

Guidance for Reviewing Deaths of Infants/Children
with Disabilities and/or Special Health Care Needs

National Center for Fatality
Review and Prevention



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INTRODUCTION

Approximately one fifth of the cases reviewed by Child Death Review (CDR) teams and entered into the CDR–Case Reporting System database are of children who had a disability or chronic illness, and 15% of those were receiving Children’s Special Health Care Services.¹ Therefore, it is critical that CDR and FIMR teams have nuanced knowledge of disability/special health care needs so they can conduct effective reviews of the deaths. Although a child’s death may be a direct result of the condition, risk factors for deaths of children with disabilities are different than for children without disabilities, and what is asked of caregivers of children with disabilities¹ is often different than for children without disabilities. Teams need to be able to recognize what role, if any, the disability/special health care condition played in the death. Only if they are armed with complete information can they craft effective disability-specific recommendations where needed to prevent unnecessary deaths of children with disabilities and special health care needs.

This Guidance was developed by the National Center for Fatality Review and Prevention and a work group of state Child Death Review coordinators with an interest in the issues.² Its goal is to help teams improve the sharing of information about and discussion of the type of disability or special health care need(s); the circumstances related to provision of services and treatment for the condition to the child and family; the risk factors related to maltreatment and neglect; and/or the circumstances of unintentional injuries.

The questions included in this document should spark discussion of additional factors that may arise when a child with a disability or special health care needs dies; it is not necessary to discuss every question. A team may make findings during a review that there were gaps in services, policies, or protocols that, if corrected, might save future lives. The Guidance provides a structure for identifying and addressing such gaps, and a number of model recommendations are included at the end of the document. It will also help teams participating in the National Fatality Review–Case Reporting System (CRS) database complete relevant sections. Throughout the Guidance, if a question is also part of the Case Reporting System, the number of the question is also listed.

The Guidance also offers a Toolkit Appendix of more extensive materials that may prove helpful when reviewing specific disability-related deaths.

The types of death at the intersection of CDR and FIMR and disability are:

- Deaths from caregiver maltreatment
- Deaths when families lack supports needed to keep child with disability healthy and safe
- Deaths in school settings
- Deaths when medical care is withheld or not available
- Deaths in out-of-home care (foster, group home, jail/detention, or institution)
- Injury deaths (e.g., drowning, fire), which occur at a higher rate for children with disabilities
- Suicide, where the issue may be unmet mental health needs

¹ As of January 2017

² At the time the Work Group was active, the Center did not yet provide resources to Fetal and Infant Mortality Review teams/programs, so only CDR coordinators were members of the group.

Definitions of Disability and Special Health Care Needs

There are many types of disabilities and many definitions of the word “disability.” One such definition is, “a physical or mental condition, or a combination of conditions, that results in ‘marked and severe functional limitations’ expected to last at least one year or to result in death.”ⁱⁱ

The Case Reporting System trigger question about disability is Question A20, which reads as follows:

20. Child had disability or chronic illness

If yes, check all that apply:

- Physical/orthopedic
- Mental health/substance abuse
- Cognitive/intellectual
- Sensory

Was child receiving Children’s Special Health Care Needs services?

“Physical impairments” may include mobility impairments, anatomical loss, and certain illnesses or disorders (e.g., epilepsy). “Cognitive/intellectual impairment” is a broad term, but includes intellectual disability and other conditions, such as autism, ADHD, and specific learning disabilities. “Mental health/substance abuse” includes mental illness and conditions arising from substance abuse, which can also be or cause a disability. “Sensory impairments” are such things as hearing and visual impairments, or a combination of the two.

“Children with special health care needs” are those who “...have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.”ⁱⁱⁱ Examples include cerebral palsy, cystic fibrosis, diabetes, asthma, and cancer. A child with a disability may or may not also be a child with special health care needs. For instance, a child with an intellectual disability may have no related medical issues at all.

A child may also be identified as having a “developmental disability.” This is a term used widely, in many different contexts, but the original definition is of a disability occurring before age 22, that is expected to last a lifetime, and that causes certain functional limitations.

The Case Reporting System Data Dictionary provides further direction on identifying disability and special health care needs.

