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## **Designing Policy to Serve Children With Special Medical Needs in Child Welfare: Lessons From New York City**

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*Despite the heightened vulnerability of children with special medical needs (CSMN), few child welfare systems have explicit policies, training, or case management procedures designed to ensure their identification and monitor their safety. This study highlights an innovative approach in New York City that aims to enhance staff's ability to work more effectively with CSMN families. The results of these efforts are compelling, and include targeted training of child protective staff, the development of a comprehensive policy for working with CSMN families, and practice changes designed to ensure staff access to medical expertise. Drawing on interviews and focus groups with staff and experts in the field of CSMN, the study describes the challenges that all child welfare agencies face in their efforts to serve CSMN, and provides recommendations for how agencies can design viable policies to address those challenges.*

**KEYWORDS** *policy issues, organizations/systems, child protection, assessment, child maltreatment*

### THE NEED FOR CHILD WELFARE POLICY THAT SERVES CHILDREN WITH SPECIAL MEDICAL NEEDS

Children with special medical needs, or CSMN, present a unique set of practice and policy challenges for child welfare agencies. Compared with their

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peers, CSMN are at higher risk for maltreatment (Crosse, Kaye, & Ratnofsky, 1993; Sullivan & Knutson, 2000), are more likely to experience recurrence of maltreatment (Fluke et al., 2008), and are more likely to be removed from their homes once maltreatment is known (Lightfoot, Hill, & LaLiberte, 2011). The repercussions of maltreatment of CSMN, moreover, are more likely to carry severe consequences, including life-threatening consequences, when compared to healthy children.

In addition to the many vulnerabilities of child welfare-involved children generally, CSMN require a higher and more consistent level of caregiving and are often in situations that demand immediate interventions. Conditions such as severe asthma, HIV infection, cognitive delays, and a host of other maladies may not be readily observed but increase the chances of a child entering an unstable physical state or engaging in unsafe behavior. Moreover, parenting CSMN puts additional stress on caregivers that can go undetected by service providers (Oulton & Heyman, 2009; Spratt et al., 2007). Despite this heightened vulnerability, few child welfare systems have targeted policies, training, or case management procedures designed to ensure the safety of CSMN (Lightfoot & LaLiberte, 2006; Shannon & Tappan, 2011a).

Even the most basic information about the intersection of CSMN with child welfare is unavailable. The size and composition of the CSMN population in the child welfare system is largely unknown because few agencies employ a standard set of criteria for how disabilities are defined and categorized, and many states do not require documentation of special medical conditions when they are encountered (Lightfoot, Hill, & LaLiberte, 2011). According to data reported to the federal government, 11% of U.S. children who were found to be victims of abuse and neglect in 2011 had one or more of the following: learning disability, physical disability, behavioral problem, mental retardation, impaired hearing or vision, or other medical condition (U.S. Department of Health and Human Services, 2012). However, wide disparities among the states suggest discrepancies in identification and documentation practices. For example, while some states—such as Maryland and Massachusetts—report that just 3% of victims of abuse and neglect have a disability, reports from Arizona cite numbers as high as 44%. Targeted studies of CSMN populations suggest the proportion of children involved in child welfare that have health challenges is likely to be significantly greater than the cited average of 11% (Leslie et al., 2002; Stahmer et al., 2005; Fox & McManus, 1996).

Research studies of the CSMN population in child welfare have been focused overwhelmingly on the causes and prevalence of maltreatment among children with disabilities. Few studies have established empirically based policy recommendations for the identification, service provision, and monitoring of this population (Shannon & Tappan, 2011a, 2011b; Stalker & McArthur, 2012). Little is known about the capacity of child welfare agencies

to work with CSMN and their families, successful practices, or what types of interventions policymakers should consider when designing policy for CSMN.

The policy analysis below describes the experience of New York City's child welfare system—The Administration for Children's Services (ACS)—in developing a formal policy for working with families with CSMN. The scope of these efforts are compelling, and include targeted training of child protective staff, the development of a comprehensive policy for working with CSMN families, and practice changes designed to ensure that appropriate medical expertise is available to assist in case planning.

Based on interviews and focus groups conducted with ACS staff as well as with national experts in the intersection of CSMN and child welfare, we describe the myriad challenges—operational, professional, legal, medical, and technological—that child welfare agencies face in their efforts to identify and protect children across the spectrum of medical needs. We describe ACS's efforts to address these challenges, the additional areas of development needed, and the core elements of policy that can guide agencies large and small to strengthen their practice with CSMN.

