CHILD WELFARE REVIEW COMMITTEE FOR THE DEATH AND NEAR DEATH OF CHILDREN WITH DISABILITIES

JANUARY 2019

ACKNOWLEDGEMENTS

The members of the Committee wish to express their gratitude to Lisa Smith, Annette Jacobi, and Michael Walsh for the professional assistance they provided to the Committee and their sincere interest in and concern for the children of our State. The members of the Committee also wish to express gratitude to the Legislature and the Governor for creating and empowering the Committee for this work and to the appointing authorities who selected dedicated members to serve on the Committee.

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COMMITTEE HISTORY

DEAR READER,

This is the Final Report of the Child Welfare Review Committee for the Death and Near Death of Children with Disabilities. The Review Committee was created in response to the deaths caused by abuse or neglect of two teenaged children with significant disabilities. In both cases the system or systems with a responsibility to provide services to these children failed.

The Committee was established by an Act of the Oklahoma Legislature in 2016. Section 1 of Enrolled House Bill 2971 was codified in 10A O.S. § 1-10-103. The Act also amended 10A O.S. § 1-6-103, making otherwise confidential Department of Human Services agency records available, without a court order, to any member of the Committee pursuant to their lawful duties. This Report does not contain any confidential or protected information.

This Committee was created to study cases where children with disabilities with previous child welfare involvement or who were in the custody or under the care of the Department of Human Services died or nearly died from abuse or neglect and to make recommendations to address any systemic issues that may have contributed to the tragic outcomes. Members of the Committee reviewed the confidential case files related to the death or near death of 12 children with disabilities. In all cases a person outside the home was aware and in a position to intervene but failed to do so.

Of the cases reviewed, the Committee believes that in all but one case the outcome may have been different if its recommendations had been in place at the time. Some reforms were implemented prior to the creation of the Committee. Members of the Committee believe that some children likely would have been saved if these reforms had already been in place. In one-third of the cases a medical provider had sufficient information to suspect abuse or neglect. In 6 cases a child was not attending school after a report to DHS was made where the child ultimately died from abuse or neglect. There were other cases in which it could not be determined if the child was in school. Half of the children were malnourished, often suffering for months before succumbing.

The members of the Committee hold that children with disabilities possess the same inherent value and rights as do all children. Members of the Committee viewed their work through that lens. To protect these children, extra effort is required to ensure their education, medical needs and well-being. Members of the Committee were often in disbelief when reviewing case files at the willingness of adults to overlook the horrific and yet preventable circumstances contributing to the deaths of these children.

The Committee is comprised of ten volunteer citizens with relevant experience, knowledge, or interests. Administrative support for the Committee was efficiently and effectively provided by the staff of the Oklahoma Commission on Children and Youth and the Department of Human Services.

The Committee was set to sunset December 31, 2018, however the report was completed in January 2019. This Report is the culmination of months of dedication and hard work by the members and the support staff of the Committee.

This Report is respectfully submitted pursuant to the requirements of state law.

Mary Ellen Stockett, MD
Chair, Child Welfare Review Committee for the
Death and Near Death of Children With Disabilities

OVERVIEW OF RECOMMENDATIONS

Children with disabilities are at increased risk of experiencing abuse or neglect. In fact, some research indicates children with disabilities experience abuse and neglect at rates nearly twice that of children without disabilities.[1] However, by most researchers' estimates, underreporting of instances of maltreatment is a large concern, partly due to the difficulty in identifying abuse among these children. Depending on the child's diagnosis and physical abilities, the child may be particularly vulnerable to abuse, neglect, and medical neglect. If not identified early, children with disabilities may experience long-term harm associated with maltreatment, including exacerbation of existing disabilities, additional permanent disabilities, and death.[2]

In 2016, House Bill 2971 established the Child Welfare Review Committee for the Death and Near Death of Children with

Disabilities. Staffed by the Oklahoma Commission on Children and Youth (OCCY), the Review Board reviewed case files associated with children diagnosed with disabilities or thought to have a disability and died. These children had previous child welfare involvement. The Review Board examined the events that took place leading up to the death, identified contributing factors and systemic failures, and made recommendations.

The most effective analysis identifies systemic root-causes associated with the reasons a family fails and the missing supports that contribute to the abuse, neglect and medical neglect of the child.

Preventative and family-centered interventions are needed before a crisis happens. There must be recognition of the exceptional vulnerability of these children and the need for commensurate support.