Preparing for the Review Meeting

Obtain all relevant records:

- Medical records (include specialist records and records from specialty hospital)
- NICU records; discharge records may be particularly relevant
- Hospital social work records
- Nurse visiting records
- Early Intervention services records
- Education records (IEP)
- If any agencies are involved, obtain their policies/protocols pertaining to their provision of services to children with disabilities. For example, if maltreatment is involved, ask for the child welfare agency's policies on children with disabilities.

Invite individuals with relevant expertise to be ad hoc members of the review team.

Examples are:

- Physician with expertise in the medical condition, such as asthma, diabetes, cystic fibrosis, etc.
- Physician and others with expertise with cerebral palsy, developmental disability, autism, or other specific condition
- Physician with expertise in medical genetics, including metabolic disorders. Look to your state's specialty hospitals for people with expertise on the standard of practice for medical care for a child with the condition.
- Title V person familiar with services offered by Children's Special Health Care Services
- School personnel
- Community mental health professionals
- Representative(s) of disability groups, such as groups about autism, cerebral palsy, intellectual disabilities, etc.
- [Protection & Advocacy Services](#)^{iv} (P&As are federally-funded advocacy organizations in each state)

Due to law or regulation, some teams may not be able to invite ad hoc experts to participate in reviews. An alternative is to invite the expert to make a presentation to the team and answer questions about the condition before convening the case review.

Background and Important Questions for Discussion at the Review

Team could consider the following questions during its review of deaths of children with disabilities and/or special health care needs, beginning with identification of the child's condition.

1. What was the disability or condition? Discuss in conjunction with answers to Case Reporting System (CRS) Question A20. Functional descriptions are the most useful for older children: whether the child can walk, talk, toilet self, feed self, etc. For infants, factors to consider include hypotonia, failure to thrive, and delayed milestones.

Medical Death or Natural Causes (CRS Section G10)

Some disabilities and medical conditions will cause the death of a child no matter how high quality and aggressive the child's care and health services are, but inquiry is recommended to assure the child received all services he/she should have received and that the parents/caregivers had the supports they needed to do their part to get needed care for their child. This is the discussion where it is important to have a resource person either at the Review or otherwise available who has expertise in appropriate health care of a child with the specific disability/medical condition. Other potential risk factors are:

- Poverty of family/economic instability/functional ability of families that impacts provision of physical care in the home and/or compliance with medical care regimens
- The distance a family lives from specialty hospitals that provide care for conditions needing specialized care

Risk factors for medical deaths of children with disabilities and special health care needs:

- Reduced mobility
- Feeding tubes or difficulty with feeding
- Poorly controlled seizures
- Aspiration, constipation, dehydration and seizures are the four major health issues that can cause death in children with developmental disabilities; they are known as the Fatal Four. The first 3 can go unrecognized until major illness or death.

- Medical issues and care needs that are not addressed medically
 - Parents not trained or do not understand care needs, or medical care withheld
 - Inconsistent medical care
2. Were the prescribed care plans appropriate for the medical condition? (CRS Section G(10)d)
 3. Were there access or compliance issues related to the death? (CRS Section G(10) i)
 - Lack of money for care
 - Language barriers
 - Caregiver distrust of health care system
 - Lack of caregiver compliance with medical regimen, e.g., missed appointments, doctor-shopping, medication requirements
 - Caregiver unskilled in providing care
 - Caregiver unwilling to provide care
 - Caregiver's partner would not allow care
 - Lack of child care
 - Cultural differences
 - Lack of family or social support
 - Religious objections to care
 - Lack of transportation
 - Caregiver has no phone
 - Limitations of health insurance coverage
 - Multiple health insurance, not coordinated
 - Medical referrals not made
 - Specialist needed, not available
 - Multiple providers, not coordinated
 - Services not available
 - Other, specify:
 4. Did child have a "medical home"? (A home base for any child's medical and non-medical care: it could be a primary care physician, or for a child with complex medical needs, it could be a specialty provider. See Toolkit for additional discussion of Medical Home.)

5. Did the child have a genetics evaluation?
6. Were parents/caregivers assigned a medical social worker and/or a care coordinator to assist them in navigating the complexities of their child's care?