### Data Sources

Using purposive sampling (Lincoln & Guba, 1985), the authors spoke with a range of stakeholders in the New York City child welfare system, each of whom represent a specific contact point where CSMN are engaged. Semi-structured interviews ( $n = 19$ ) and focus groups ( $n = 5$ ) were held with more than 50 staff from the following groups: 1) ACS executive staff from foster care, preventive services, policy and planning, child and family health and quality improvement divisions; 2) child protection managers and supervisors; 3) medical consultants based in the local offices; 4) forensic nurses who evaluate children who have been removed from their homes; 5) foster care and preventive agency medical directors and leadership; 6) medical facility social workers and administrators. The authors also reviewed policy documents, training materials, and other relevant documents. To better understand how the agency collects, stores, and analyzes health data, the team reviewed administrative data entry forms and database screens, as well as aggregate quantitative data.

In addition, semi-structured interviews were conducted by phone with eleven national experts working in the field of CSMN and child welfare research as well as with staff from two state systems. A review of research and snowball sampling was used to identify participants who could speak to other states' approaches to tracking and monitoring CSMN. The experts represent a range of disciplines, geographic areas, and policy perspectives—from public health practitioners and child welfare officials to scholarly experts and child health advocates.

While there is no consensus on a precise definition of special medical needs, we refer here to moderate to severe physical, developmental, or behavioral disabilities that require adult care to address. Stakeholders in the child welfare, healthcare and research communities do not share a standard definition for “children with special needs” or “children with disabilities” or “medically fragile children.” The relevant factor shared among these concepts is that all types of special medical needs put stress on both parents and the child and require special services.

### THE BARRIERS TO SERVING FAMILIES WITH CSMN IN CHILD WELFARE

Interviews with national experts conducted as part of this study found that few states or localities have child welfare policies specific to CSMN. There are many explanations for this anomaly. Staff on the frontline of child welfare investigations, known as child protection workers, are typically not trained to identify and assess medical conditions (American Academy of Pediatrics: Committee on Child Abuse and Neglect and Committee on Children with Disabilities, 2001; Hibbard & Desch, 2007). Traditionally, child protection training for investigators, judges, attorneys, and other stakeholders focuses on the fitness of the parent, with special attention paid to caregiver characteristics that triggered system involvement such as substance abuse and mental health issues. Personnel in the child welfare system, moreover, work under intense time pressures with families who may have several children and who face multiple challenges—including immediate safety risks that are unrelated to health (Smith & Donovan, 2003).

In addition to limited training and policy guidance regarding CSMN, child welfare staff work with caregivers who may have their own cognitive disabilities and have a limited understanding of their children’s diagnosis (Azar & Read, 2009). In some situations, special medical conditions may be undiagnosed when a child welfare case is opened. Among caregivers who are knowledgeable of their child’s diagnosis, some are reluctant or embarrassed to reveal this information or may be in denial of its severity (Forrester, Westlake, & Glynn, 2012). According to ACS staff interviewed for this study, families may not share information because they have reasonable fears that ACS or the courts may use medical information against them.

Access to medical personnel and records is of particular importance when special medical needs are not obvious or a CSMN is not the subject of the report. However, child protection services (CPS) in New York City report that they often receive limited or inaccurate information from providers, and the process for obtaining medical records is usually arduous and time consuming. Many providers are unaware of ACS’s right to access records without Health Insurance Portability and Accountability Act (HIPAA) consent.<sup>1</sup> The

process is further complicated by the fact that child welfare-involved families often obtain medical care at local clinics that have a revolving set of physicians, or in emergency rooms. Additionally, repeated moves due to unstable housing situations can also result in frequent changes in medical providers.

These conditions create weighty challenges for child welfare staff that can have tragic consequences. In some cases, CPS workers may misinterpret conditions in ways that lead them to inaccurately substantiate maltreatment (Hibbard & Desch, 2007). CPS workers may mistake symptoms of medical conditions, such as hemophilia that leads to frequent bruising or orthopedic conditions that lead to easily broken bones, for child maltreatment. Parents of CSMN often face intense financial, emotional, and social stressors that may lead to behaviors that investigators interpret as overly defensive, aggressive, depressed, or uncaring—and these interpretations may contribute to determinations that a child is maltreated without attention to the types of support parents need to successfully care for their children's special needs (Kuhlthau et al., 2010).

