYSHCN or the review may uncover a previously unknown condition**



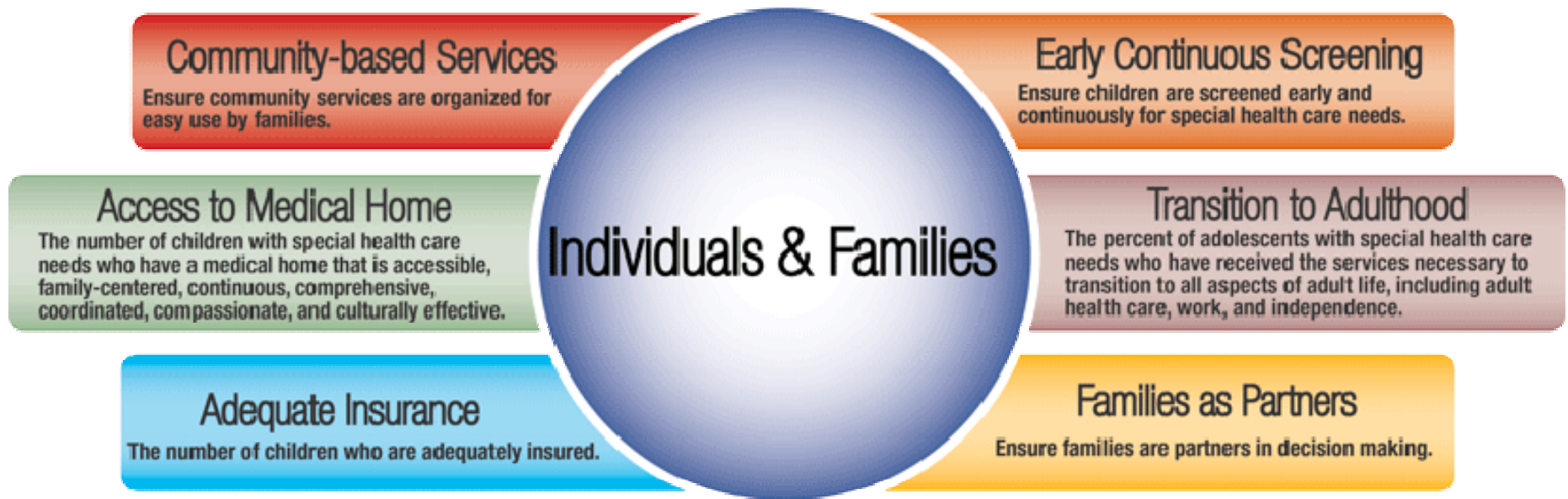
State Title V CYSHCN Programs

- Supported through Title V of the Social Security Act
- At least 30% of Title V Block Grant funds must be used for children and youth with special health care needs
- Each state and territory, including the District of Columbia, has a dedicated CYSHCN program serving CYSHCN and their families



State Title V CYSHCN Programs

- Assume a leadership role in the development of family-centered, community-based, coordinated systems of care for CYSHCN and their families
- Guided by the six core systems outcomes for CYSHCN



<https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs>

State Title V CYSHCN Programs

- States determine:
 - Eligibility requirements
 - Types of services provided
 - Moving away from direct care services and towards infrastructure-building, systems of services activities



State Title V CYSHCN Programs

Resources

- [Division of State and Community Health \(DSCH\)](#)
 - Provides a high level overview of State Title V programs
 - <https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program>
- [Title V Information System \(TVIS\)](#)
 - Captures key financial, program, and performance/indicator data as reported by State Title V programs
 - <https://mchb.tvisdata.hrsa.gov/>
- [Association of Maternal and Child Health Programs \(AMCHP\)](#)
 - National association of Title V programs linking to other resources
 - <http://www.amchp.org/pages/default.aspx>
- [National Standards for Systems of Care for CYSHCN](#)
 - Framework of structural and process systems standards for CYSHCN
 - <http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20Charts%20FINAL.pdf>