A care coordinator is a person who assists the family to make and coordinate multiple appointments, apply for services, arrange transportation, assist with financial issues, and similar activities. This person may be a government employee or work for a private contract agency. Some but not all service agencies and hospitals provide care coordinators to families. Also, tasks that care coordinators do may vary by agency, location or jurisdiction.

7. Was end-of-life care comparable to standard end-of-life care for any child? If not, why not? If doctors were not allowed by parents/caregivers to give treatment, what was the hospital's protocol/process that allowed parents/caregivers to withhold treatment? Was the process and/or protocol consistent with the laws of the state?

Maltreatment as a Factor

While the number of deaths of children with or without disabilities from maltreatment has been a subject of some disagreement,^v there is no dispute that research shows that children with disabilities^{vi} have a greater risk for abuse and neglect than their typical peers,^{vii} and are more likely to be more seriously injured or harmed.

- Approximately 5-8% of children in the U.S. have disabilities.
- In 2010, 16% of unique victims of maltreatment had disabilities.^{viii} Another population-based study found 31% of children with disabilities had been maltreated.^{ix}
- Children with disabilities are 1.7 - 3.4 times more likely to suffer maltreatment.^x
- Maltreatment is sometimes masked by the disability and missed by school and/or health providers.
- Children with disabilities are 2.9 times more likely to be sexually abused than children without disabilities.^{xi}

Maltreatment also varies by type of disability, and the type of maltreatment varies by the type of disability as well:

- Children with mental illness or intellectual impairments tend to be the most vulnerable, with 4.6 times the risk of sexual violence compared with their peers without disabilities.
- Children with moderate to severe learning difficulties are at 6-7 times the risk of sexual abuse than children without a disability.^{xii}
- A high percentage of deaf adults report being abused as children.^{xiii}
- One study found that 18.5% of children with autism were physically abused and 16.6% had been sexually abused.

There are a variety of reasons children with disabilities experience higher rates of physical abuse. They may be more vulnerable than children without disabilities because of mobility impairments; they may be seen by predators to be more vulnerable; perhaps they can't report abuse because of speech or intellectual disabilities; and, because they need special services, they may be exposed to more non-familial caregivers than non-disabled children.^{xiv}

Children with disabilities are also more vulnerable to neglect because families may lack the resources or supports needed to keep the child healthy and safe; may lack financial resources to get the child to a distant specialty hospital; or lack the coping and other skills needed to respond to the child's condition, comply with medication or other regimens, and/or provide extensive daily physical care.

Therefore, it is important that deaths of children with disabilities or special health care needs be examined carefully for maltreatment indicators. The Case Reporting System questions about deaths from "acts of omission or commission, including poor supervision, child abuse and neglect, assaults, and suicide," are found in Section I. When Section I is completed about omission or commission, the following additional questions can also be considered for a child with a disability.

8. Were signs of abuse, neglect, or illnesses recognized promptly by health, school, and other care providers?
9. Did the child have a medical condition that could lead to symptoms that can be mistakenly identified as evidence of abuse?

10. Were services available to support the parents/caregivers, such as respite care or aides to help in the home? If yes, were parents/caregivers aware of the services? If yes, were parents/caregivers using available services? If no, why not?
11. Did the family have a care coordinator at the time of death?
12. Did caregiver(s) have unmet needs due to disability or chronic illness? (CRS Section B13)? If yes, describe.
13. Consult your state's CPS policy on disability: Is identification of presence of a disability a required element of screening or of safety assessments? Were service needs identified in the screening provided?

Death in Special Situations

Death in foster care or group home – (CRS Section D4, Place of incident is licensed foster care home, relative foster care home, or licensed group home.)

Research shows that about 80% of children in foster care have at least one chronic medical condition; one out of four of those have three or more chronic medical conditions; and around half of all children in the child welfare system have mental health problems that require clinical intervention.^{xv} However, children entering foster care are often not screened for disabilities or health conditions. The American Academy of Pediatrics (AAP) has been very active on this issue and issued a Policy Statement in 2015 describing the problem and setting out core components of effective screening and provision of health services to children in foster care.^{xvi}

14. Were foster parents given sufficient training and supports to care for the child?
15. Was there sufficient oversight of the child by CPS (e.g., visits and other communications from caseworker to assure the child's needs were met)?
16. Was there coordination of care / collaboration between medical care and the assigned social worker/organization that managed the child's case?