Alternatively, CPS workers without the proper training or supports may *underestimate* the extent of risk and safety concerns faced by CSMN (Manders & Stoneman, 2009). An unsanitary environment for a typical child may present only minor risks that do not put a child in imminent danger. The same environment for a child with an autoimmune disorder, however, may be life-threatening. An inattentive parent of a typical child may appear to need parenting classes and perhaps mental health treatment, but the imminent danger to a typical child is often minimal or nonexistent. For a child with a severe cognitive delay or a tracheotomy, caregiver inattention can create threats that need to be immediately addressed.

Emergency removals from the home, in which staff must create service plans immediately and have little time to gather extensive information about families, point to another set of risks and challenges. When CPS workers are not privy to information about medication routines or special provisions needed for medical care, placement homes may be unsuitable, or more seriously, the children's health may be endangered. Interviews with ACS and provider staff reveal that when children are removed in emergencies it is not unusual for information pertaining to health conditions to emerge *after* children are placed in foster homes.

#### LESSONS TO GUIDE CSMN POLICY: THE NEW YORK CITY EXPERIENCE

As is often the case in child welfare agencies across the globe, the death of a child in New York City spurred reforms. In September 2010, a 4-year-old girl with a trachea tube and other special medical needs died in

her home in Brooklyn. At the time of the fatality, the family was receiving preventive services as part of an open child protective case. The case opened due to the mother's substance use, which was identified at the birth of the child's younger brother. The nonprofit agency providing preventive services to the family under contract to ACS did not document the girl's medical condition in its case notes even though she was medically fragile and had resided in medical facilities for most of her life. The subsequent criminal investigation determined that the child's death was a result of her mother's and grandmother's abuse and neglect; the mother was convicted of murder and her grandmother convicted of manslaughter (Associated Press, 2012).

After an extensive review, ACS's Division of Child Protection implemented its first ever policy for cases involving CSMN in March 2012, entitled "Assessment and Safety Planning with Special Medical Needs Children."<sup>2</sup> The implementation of the policy, which took place over the course of several months, changed the process for conducting investigations involving families with CSMN in fundamental ways. As the largest child welfare agency in the United States, it is no small task for ACS to implement sweeping reforms. Each year, ACS conducts more than 55,000 investigations of child maltreatment involving more than 90,000 children (New York City Administration for Children's Services, 2013). Discussions with CPS staff indicated high levels of support for the policy among CPS and a substantial increase in the identification and documentation of CSMN.

ACS's new approach to working with CSMN has several interlocking components: 1) policy guidelines for case management practice; 2) staff training; 3) availability of medical expertise to consult on cases; and 4) a team-based case management process.

## The Policy

Prior to the initiation of ACS's new policy, the Division of Child Protection (DCP) required staff to survey homes for the presence of CSMN and to assess the ability of the parent to protect the child's safety as part of routine investigative practice. The new policy articulates these actions in more explicit language and mandates specific procedures. It reads:

DCP staff is required to screen every child that comes to their attention to determine if the child is a special medical needs child. Staff is then required to assess the care that the special medical needs child is receiving to determine if the caretaker has the capacity and the services to meet the child's healthcare and medical needs. When a child's needs are not being met, staff is required to act quickly to assist the caretaker with obtaining the required services and implement safety interventions to keep the child safe. (New York City Administration for Children's Services, 2012b, p. 1)<sup>2</sup>

The policy includes a host of procedures and expectations for work with CSMN including requirements for ongoing contact with service providers and the use of developmental assessment tools. CPS workers must also adhere to documentation standards that include detailed information about the child's medical condition, treatment plan, and providers' contact information.

Of special importance is the policy's designation of a clear case management process that calls for unique treatment of CSMN cases. Specifically, when an intake worker or CPS worker determines that a special medical need may exist, an alert is sent to the Child Protective Manager (the unit supervisor) and the case is assigned a second worker called a "Special Medical Needs Coordinator," who has additional training and experience in the coordination and supervision of CSMN cases (described in following text). The Coordinator, along with a nurse practitioner, meets with the CPS worker to support their handling of the investigation. Another core part of the policy is its emphasis on steps CPS workers must take to solicit health information about the presence of special medical conditions and caregiver capacity to manage those conditions as part of routine safety assessments, skills that were emphasized in the CSMN training mandated for all staff.