FAMILY PERSPECTIVE

Two parents raising children with significant intellectual disabilities and life limiting diagnoses were appointed to the Review Board to ensure family perspective was included in the case review and recommendations process. The parent members have life experience with systems of care for children with disabilities as well as extensive interactions with pediatric specialists, the Oklahoma Department of Human Services (DHS), Medicaid, and the public school system. Furthermore, both work as professional disability advocates in family support programs and public policy.

From the family perspective, a significant concern about the cases reviewed is the assumption a disability diagnosis leads to death. Frequently, the cases reviewed involved a deceased child who died with a disability diagnosis of, for example, cerebral palsy (CP). Medical professionals, social workers and educators presumed indications of malnutrition, bruising and lethargy were typical of a CP diagnosis even though CP is rarely fatal. With proper hygiene, nutrition, assistive technology and consistent medical care, people with CP live well in adulthood, as evidenced by the half million Americans living with that diagnosis today.[3]

Information, emotional support and access to daily supports - often best delivered by trained parents raising children with a similar diagnosis – are vital to ensuring children are in safe and healthy environments. When the expectation is that a child with a significant diagnosis which involves disability has a terminal medical condition, gaps in care and monitoring arise as the situation appears hopeless. Parents may believe there is little they can do for the child, often because they are not provided appropriate and adequate support around the diagnosis. For parents who are coming to terms with their child's disability, evidence shows a similarly-situated parent can serve as a trusted resource and support system.

That is why the recommended strategies emerging from this committee include:

Improve communication and information sharing between departments and agencies.

- Expanding policy-driven collaborations between Disabilities Services and Child Welfare (CW), including tracking how, when, and what sort of information is shared between disabilities and CW and developing a framework to standardize case reviews.
- Compiling better reports with accurate sequencing, procedures for flagging and reviewing for inconsistencies, and appointing an independent reviewer to deconstruct cases and issue recommendations as their primary job.
- Requiring CW to investigate and report the child's educational situation, including such things as attendance, grade level, withdrawal from school, and home school status. This information should be obtained from the district and not simply as reported by the person responsible for the child.
- Using law enforcement and DHS liaisons to improve communication standards and practices in cases of CW.

Execute better training about disabilities and the symptoms that are and are not typical of such diagnoses.

- Reviewing existing curricula required to be completed by case workers working with children with disability and determining if disability advocates and experienced social workers find it to be sufficient.
- Training and assessment of staff by professionals outside of the agency, especially self-advocates and their family members.
- Training CW workers to liaise with DHS legal to get documents and responses from law enforcement.
- Guaranteeing all staff understand that minor children are not appropriate primary caregivers for medically fragile siblings.

Increase support and professional development for case workers.

- Exploring ways to improve support to case workers who become overwhelmed.

Improve processes for intake, program and service eligibility, and case reviews.

- Reconsidering the Assessment of Child Safety (ACS) intake process to determine which questions are missing, which measures are inadequate, and if an ACS tool specific to children with disabilities is needed.
- Identifying all services and supports for which children may be eligible and why the services were not secured as a part of standard review practice.
- Creating a navigation system for families to assure access to supports and services that help children with disabilities.
- Ensuring multidisciplinary teams include someone other than the person responsible for the child to serve as an advocate with accurate knowledge of how the disability manifests in the child's life.
- Making use of parent navigators – those who also have children with disabilities – to support parents in identifying disability supports and completing forms a standardized DHS practice and a core component of safety planning. Organizations such as the Oklahoma Family Network and Developmental Disabilities Council of Oklahoma may be able to help with this.

Educate families about processes and language for requesting needed services in ways that result in connections to services.

ISSUE:
CHILD CARE

Availability of affordable, appropriate and accessible child care for children with significant disabilities.

Child care facilities for medically fragile children or those with significant communication, behavioral and/or physical limitations are rare in Tulsa and Oklahoma City – and virtually nonexistent in other parts of the state. DHS provides a Special Needs Subsidy to centers for children with disabilities who qualify for subsidy and meet special needs care qualifications. However, this subsidy is insufficient to support additional staff, accommodate a child's unique support needs, and comply with the center's ratio rates. Access to such affordable, appropriate and accessible care for children with disabilities:

- Allows parents to pursue employment;
- Provides respite to family caregivers;
- Provides easier access for therapeutic interventions; and
- Enhances the level of monitoring of a child's development.

RECOMMENDATIONS

- Increase the number of child care centers for children with significant disabilities and/or medical conditions.
- Ensure families are informed by CW and Sooner Start staff that child care is available to children with eligible disabilities through the child's 19th birthday.