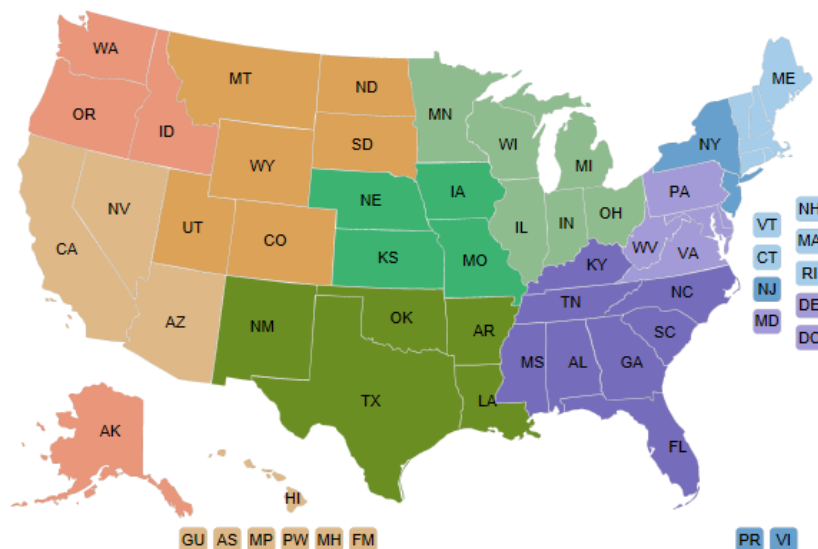
Explore the Title V Federal-State Partnership

As one of the largest Federal block grant programs, Title V is a key source of support for promoting and improving the health of the Nation's mothers and children. The purpose of the Title V Maternal and Child Health Services Block Grant Program is to create Federal/State partnerships that enable each state/jurisdiction (**hereafter referred to as state**) to address the health services needs of its mothers, infants and children, which includes children with special health care needs, and their families.

National ▼

National Data

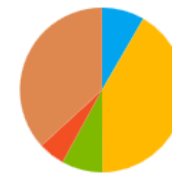
FY 2015 Expenditures: \$6,286,875,668 | FY 2015 Populations Served: 57,064,187



Region 1 Region 2 Region 3 Region 4 Region 5 Region 6 Region 7 Region 8 Region 9 Region 10

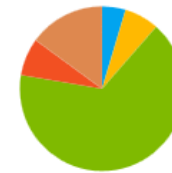
FY 2015 Expenditures

National: \$6,286,875,668



FY 2015 Population Reach

National: 57,064,187



to mothers, infants and children, which includes children with special health care needs, and their families.

Maryland ▼

FY 2015 Expenditure

Maryland

57,064,187

Total Funding : \$20,285,051

Total Individuals Served: 371,716

[Go to State Data](#)

State Contacts:

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CSHCN Director

Donna X. Harris, BS

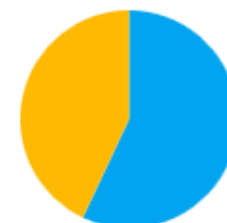
Director, CSHCN

Donna.Harris@maryland.gov

Tel: (410) 767-6730

FY 2015 Expenditures

Maryland: \$20,285,051



FY 2015 Population Reach

Maryland: 371,716



Region 1 Region 2 Region 3 Region 4 Region 5 Region 6 Region 7 Region 8 Region 9 Region 10

National Performance Measures – Selection Breakdown



Other resources

- 51 HRSA supported Family-to-Family Health Information Centers and the National Center for Family Professional Partnerships

National Center for Family Professional Partnerships
a project of Family Voices, Inc.

Home NCFPP F2F HIC CYSHCN Activities Tools-Resources Partners Quality Health Care Contact Blog

Providing Leadership
in helping families of children and youth with special health care needs / disabilities and professionals partner to improve care
A national center funded by the Health Resources Service Administration (HRSA), Maternal and Child Health Bureau (MCHB)


Partnering with providers improves health outcomes and patient and provider satisfaction
Learn More about Partnering with Providers

TRANSLATE:
Select Language

SEARCH:
Enter Search Term GO

RESOURCES
Find a Family-to-Family Health Information Center:
[Map of the United States showing F2F HIC locations]
Find a Family-to-Family Health Information Center:
Select State
Enlarge Map

Family Voices Newsletters Sign-up

HIGHLIGHTS
Washington DC Update Highlights
1/11/2017: *This Week in Washington Update:*
• Senate and House pass budget resolution to pave the way to repeal ACA.
• Some concern from Republicans about repealing ACA without immediately enacting replacement.
• ACA Open Enrollment continues.
• DOT issues new materials to clarify rights and responsibilities related to air travel by people with disabilities.

Washington DC Update is a weekly e-newsletter sent to subscribers and is also archived on the Family Voices website.

NCFPP Awarded Funding to Support Families in the Territories
Family Voices is pleased to announce supplemental funds to expand opportunities for families in the US territories, particularly those exposed to or affected by the Zika virus. These funds will allow us to expand collaboration efforts with multiple family groups and individuals, Title V, MCHB programs and agencies, and other professional partners in the territories as well as key national MCHB partners. This funding opportunity represents an important step forward for families in the territories toward the goal of engaging families in their child's health care and as partners in programs and policies.