17. Was provision of care compromised or complicated because the social worker worked for a contractor rather than the state/county?

Death in institution – (CRS Section D4 is “Other” and is a place where many children live.) Examples would be state or private institutions for individuals with cognitive impairments, or state or private institutions for people with mental illness.

Many people believe that placing children with significant disabilities into institutions will keep them safer than they would be in the family or foster home. However, for several reasons, such as inadequate staffing or staff training, the power differential in institutions, vulnerability to other children, and lax investigations or reporting of abuse, that is not always the case.

18. Was there sufficient supervision of the child?
19. What are the institution’s policies regarding:
- Use of restraint and seclusion
 - Use of prone (facedown) restraints (see *Death in Schools or School Bus*, p. 10)
 - Investigation and reporting of incidents
 - Under what circumstances are reports to police required?
20. Did the institution follow its policies?
21. In the opinion of the team, were the policies sufficient as written to protect children? If not, consider crafting a recommendation to address this issue.
22. What could the institution have done to prevent this death?
23. Was CPS notified of the death by the institution?

Death in jail/detention facility – (CRS Section D4 Place of incident is jail/detention facility.) “Almost 70 percent of children in state and local juvenile justice system have a diagnosable mental health disorder with at least one in five experiencing symptoms so severe that their ability to function is significantly impaired.”^{xvii}

24. Was there a mental health assessment of the child when he/she entered the facility?
25. Was there a physical health assessment of the child when he/she entered the facility?
26. Was the death a result/sequelae of an arrest-related incident? If yes, were the child's special needs/disability viewed as threatening to the officers?
27. What are the jail/detention facility's policies regarding:
 - Use of restraint and seclusion
 - Use of prone (facedown) restraints
 - Investigation and reporting of incidents
28. Did the jail/detention facility follow its policies?
29. In the opinion of the team, were the policies sufficient as written to protect children? If not, consider crafting a recommendation to address this issue.
30. What could the jail/detention facility have done to prevent this death?
31. Was CPS notified of the death in the jail/detention facility? If yes, were services provided in accord with identified needs?

Mental Health Services for Children in Care

Nearly half of all children coming into contact with child welfare agencies nationally have clinically significant emotional or behavioral problems, and 40% to 60% of children in the child welfare system may have a psychiatric diagnosis. All too often there is no continuity of medical and/or mental health services when a child enters care. In addition, many therapists are not trained to deal with the trauma the children have experienced. Unmet mental health needs can have many results, including suicide. There are national standards for screening and assessment of mental health and substance abuse needs of children in foster care that were developed by the AAP and the Child Welfare League of America (see Toolkit). However, one researcher found that “only around half (54.6%) of all children received services consistent with at least 1 national standard; less than one tenth (9.8%) received care consistent with all these standards.”^{xviii}

32. Has your state adopted the standards in the policy statement described above?
33. If your state uses the policy, was it followed?
34. Review the child welfare agency's protocols regarding mental health assessment and needs of children in care and determine if they were followed.
35. In the opinion of the team, are these protocols sufficient to provide adequate care to children in care? If not, consider crafting a recommendation to address this issue.
36. Was there a mental health assessment by the child welfare agency when the child went into care? If yes, were services provided in accord with identified needs?
37. Was there a coordinator of mental health services for the child?
38. Who was involved in provision of mental health services (e.g., parent/caregiver, foster parents, or school counselor)? Were the parents/caregivers and/or foster parents included in provision of mental health treatment?

Death at School or on School Bus

Schools can be a dangerous place for students with disabilities or special health conditions. Children with disabilities that cause behavior issues can result in dangerous discipline. Prone restraint, which is when the child is held down in the facedown position, is one of the most dangerous disciplinary techniques because it can result in decreased oxygen delivery. It is considered so dangerous that some school districts have banned its use. Children with disabilities have also been left alone in seclusion spaces (which might be separate rooms, or even closets), often for significant periods of time. Another danger is the school bus. One study showed that 5% of all students with disabilities who reported sexual abuse identified the school bus driver as the perpetrator.^{xix}

39. Did death take place at school or on school bus? (D 4. Place of incident is school.)

40. If yes, was the child being disciplined at the time? If yes, what are the school's and the school district's policies on restraint and seclusion, particularly on prone restraint and bullying?
41. Are these policies sufficient to protect children with disabilities and special health care needs? If not, consider crafting a recommendation to strengthen/amend the policies.
42. If the child died at the bus stop or on the school bus, had appropriate steps been taken to protect vulnerable children at the bus stop and in the bus?
43. There are models for training teachers, school resource officers and other school employees about alternatives to restraining and secluding children, defusing the situation, etc. Were the teachers, resource officer, and paraprofessional staff who worked with the child trained about alternatives to restraining and secluding children? If not, consider crafting a recommendation to address this issue.