### Staff Training

ACS leaders hoped that investments in staff training would help staff become oriented to the importance of CSMN identification, boost their abilities to assess and act on health information, and increase their confidence in dealing with health issues. Because ACS was unable to identify any existing curricula on the topic, the agency contracted for the development of a curriculum on CSMN for use in staff training. Following the curriculum's completion in 2011, ACS trained every member of its child protective division—more than 2,000 child protective staff and managers—and made the training a standard requirement for new workers (New York City Administration for Children's Services, 2012a). The training covered strategies for how CPS workers should solicit information from parents and how to recognize particular indicators of CSMN, such as the presence of equipment, medications, or frequent injuries and hospitalizations. The training also provided instruction for what to look for in assessing the safety risks associated with special medical needs, including the level of stability of the condition, the capacity of caretakers to manage the child's health needs, and the appropriateness of the physical home environment. Workers also learned how various safety risks not related to the medical condition itself (e.g., parental substance abuse or mental illness) can put CSMN at higher risk of harm compared to typical children in the same families.

The need for CPS worker training in CSMN, as well as CPS workers' interest in receiving specialized training, has been well documented by child welfare researchers (Bonner, Crow, & Hensley, 1997; Orelove, Hollahan, &



Myles, 2000; Shannon & Tappan, 2011). Prior research suggests that training should educate staff about the different types of special medical needs, the importance of CSMN identification to child safety, and strategies for accessing health information in the home and throughout the life of the case (Child Welfare Information Gateway, 2012; Shannon & Tappan, 2011).

### Incorporating Medical Expertise Into Investigations

Prior to the development of the new CSMN policy, ACS had contracted with a pediatric hospital to provide nurse practitioners, called “Medical Consultants,” to work alongside CPS workers in the investigative offices. In the past, CPS workers initiated case consultations on a voluntary basis. Because the new ACS policy mandates that CPS workers coordinate with medical consultants on all cases involving confirmed or suspected special medical needs, the agency expanded the number of nursing staff to meet the increased demand.

The medical consultants are available to work with CPS workers to help identify conditions and interpret health information, as well as to establish the appropriate set of actions to alleviate the potential for harm. Their role is to help CPS workers identify the potential for immediate and longer term safety risks, distinguish between the varying levels of CSMN vulnerability, and to ensure the best agency response. For example, children with autism, asthma, developmental delays, or diabetes have medical issues that range from mild to severe, and may be in a stable or unstable physical state. Despite having the same medical condition, some children may require more monitoring than others.

Importantly, the medical consultants are based locally in the CPS offices so that consults can take place in person, on short notice. Some child welfare agencies have used co-located nurses to assist in the monitoring of the health of children in foster care as well as advocate for their needs (Kiwunuka, Boyar, & Jensen, 2013; Schneiderman, 2007). In some states, medical staff help to obtain medical records and make appointments. In Utah and New Jersey, for example, nurse practitioners are involved in all aspects of health assessment, coordination, tracking, and monitoring for children in foster care.<sup>3</sup>

### Team-Based Approach

To ensure strong execution of the new policy, ACS created the new staff role, “Special Medical Needs Coordinator,” which adds additional capacity and expertise to these challenging cases. Four staff members—the Coordinator, CPS worker, unit supervisor, and the medical consultant—work together as a team to guide the identification, safety assessment, and service planning for CSMN. Decisions about service assignments (such as to specialized preventive programs or home visiting programs) are made collaboratively. In

addition, health information gathered is documented by each of the team members and later transferred onto the preventive or foster care agency if contract agency services are requested.

ACS's team based approach is intended to provide extra support to the CPS worker, who may have limited time or depth of experience to address the health matters in the case, and adds new layers of oversight and supervisory authority to these challenging cases. Like other team-based decision making models, having nurses, caseworkers, and supervisors work side-by-side facilitates the sharing of medical and social work expertise to create more comprehensive service plans that can address the special circumstances of CSMN (Crea, 2010; Nouwen, Decuyper, & Put, 2012).

### ADDITIONAL NEEDS AND OPPORTUNITIES FOR CSMN POLICY

ACS's experience implementing the CSMN policy revealed additional challenges. These challenges resonated with national experts as issues child welfare systems typically struggle to address in their work with CSMN. Presenting issues include use of and access to data systems, defining the population of CSMN, system capacity and performance and cross system practice coordination. This section describes these issues and considers how policies that address CSMN in child welfare may extend beyond the initial stage of investigation.

#### High Quality Data Systems

The ability of staff to access, track and share health information was a challenge raised consistently among the experts and staff interviewed. ACS and contract agency staff expressed frustration at the lack of a central database repository for health information, which would enable them to locate health data and medical provider contact information that might have been collected in prior investigations or consultations. Information stored in a central repository where it is accessible to multiple parties saves workers time, reduces duplication, and helps ensure that a concern known to one worker in one part of the system does not go unnoticed by another—a particularly important benefit given the high turnover rates of child welfare staff generally (Curry et al., 2005).