Quick Links
How The ACA is Helping Children with Special Needs and Their Families
2014-2015 F2F Data Report
2016 Family Leadership Meeting: *Expanding our Reach, Impacting the Future*
ACA Tip Sheets
Request to Use Family-Centered Care Assessment
Family-to-Family Health Information Center Brochure

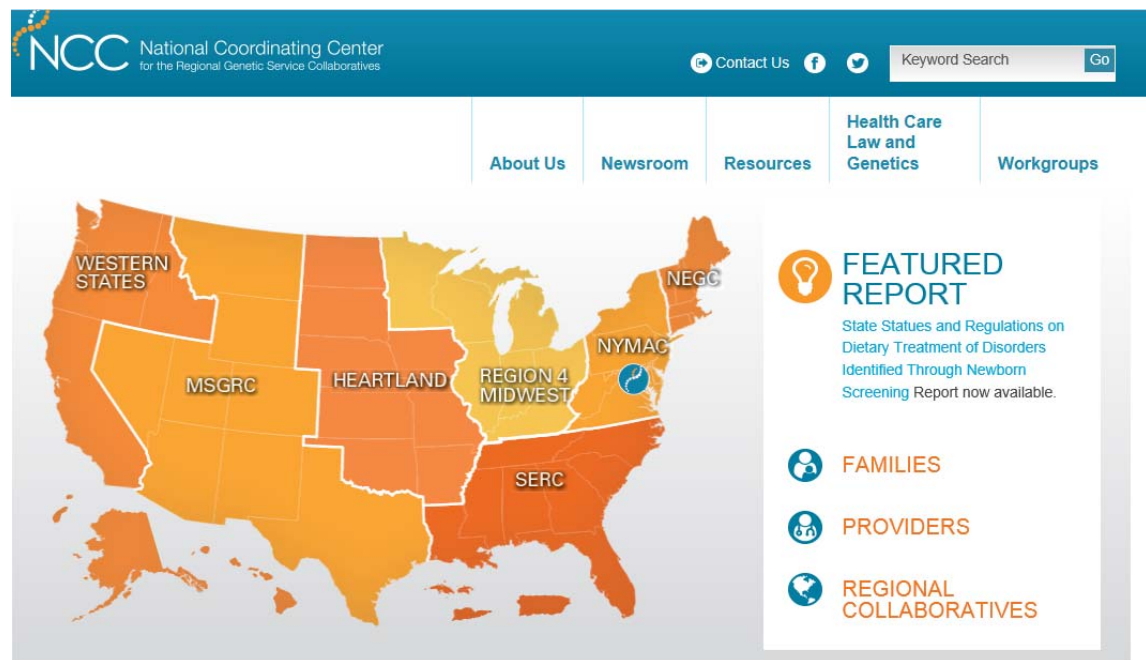
News & Happenings
Tell us about an upcoming event you would like to have posted in this column.
Subscribe
1/25/17, 1:00-2:00 pm ET: **Family Engagement Strategies from the broader MCH Community**
Sponsored by the National Center for Hearing Assessment and Management (the National Technical Resource Center for Early Hearing Detection and Intervention systems).
1/25/17, 12:00-1:00 pm ET: **TRICARE Pharmacy Options**

<http://www.fv-ncfpp.org/>



Other resources

- The National Coordinating Center for Regional Genetic Service Collaboratives



<http://www.nccrcg.org/>

Welcome to the National Coordinating Center for the Genetic Service Collaboratives (NCC). NCC focuses on bringing quality genetic and newborn screening services to local communities, and building bridges between public health, primary care/ Medical Home, geneticists and other specialists, and families and consumers.



Contact Information

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Why is it important that a review team know about disability and special health care needs?

- Different reports of the prevalence of children have disabilities in the US
- In the National Center's Case Reporting System:
 - Over 20% of the deaths entered into the Case Reporting System are identified as having disabilities or a chronic health condition
 - 15% of those were receiving Children's Special Health Care services



- Risk factors for death of infants and children with disabilities/special health care needs (SHCN) are different than for those without disabilities
- What is asked of caregivers of infants and children with disabilities/SHCN is different than for those without disabilities.