Injury Deaths (CRS Section G, 1-9)

“Children with certain types of disabilities are at a significantly higher risk of injuries than are children without disabilities, but the characteristics of injuries are similar.”^{xx}
The higher risk of injury varies depending on the type of disability. For instance, people with developmental disabilities have a lower risk of homicide, suicide, and poisoning, but a much higher risk of other external injuries, particularly drowning.

44. Was the death from injury a result, in whole or in part, of the child's vulnerability due to disability and/or special health care needs?
45. What if anything could have been done to prevent the death from injury?

What Risk Factors Were Present?

Vulnerability to maltreatment
Paid caregivers (for example, home help workers in the home paid to assist parents/caregivers with care of the child)

Out-of-home care
Medication non-compliance
Prone restraint (being restrained face down on a floor or other surface)
Other restraint and/or seclusion
Unmet mental health needs
Mental health providers not trained to provide trauma-informed care
Poverty of family/economic instability/family functioning level
Distance from primary and specialty medical care

Sample Recommendations

Without knowledge of a state or community and its agencies, services, etc., it is difficult to write sample recommendations with specificity. Every team will need to develop its own detailed recommendations. The following examples, however, might serve to facilitate such discussions.

Recommendations for Policy or Practice Improvement in Child Welfare Agency

Whether a child has a disability and/or special health care needs should be a question asked as part of screening and safety assessment of each child about whom an allegation of abuse or neglect is made. If a disability or special medical need is identified, a process must exist to identify and meet the child's medical or other needs related to the disability or special health care need. The mechanism by which these determinations would be made will vary by state/locale, but here are some samples:

1. That the Child Welfare Agency adopt policy that during determination whether to substantiate an allegation of abuse or neglect and/or during safety assessments, its process must include screening to identify whether the child has a disability or special health care needs.
2. That the Child Welfare Agency adopt policy that all CPS workers are to be trained to recognize and respond to mental health and disability needs in the children they encounter.
3. 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.

Foster Care

4. That the Child Welfare Agency adopt protocol requiring assessment of all children entering foster care for mental health and other disability-specific needs, using evidence-based tool.^{xxi}
5. That the Child Welfare Agency adopt a policy that when a child who has been identified by the agency to have a disability and/or special health care needs enters foster care or any other congregate residential facility, a thorough assessment of the child's mental and physical health needs will be conducted, and the caseworker will be required to assure that the service needs identified in the assessment are met and that the foster family has been appropriately trained and equipped to care for the child.
6. That the Child Welfare Agency adopt a policy that when a child with a physical, mental, or intellectual disability is to be placed with foster parents, the foster parents receive child- and disability-specific training.
7. That the Child Welfare Agency adopt policy requiring provision of age- and needs-appropriate mental health services to all children in foster care identified to need them.

Mental Health Needs of Children in Care

8. That the Child Welfare Agency adopt the policy statement and standards (see Toolkit) for screening and assessment of mental health and substance abuse needs of children in foster care of the American Academy of Child & Adolescent Psychiatry and the Child Welfare League of America or other major child medical group.

Schools/Restraint and Seclusion

9. Local: That the School District adopt a policy prohibiting 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.^{xxii}
10. That the State Education Agency adopt a policy prohibiting the use of prone restraint of students in schools.

11. That the State Education Agency adopt policy 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.
12. That State Education Agency adopt as goal elimination of use of seclusion in schools, and provide staff with prevention tools and training on prevention and intervention skills such as avoiding power struggles and de-escalating situations.