As part of ACS's new policy, child health information is documented by all staff involved in the investigation: the CPS worker, the Special Medical Needs Coordinator, and the medical consultants. As a result, the agency can now track how many CSMN children are involved in child welfare investigations, where they live, and their diagnoses. At the time this research was conducted, these data are stored on individual spreadsheets or narrative

documents and not accessible to staff across roles. ACS is currently assessing ways to keep information in standard, centralized formats that can be easily accessed from other divisions or agencies and that meets legal requirements concerning the confidentiality of medical data.

In New York City, developing a centralized repository of data is a challenge. New York's Statewide Automated Child Welfare Information System (SACWIS), Connections (CNNX), includes limited screens for inputting health information. The diagnoses and medication codes used by CNNX, however, are not consistent with codes used for Medicaid reimbursement, and thus are rarely completed by contracted foster care and preventive service providers who would have to double enter every diagnosis.

Furthermore, CNNX cannot accept attachments such as psychological assessments or lab reports. CNNX incorporates HIPAA-related authorization rules that limit the types of staff who can access health information. CPS workers, for example, are not allowed access to the health information, which must be stored in narrative format in CNNX. Narrative information cannot be easily aggregated or identified quickly by other users working on the case. Because CNNX is a state supervised system of record, it is difficult for ACS to design changes to how data is stored and used when new policies call for innovation.

In addition to the many advantages for practitioners working with CSMN, cross-user tracking and storage capacity make it possible for agency leaders to obtain reliable aggregate reports on the number of children with specific conditions, their locations, and their treatment that can guide policy and resource allocations (Bonner, Crow, & Hensley, 1997; Shannon & Agorastou, 2006). ACS managers are not able to generate comprehensive reports regarding the scope of the CSMN population, the prevalence of particular conditions, or the locations of CSMN residential or hospital providers. As a result, learning about a specific trend requires staff in ACS's health division to assemble data from hand counts, data kept by private contract agencies, or other sources—a process that is expensive and time consuming.

These challenges are not unique to New York City. In many jurisdictions, CPS workers are not required to document information about CSMN as part of their routine work requirements. In one study of child protection agencies in 50 states, researchers found that only 14 states (28%) require the documentation of specific disabilities, and only 31 states (62%) indicated that disability-related information could be documented in the narrative section of the report form used in their state, although this information was not required (Shannon & Agorastou, 2006).

One promising practice in New York City is the growing use of electronic health records systems by foster care agencies, which have the potential to be used in all parts of the system. Advocates emphasize the potential to link to Medicaid reimbursement systems and state immunization records, as well as to standardize electronic assessment templates. In addition, when

children are transferred from one agency to another, medical records could be easily moved with the child. Audits could be conducted remotely instead of on site, increasing audit capacity by reducing travel costs. Electronic records are more easily and reliably stored than paper records, which is especially advantageous for children with long foster care histories or who transition out of foster care.

### Defining the Population

The new ACS policy defines a special medical needs child as “a child with a significant injury, congenital disorder, or any other diagnosis or medical condition that results in an unstable physical state” (New York City Administration for Children’s Services, 2012b, p. 2). In the early months of implementation, ACS staff struggled with the challenge of how to define which CSMN condition along the continuum of conditions fell under the purview of the policy, particularly given the high prevalence of certain chronic conditions in the ACS-served population, such as asthma and diabetes, which may or may not require immediate intervention. Medical consultants were more likely than CPS workers to define the boundaries of the policy through a medical lens, assessing risk in terms of the physical or emotional *stability* of the child. As the policy became more firmly incorporated into case practice, managers worked with the staff to establish where the definition of CSMN begins and ends in real practice decision-making.

Experts believe agencies should conceptualize medical assessment as an iterative process—particularly for children in foster care—that measures the acuity of a child’s medical condition through ongoing assessments. This approach incorporates the fluid nature of medical conditions, which often change as children undergo procedures, recover from illnesses, or begin new therapies. It also recognizes that a condition may be severe in one child and manageable in another. Best practices from other jurisdictions include Utah’s “acuity scoring system” for all foster care cases that differentiate between children in need of ongoing monitoring and those whose health needs are less severe.<sup>4</sup>

Indeed, how broad or narrow an agency defines its CSMN purview has real fiscal implications that must align with the agency’s ability to manage the scope of cases resulting from the classification system, as well as the availability of local services to address particular special needs. Our research suggests that employing a broad definition in order to protect as many children as possible is often in tension with limited resources.