Physical

- Mobility
- Anatomical loss
- Illnesses or disorders fit here too

Mental/cognitive/intellectual impairments

- Mental illness
- Intellectual disability
- Other conditions, such as autism
- Attention Deficit Hyperactivity Disorder
- Learning disabilities

Sensory impairments

- When one or more of the senses is impaired
 - Hearing
 - Vision
 - Smell
 - Touch
 - Taste
 - Spatial awareness



Developmental disabilities

- Before age 22
- Expected to last a lifetime
- Interferes with “functioning”

Scenario

- Joey was 3 years old when he died. He had significant cerebral palsy and other conditions; he couldn't speak, walk, sit up, or feed himself. He could smile, cry, see, and hear.
- Feeding Joey was time consuming, and it was difficult even though he ate only pureed food because the cerebral palsy affected his swallowing muscles; he was always in danger of choking or aspirating (inhaling food into his lungs), which can cause aspiration pneumonia.
- In addition to financial benefits and Medicaid for the family, Joey received , Children's Special Health Care Services, and physical and swallowing therapies from the education system

- Joey was hospitalized three times with pneumonia. Each time, the hospital recorded that he was malnourished, and one time he was admitted with a pressure sore on his bottom.
- On the day he died, his mother brought him in to the hospital, and he died shortly after.
- The autopsy showed severe malnourishment and abusive head trauma.

Risk factors for death of infants/children with disabilities

Maltreatment risk and disability

- Studies vary as to how much higher their risk of maltreatment is
 - Children with disabilities are 1.7 - 3.4 x more likely to suffer maltreatment

Maltreatment risk varies by disability

- Children with mental illness or intellectual impairments tend to be the most vulnerable, with 4.6 x the risk of sexual violence compared with their peers without disabilities
- 18% of deaf adults report being sexually abused as children; 30% physically abused by residential staff; 19% caregiver physical abuse.
- One study found that 18.5% of children with autism were physically abused and 16.6% had been sexually abused.

Why do infants/children with disabilities experience higher rates of maltreatment?

- Because they need services, they are exposed to more non-familial caregivers than those without disabilities
- Seen by predators as more vulnerable: perhaps unable to flee or make a report
- Parenting a child with disabilities can be demanding, particularly if the parents have no services to help with the child's care or if they are not equipped to meet the demands of the care

Medical risks

- Aspiration, constipation, dehydration and seizures are the four major health issues that can cause death in infants and children with developmental disabilities. The first 3 can go unrecognized until major illness or death.
- Lack of independent mobility and independent feeding
- High demands on parents
- Complex and/or uncommon medical issues
- Medical care withheld



School can be unsafe too

- Bullying
- Prone restraint, or otherwise pinned on the floor
- Put in seclusion rooms
- Bus drivers



Risks in out of home placement – foster care

No continuity of medical/mental health services

Mental health needs

- 40-60% of kids in care may have psychiatric diagnosis
- National standards
 - ½ of kids received services complying with 1 standard; only 10% received care consistent with all standards



Physical/medical disability

- Danger of insufficient training of family

Out of home placement - institutions

- 2% of children with disabilities live in institutions
- Power differential; vulnerability to other children
- Lack of procedures for investigating/reporting abuse



Suicide

- Mental health issues
- Children with physical disabilities
- Bullying

Preparing for the review

What records do we need?

- Hospital/any specialty hospitals
- Medical home/pediatrician
- Specialists
- Early Intervention service providers
- Education records (IEP)
- If any agencies were involved, obtain their records about the child and also their policies/protocols pertaining to services to infants/children with disabilities.

Invite the right people

Invite people with relevant expertise to be ad hoc members of the review team. Examples may be:

- Specialty physician with expertise in the child's medical or disability condition who can talk about it and can speak to the expected standard of practice for treatment of the condition.
- Ask someone from the state Children's Special Health Care Services
- School or mental health personnel

Discussion about Joey

- Did he have a care coordinator?
- Who was helping Mom:
 - With Joey's physical care?
 - With transportation to appointments?
- Who was watching out for Joey?
 - Hospital personnel each time he presented?
 - Therapist providing him direct services?
- Where did the system break down?
- What can we do to fix it so the next mother has the help she needs, and the next severely disabled child is well-cared for and safe?

Possible recommendations from Joey's case

Recommendations in Joey's case would depend on what is learned in the discussion. But here are some potential recommendations that may be suggested by the scenario's details.

- That policy be adopted that all early intervention providers who go into homes to provide services to infants/children with disabilities and/or special health care needs be trained to recognize signs of neglect and abuse, and what to do if they see anything suspicious.
- Team could, depending on what it discovers about during discussion, make a recommendation tailored to an effort to improve reporting by hospital personnel when a presenting child is malnourished and/or has a pressure sore.