Services for Children and to Support Parents

13. That the relevant agency adopt policy that all early intervention providers and home visitors who go into homes to provide services to children with disabilities and/or special health care needs be trained to recognize signs of neglect and abuse and how to respond if they see anything suspicious, and that the training be included in the agency's training curriculum.
14. That the relevant agency adopt policy that:
 - i. Every newborn with a known disability leave the birth hospital with a care plan and a service/care coordinator to assist with connecting the family to needed services.
 - ii. Parents of a 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 as appropriate.

Jails/Detention Facilities

15. That the relevant agency adopt a policy prohibiting prone (facedown) restraint of all children in jail and/or detention.
16. That the relevant agency adopt a policy requiring that every child be screened upon entry into the jail or detention facility for mental health needs and for physical health needs, in accordance with national standards of the American Academy of Child & Adolescent Psychiatry and Child Welfare League of America (see Toolkit), and that identified service needs to be provided to the child.

17. That the relevant agency adopt policy that it will make greater use of structured risk and needs assessments to direct young offenders with mental health needs to services, evaluate mental health needs of young offenders, provide treatment for substance use disorders, and integrate residential treatment services more closely with community-based aftercare.

Institutions

18. That the relevant agency adopt a policy prohibiting prone (facedown) restraint of all children in institutions that receive funding from the state for the care of such children.
19. That the relevant agency adopt a policy requiring that institutional workers be trained in Trauma Informed Care and in trauma-informed incident management techniques.
20. That the relevant agency adopt clear policy requiring investigation of all potential abuse and requiring notification of police of abuse incidents.

TOOLKIT CONTENTS

PowerPoint

- National Center Presentation on CDR and Children with Disabilities and Special Health Care Needs, October 2015. Presentation based on the work group's work. [http://www.ncfrp.org/about-us/products and publications/](http://www.ncfrp.org/about-us/products-and-publications/)

Children with Disabilities and the Child Welfare System

- Screening, Assessing, Monitoring Outcomes and Using Evidence-Based Interventions to Improve the Well-Being of Children in Child Welfare, February 2014. <http://gucchdtacenter.georgetown.edu/resources/WP2%20-%20Screening%20Assesing%20and%20Monitoring%20508%20v2.pdf>.
- Mental Health Screening and Assessment Tools for Primary Care. AAP. MENTAL HEALTH SCREENING AND ASSESSMENT TOOLS FOR PRIMARY CARE, AAP. Undated. https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf
- Promoting Social and Emotional Well-Being for Children and Youth Receiving Child Welfare Services. U.S. Department of Health and Human Services. 2012. <https://www.acf.hhs.gov/sites/default/files/cb/im1204.pdf>.
- American Academy of Child & Adolescent Psychiatry and Child Welfare League of America. 2003. Policy Statement on Mental Health and Substance Use Screening and Assessment of Children in Foster Care. https://www.aacap.org/aacap/Policy_Statements/2003/Mental_Health_and_Use_of_Alcohol_and_Other_Drugs_Screening_and_Assesment_of_Children_in_Foster_Care.aspx
- Practice Parameters for Developmental and Mental Health Care. AAP District II, New York State, Task Force on Health Care for Children in Foster Care. Fostering Health: Health Care for Children and Adolescents in Foster Care, 2nd edition. 2005. <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Documents/FosteringHealthBook.pdf>.

Children with Disabilities and Services

- HRSA discussion of Medical Home. <http://www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html>

Seclusion and Restraint

- School Is Not Supposed To Hurt. 2012. National Disability Rights Network. http://www.ndrn.org/images/Documents/Resources/Publications/Reports/School_is_Not_Supposed_to_Hurt_3_v7.pdf.

- Promoting Alternatives to the Use of Seclusion and Restraint. Issue brief #1: A National Strategy to Prevent Seclusion and Restraint in Behavioral Health Services. 2010. Rockville, MD: Substance Abuse and Mental Health Services Administration/U.S. Department of Health and Human Services. http://media.samhsa.gov/matrix2/IssueBrief1_B.pdf.
- Alternatives to Seclusion and Restraint in Behavioral Health Care. 2011. http://www.integration.samhsa.gov/clinical-practice/promoting_alternatives_to_seclusion_and_restraint.pdf.
- Roadmap to Seclusion and Restraint Free Mental Health Services. Training curriculum on avoiding seclusion and restraint in mental health services. Available to order or to download. <http://store.samhsa.gov/product/Roadmap-to-Seclusion-and-Restraint-Free-Mental-Health-Services-CD-/SMA06-4055>.