### System Capacity and Performance

In addition, experts recommended policy approaches should take into account all parts of the child welfare system that serve CSMN, as well as the

healthcare providers and other agencies with which CSMN and their families interact. By and large, the ACS approach focuses on the investigative stage of system involvement. Training is not currently offered to staff outside of the Division of Child Protection.

At the time this study was conducted, the impact of the policy on the demand for CSMN services and the ability to meet that demand was unknown. New York City's system is unique in that it is home to a wide array of specialized foster care and paid preventive service programs with whom ACS contracts for its CSMN population. These programs tend to have significant case management resources compared to traditional agencies: smaller staff-child ratio, onsite doctors and nurses, higher wages and lower staff turnover. Staff overall have a higher level of skill in their ability to monitor medical risks and conditions, navigate the healthcare system, and advocate for CSMN and their families.

ACS and provider staff, however, raised the concern that the requirements for performance monitoring for contracted agencies need to be more robust, and the quality of available services for families with CSMN should be evaluated in depth to ensure high standards of care. In addition, stakeholders called for policies and practices to assess and develop capacity among providers to work with special populations of CSMN.

### Cross-System Practice Coordination

CSMN families are served and impacted by multiple agencies and organizations outside of the child welfare system, including Medicaid clinics and case managers, skilled nursing facilities, hospitals, income maintenance and other government agencies, and community-based organizations. Our research revealed gaps in communication between ACS and healthcare facility staff that, like child protective staff, work under intense time pressures and heavy workloads. Often staff on each side are not aware of the other's role or responsibilities, and the policies and conditions under which they work. Key information such as medical information, discharge plans and schedule, safety concerns regarding caregiver capacity, court documentation, parental rights and consent issues is often not shared. As a result, the overlapping missions of the two systems are often undermined. Finding ways to align system efforts can help ensure that case management and long term discharge planning is done effectively.

## DISCUSSION

This study describes the multiple challenges child welfare agencies face in their efforts to identify, monitor, track, and support the special medical needs of children in their care. Child welfare staff work under conditions that make

it difficult to address the health risks of children, especially when those risks are not visible or known. New York City's new approach to working with families with CSMN is compelling because it addresses multiple facets of the operational environment. Along with in-depth staff training, ACS's targeted policy is intended to ensure CSMN issues are part and parcel of safety and risk assessments. The policy establishes a clear set of procedures to facilitate timely identification, including the use of nurse practitioners located in the office to interpret complex health information and recommend service options. CSMN cases are further overseen and coordinated by a CSMN Coordinator, who provides extra decision-making and case management support to CPS workers.

ACS's experience demonstrates the real potential for child welfare agencies to address key challenges in working with families with CSMN and offers viable strategies that can guide policy development in other jurisdictions. Child welfare policymakers should heed some caution, however, in gleaning lessons from ACS's experience in light of several limitations of this study. At the time of data collection, ACS's new policy was in the first few months of implementation—too soon to study the policy's long-term impact on child safety and maltreatment prevention. The study did not evaluate the experience of workers with the new policy, or the degree to which the policy was implemented faithfully, or whether ACS leadership sustained its commitment to support and regulate the policy over time. Nor did we have the opportunity to talk with families who are the recipients of the new policy and understand their experience.

It is also important to consider the ways ACS's experience may not be easily extrapolated to other settings. As New York State is a county-based system, ACS can act independently of the state in ways other agencies cannot. The population ACS serves is larger, more urban, and more geographically dense than most other municipalities. In addition, agencies of the size and capacity of the ACS often have greater ability than smaller agencies to command the resources needed to conduct staff trainings and expand its ranks of specialized staff. We recognize that the resources needed to contract nursing staff, for example, may fall beyond the reach of other jurisdictions, as wide disparities exist in the levels of state and federal financing local systems receive.

Most importantly, the need of the ACS to respond to the high profile death of a medically fragile child in its care was a key facilitating factor of this reform initiative. Though homicides among system-involved children are extremely rare, high profile deaths that capture the imagination of the community invariably force agencies to address weaknesses in their practice. The tragedy forced the agency to implement sweeping operational improvements in a short period of time. The event also enabled ACS to shore up the political will and staff buy-in that make far-reaching, resource-intensive reforms of this scale possible.

At the same time, the New York City case highlights the challenges that *all* child welfare agencies face in their work with CSMN and provides a compelling approach to resolving many of those challenges. Lessons from ACS are especially valuable in context of the dearth of information available about promising practices in the field and the lack of a common language for describing the CSMN population in child welfare. As our research suggests, most child welfare agencies are poorly informed about the weaknesses in their ability to identify CSMN, or the scope of the demand for CSMN services in their community.