- That policy be adopted by the relevant agency that every newborn with a known disability leaves the birth hospital with a care plan and a service coordinator to assist with connection to needed services and to follow up to see that caregivers have sufficient help in the home and that care provided in the home is adequate for child's health and safety.
- That the Child Welfare Agency develop committees of persons knowledgeable in disability to manage training for and be consultants to workers whose clients have disabilities.

Suggested discussion questions

Caregiver maltreatment

- Were services available to support the parents, and, if so, did they know about them?
 - Did they have a care coordinator?
 - Did the infant or child have a medical home?
- Were parents using available services, and, if not, why not?
- Did parent(s) have unmet mental health needs?

Caregiver maltreatment

- Were signs of abuse, neglect, or illnesses recognized and reported to promptly by health, school, and other care providers who have reporting duties?
- What is the welfare agency's policy on children with disabilities? Is there a consulting committee? Is disability a required element of screening or safety assessments? Is the requirement strong enough?

Medical deaths

- Did this infant or child receive the medical services he or she needed?
- If not, why not?
- Was this infant or child's life, health and safety taken as seriously as the life, health and safety of an infant or child without a disability?
- If doctors were not allowed by parents to give treatment, what was the process that allowed parents to withhold treatment?

Death at school

- What are the school and the school district policies on restraint and seclusion, and particularly prone restraint, and on bullying?
- There are models for training teachers alternatives to restraining and secluding children. Did the school know about them/use them?

Death in foster care

- Were foster parents given sufficient training and supports to care for the infant/child?
- Was there sufficient oversight of the infant/child and family?

Death in institution

- What caused the death?
- Was there sufficient supervision of the child?
- What are the policies in place on restraint and seclusion; prone restraints? Investigation and reporting of incidents?
- What could the institution have done to prevent this death?
- Was CPS notified?

Suicide in foster care

- There are proposed national standards for mental health assessment and services in foster care: were they followed?
- What are the welfare agency's protocols regarding mental health assessment and needs of children in care?
- Was there a mental health assessment by the child welfare agency when the child went into care?

Suicide in foster care (cont.)

- Were services provided in accord with identified needs?
- Was there a coordinator of mental health services for the child?
- Were the biological parents included in provision of mental health treatment?

Examples of recommendations

Maltreatment

- That safety assessments by CPS workers include a question regarding identification of an infant or child's disability and identification of specific disability-related services needed.
- That a policy be adopted by Child Welfare Agency that all CPS workers are to be trained to identify disabilities and specific disability-related needs of infants/children with disabilities, and that the training be incorporated into the curriculum.

Maltreatment (cont.)

- That the Child Welfare Agency develop committees of persons knowledgeable in disability to manage training for and be consultants to workers whose clients have disabilities.

Maltreatment (cont.)

- That policy be adopted that all early intervention providers who go into homes to provide services to infants/children with disabilities and/or special health care needs be trained to recognize signs of neglect and abuse, and what to do if they see anything suspicious.
- Repeat same recommendation for “home visitors.”

Foster care

- That protocol be adopted requiring assessment by the child welfare agency, using evidence-based tool, of all infants/children entering care for mental health and other disability-specific needs
- That the child welfare agency adopt a policy that when a infant/child with a physical, mental, or intellectual disability is to be placed with foster parents, the foster parents receive child- and disability-specific training.

Foster care (cont.)

- That a policy be adopted by the relevant agency requiring provision of evidence-based mental health services to all children in care identified as in need of them.

Schools

- Local: That the school district adopt a policy forbidding physical restraint of children with disabilities or special health care needs, and that school staff be trained by evidence-based program on incident management to avoid the need for restraints/seclusion
- State: That the state education agency adopt a policy forbidding the use of prone restraint of students in schools.

Schools (cont.)

- That a policy be adopted by the school system that all school personnel, including aides, bus drivers, teachers and other providers, undergo criminal background checks prior to hiring, and that they not be hired if their backgrounds reveal history of violence of any type or neglect of a child.

Services to support parents

That policy be adopted by the relevant agency that:

- every newborn with a known disability leaves the birth hospital with a care plan and a service coordinator to assist with connection to needed services.
- parents of newborn with a disability are referred before discharge to Medicaid/EPSDT, Children's Health Insurance Program (CHIP), Social Security, Early Intervention services, and/or Children's Special Health Care Services.

Institutions

- That the relevant agency adopt a policy requiring that institutional workers be trained in Trauma Informed Care and in trauma-informed incident management techniques.
- That the agency responsible for mental health and developmental disabilities institutions adopt a policy prohibiting prone restraint.