Endnotes

ⁱ Weisleder P. 2013. Family Interventions to Prevent Maltreatment of Children with Disabilities. *Journal of Child Neurology* 26 (8) 1052-1053.

ⁱⁱ SSI definition from 20 CFR 4.6.906

ⁱⁱⁱ From HRSA website.

^{iv} <http://ndrn.org/index.php>

^v Child Maltreatment: Strengthening National Data on Child Fatalities Could Aid in Prevention. 2011. GAO 11-599.

^{vi} The relevant research does not specifically address maltreatment of children receiving Children's Special Health Care Services.

^{vii} The risk and prevention of maltreatment of children with disabilities. 2012. Child Welfare Information Gateway. Children's Bureau/ACYF. Embry RA. 2001. Examination of risk factors for maltreatment of deaf children: Findings from a National Survey. Paper presented at the 7th International Family Violence Research Conference, Portsmouth, NH.

^{viii} Child Maltreatment 2010, US Administration on Children, Youth and Families, USDHHS

^{ix} Sullivan, P.M. & Knutson, J.F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24, 1257-1274.

^x The Risk and Prevention of Maltreatment of Children with Disabilities. (2001. Child Welfare Information Gateway. ACF.DHHS.

^{xi} Sexual Abuse of Children with Disabilities: A National Snapshot. 2013. <http://archive.vera.org/sites/default/files/resources/downloads/sexual-abuse-of-children-with-disabilities-national-snapshot-v2.pdf>.

^{xii} Spencer N, Devereux E, Wallace A, et al. 2005. Disabling conditions and registration for child abuse and neglect: a population-based study. *Pediatrics* 116:609-613.

^{xiii} Forty-five percent of the sample reported some type of abuse, 19% reported caregiver physical abuse, 30% reported residential staff physical abuse, 18% reported sexual abuse, and 9% reported physical neglect. Embry, R.A. 2001, July. Examination of risk factors for maltreatment of deaf children: Findings from a National Survey. Paper presented at the 7th International Family Violence Research Conference, Portsmouth, NH.

^{xiv} One study showed that over 50% of offenders targeting individuals with intellectual disabilities for sexual abuse had contact with their victims through some type of disability service the individual with the disability was receiving. Goldman RL. 1994. Children and youth with intellectual disabilities: Targets for sexual abuse. *International Journal of Disability, Development, and Education*; 41: 89-102.

^{xv} Fostering Health: Health Care for Children and Adolescents in Foster Care. 2005. AAP. Raghavan R, Inoue M, Ettner S, Hamilton B, & Landsverk J. 2010. A preliminary analysis of the receipt of mental health services consistent

with national standards among children in the child welfare system. *American Journal of Public Health*; 100(4): 742-749. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2836330/>.

^{xvi} <http://pediatrics.aappublications.org/content/136/4/e1131>

^{xvii} Children's Defense Fund Mental Health Fact Sheet. March 2010.

^{xviii} Raghavan R, Inoue M, Ettner S, Hamilton B, & Landsverk J. 2010. A preliminary analysis of the receipt of mental health services consistent with national standards among children in the child welfare system. *American Journal of Public Health*; 100(4): 742-749. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2836330/>.

^{xix} Helander E. 2004 *The World of the Defenseless: A Global Overview of the health of maltreated children, effects of interventions, human rights issues and development strategies.*

^{xx} Sinclair S, Xiang H. 2008. Injuries among US children with different types of disabilities. *Am J Public Health*. 2008; 98:1510-1516. doi:10.2105/AJPH.2006.097097

^{xxi} The American Academy of Pediatrics has identified tools for screening children/youths.

^{xxii} Roadmap to Seclusion and Restraint Free Mental Health Services. Training curriculum on avoiding seclusion and restraint in mental health services. Available to order or to download: <http://store.samhsa.gov/product/Roadmap-to-Seclusion-and-Restraint-Free-Mental-Health-Services-CD-/SMA06-4055>.

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The National Center for Fatality Review & Prevention is a program of the Michigan Public Health Institute. The Center is supported in part by Grant No. UG7MC28482 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.