The findings presented here suggest several opportunities for future research to look more closely at the potential for innovative strategies in the field. Additional research is needed to understand how the New York City policy will impact the safety, permanency and health of CSMN, how staff are managing the new requirements, and the degree to which such strategies can be replicated elsewhere. Research is also needed to assess staff training curricula in New York City and other jurisdictions, including training availability, quality, and impact on staff practice. Researchers and policymakers alike should consider ways to address the crucial challenges that go beyond the purview of ACS's recent efforts, such as the need for high-quality data systems that allow for ongoing data sharing and trends analysis, as well as the need to coordinate cross-divisional, cross-agency, and cross-system approaches to serving families with CSMN. Finally, more research is needed that can help assess how particular practices are more or less relevant to particular types of disabilities. Learning disabilities, for example, require distinct assessment and case management strategies that may not resemble those needed to address other medical conditions.

## CONCLUSION

Child welfare agencies have a great deal of work ahead to strengthen their practice with children who have special medical needs. It is anticipated that the findings presented here can provide a roadmap for thinking about how policymakers can approach this work in order to ensure the needs of this exceptionally vulnerable population and their families are met effectively.

## NOTES

1. Sections 160.203, 164.502(g) (5), and 164.512 of HIPAA have regulations that pertain to child abuse and neglect investigations. For more information, see Davidson (2003).
2. In response to the child's death, ACS appointed a panel of experts to guide the agency's response to the tragedy, which comprised service providers, child welfare experts, agency

- staff, and advocates and leaders from the community of child healthcare providers. The panel, ACS, and the city's elected Public Advocate issued a joint report with recommendations for reforms (see New York City Administration for Children's Services, 2011).
3. The authors learned about these programs through their interviews with national experts and program directors using the model. Information about Utah's Fostering Healthy Children Program can be found at <http://health.utah.gov/cshcn/FHCP/> and information about the Child Health Program in New Jersey can be found at <http://www.fxbcenter.org/childwelfare/nursing.html>
  4. This information was drawn from interviews with national experts and program directors. Information about Utah's Fostering Healthy Children Program can be found at <http://health.utah.gov/cshcn/FHCP/>

## REFERENCES

- American Academy of Pediatrics: Committee on Child Abuse and Neglect and Committee on Children with Disabilities. (2001). Assessment of maltreatment of children with disabilities. *Pediatrics*, *108*(2), 508–512.
- Associated Press. (2012, June 6). Prison term for mother of a girl, 4, found dead. *The New York Times*. Retrieved from <http://www.nytimes.com/2012/06/07/nyregion/mother-gets-prison-term-in-marchella-pierces-death.html>
- Azar, S. T., & Read, K. N. (2009). Parental cognitive disabilities and child protection services: The need for human capacity building. *Journal of Sociology & Social Welfare*, *36*(4), 127–151.
- Bonner, B. L., Crow, S. M., & Hensley, L. D. (1997). State efforts to identify maltreated children with disabilities: A follow-up study. *Child Maltreatment*, *2*(1), 52–60.
- Child Welfare Information Gateway. (2012). *The risk and prevention of maltreatment of children with disabilities*. Washington, DC: U.S. Department of Health and Human Services, Children's Bureau. Retrieved from <https://www.childwelfare.gov/pubs/prevenres/focus/focus.pdf>
- Crea, T. M. (2010). Balanced decision making in child welfare: Structured processes informed by multiple perspectives. *Administration in Social Work*, *34*(2), 196–212.
- Crosse, S., Kaye, E., & Ratnofsky, A. (1993). *A report on the maltreatment of children with disabilities*. Washington, DC: National Center on Child Abuse and Neglect.
- Curry, D., McCarragher, T., & Dellmann-Jenkins, M. (2005). Training, transfer, and turnover: Exploring the relationship among transfer of learning factors and staff retention in child welfare. *Children and Youth Services Review*, *27*(8), 931–948.
- Davidson, H. (2003). The impact of HIPAA on child abuse and neglect cases. *Child Law Practice*, *22*(1), 11–13.
- Fluke, J. D., Shusterman, G. R., Hollinshead, D. M., & Yuan, Y. T. (2008). Longitudinal analysis of repeated child abuse reporting and victimization: Multistate analysis of associated factors. *Child Maltreatment*, *13*(1), 76–88.
- Forrester, D., Westlake, D., & Glynn, G. (2012). Parental resistance and social worker skills: Towards a theory of motivational social work. *Child & Family Social Work*, *17*(2), 118–129.
- Fox, H. B., & McManus, M. A. (1996). *The effect of managed carer on Medicaid financing for public programs serving children with special health needs*. Washington, DC: Maternal & Child Health Policy Research Center.



- Hibbard, R. A., & Desch, L. W. (2007). Maltreatment of children with disabilities. *Pediatrics*, *119*(5), 1018–1025.
- Kiwanuka, A., Boyar, V., & Jensen, M. (2013). A nursing brief: Emerging best practice in Department of Children and Families Nursing. *Pediatric Nursing*, *39*(1), 28–36.
- Kuhlthau, K., Kahn, R., Hill, K. S., Gnanasekaran, S., & Ettner, S. L. (2010). The well-being of parental caregivers of children with activity limitations. *Maternal and Child Health Journal*, *14*(2), 155–163.
- Leslie, L. K., Gordon, J. N., Ganger, W., & Gist, K. (2002). Developmental delay in young children in child welfare by initial placement type. *Infant Mental Health Journal*, *23*(5), 496–516.
- Lightfoot, E. B., & LaLiberte, T. L. (2006). Approaches to child protection case management for cases involving people with disabilities. *Child Abuse & Neglect*, *30*(4), 381–391.
- Lightfoot, E. B., Hill, K., & LaLiberte, T. L. (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. *Children & Youth Services Review*, *33*(11), 2069–2075.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (vol. 75). Newbury Park, CA: SAGE Publications, Inc.
- Manders, J. E., & Stoneman, Z. (2009). Children with disabilities in the child protective services system: An analog study of investigation and case management. *Child Abuse and Neglect*, *33*(4), 229–237.
- New York City Administration for Children's Services. (2011). *Children's Services Planning Group Final Report, issued by ACS on March 31, 2011*. [internal document]. New York, NY: Author.
- New York City Administration for Children's Services. (2012a, January). *Special medical needs training curriculum* [internal document]. New York, NY: Author.
- New York City Administration for Children's Services. (2012b, March 29). *Assessment and safety planning with special medical needs children* [internal document]. New York, NY: Author.
- New York City Administration for Children's Services. (2013). *Statistics and links*. Retrieved from [http://www.nyc.gov/html/acs/html/statistics/statistics\\_links.shtml](http://www.nyc.gov/html/acs/html/statistics/statistics_links.shtml)
- Nouwen, E., Decuyper, S., & Put, J. (2012). Team decision making in child welfare. *Children & Youth Services Review*, *34*(10), 2101–2116.
- Orelove, F. P., Hollahan, D. J., & Myles K. T. (2000). Maltreatment of children with disabilities: Training needs for a collaborative response. *Child Abuse and Neglect*, *24*(2), 185–194.
- Oulton, K., & Heyman, B. (2009). Devoted protection: How parents of children with severe learning disabilities manage risks. *Health, Risk & Society*, *11*(4), 303–319.
- Schneiderman, J. U. (2006). Innovative pediatric nursing role: Public health nurses in child welfare. *Pediatric Nursing*, *32*(4), 317–323.
- Shannon, P., & Agorastou, M. (2006). Identifying children with developmental disabilities receiving child protection services: A national survey of child welfare administrators. *Families in Society*, *87*(3), 351–357.
- Shannon, P., & Tappan, C. (2011a). A qualitative analysis of child protective services practice with children with developmental disabilities. *Children & Youth Services Review*, *33*(9), 1469–1475.
- Shannon, P., & Tappan, C. (2011b). Identification and assessment of children with developmental disabilities in child welfare. *Social Work*, *56*(4), 297–305.

- Smith, B. D., & Donovan, S. E. (2003). Child welfare practice in organizational and institutional context. *Social Service Review*, 77(4), 541–563.
- Spratt, E. G., Saylor, C. F., & Macias, M. M. (2007). Assessing parenting stress in multiple samples of children with special needs (CSN). *Families, Systems, & Health*, 25(4), 435–449.
- Stalker, K., & McArthur, K. (2012). Child abuse, child protection and disabled children: A review of recent research. *Child Abuse Review*, 21(1), 24–40.
- Stahmer, A. C., Laurel, L. K., Hurlburt, M., Barth, R. P., Webb, M. B., Landsverk, J., & Zhang, J. (2005). Developmental and behavioral needs and service use for young children in child welfare. *Pediatrics*, 116(4), 891–900.
- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257–1273.
- U.S. Department of Health and Human Services. (2012). *Child maltreatment 2011*. Retrieved from <http://www.acf.hhs.gov/programs/cb/research-data-technology/statistics-research/child-maltreatment>

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