- Make supported transportation available, including wheelchair accessible vehicles. Possible funding sources are the Oklahoma State Department of Education (OSDE) and, if the child care center provides medical care, Sooner Start and Early and Periodic Screening, Diagnostic, and Treatment (EPSDT).
- Braid funds from Medicaid, OSDE, Tribal child care, DHS child care subsidy and federal Head Start to assist families with the higher cost of child care for children with disabilities.
- Use DHS resources to list child care centers capable of providing care for children diagnosed with disabilities.
- Explore innovative funding models to support centers delivering specialized care, such as demonstration training grants for providers. Additional grant dollars could explore the feasibility of having child care at pediatric care centers like The Children's Center Rehabilitation Hospital in Bethany or the JD McCarty Center.
- Enact incentives from DHS for agencies or facilities to operate in rural areas.
- Explore options to compensate a parent who stays home to care for a child with disabilities as you would daycare.
- Collaborate with tribal resources if child is Native American.

BEST PRACTICE

The World of Care (WOC) helps at-risk infants, toddlers, and preschoolers develop skills to prepare for school, and supports their families through counseling, parent education, support groups, case management and advocacy. WOC also works to train the next generation of service providers in best practices including family-centered care and inclusion. WOC uses a braided funding model to provide early intervention services, comprehensive assessments, family support services, parent education, counseling and specialized child care.[4]

ISSUE:
HEALTH CARE

Lack of regular physical examinations or follow up for missed medical appointments.

Health care professionals must physically see and assess children with disabilities regularly in order to monitor their health and nutritional status. This may be a physician, visiting nurse, DHS nurse or other trained health care provider. In the cases reviewed, such regular assessments and monitoring could have identified neglect earlier. Most pediatricians see a child only a handful of hours each year. They rarely have knowledge of a child's typical day, including how the disability or medical condition manifests or knowledge of conditions in the home.

That is why it is also vital for someone to follow up when appointments are missed. Follow up should be monitored by the Oklahoma Health Care Authority (OHCA) or by the health care provider where care is delivered to ensure the optimal health of the child and avoid medically neglectful situations.

RECOMMENDATIONS

- Require the Oklahoma Health Care Authority (OHCA) or health care provider monitor when appointments are missed and follow up to reschedule.
- Educate doctors about how Sooner Care/Medicaid can put critical disability supports into the home.

- Establish standards for health care providers and clinical social workers to report to DHS when medically vulnerable children miss appointments.
- Require DHS and law enforcement agencies to refer all child deaths to a medical provider who is part of the network of child maltreatment medical evaluators recognized by OCCY for evaluation to determine if the child suffered child maltreatment.

ISSUE:

EDUCATION

Lack of participation in public education.

The majority of the cases reviewed included children with chronic, unexcused absenteeism or withdrawal from school all together. In some cases, a child stopped attending school with no follow up with the family, only removal from the school roll after 10 consecutive absences. Yet, all of these children were entitled to a free and appropriate public education, regardless of the financial and logistical burden to local education agencies. Formalizing a relationship between DHS and OSDE that includes regular meetings could help to create proactive solutions to keep children with disabilities enrolled, such as the development of joint professional training and the creation of processes for verifying student enrollment and attendance. It is not appropriate for the person responsible for the child to be the sole reporter of this information, and such verification would be especially helpful in cases where the CW worker has lost track of the child.

Many of the cases reviewed also did not include all relevant personnel in the investigations. Many times, actionable information could be obtained from those individuals who work closely with students. Additionally, under IDEA, the OSDE must develop and implement effective methods to identify children who are in need of early intervention services and coordinate those services with other agencies, such as child protection and child welfare programs. CW workers are in a unique position to make such a referral and, given the trauma children suffer through child abuse and neglect, local education agencies are in a position to offer many supports to these children.

RECOMMENDATIONS

- Develop policies to implement routine screening for all young children who come to the attention of child welfare to ensure equal opportunity to receive early care and intervention as needed.
- Increase information sharing among agencies by revising existing Memorandum of Understanding (MOU) between the OSDE and DHS to include:
    - Formalizing partnerships with representatives from OSDE and DHS that outlines formal liaisons and includes, at a minimum: quarterly meetings and development of joint trainings to benefit both educators and CW workers.
    - Data sharing agreement that includes: record matching to occur at least monthly and access to the OSDE online Individualized Education Program (IEP) system.
- Implement policies that require better coordination of referrals, services, investigations, and training among DHS, OSDE and Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS).
    - Require schools appoint a school site liaison for CW, such as a counselor, nurse, or principal, to be advised of every enrolled student with an open CW case.
    - Require all school personnel to be included in CW investigations (e.g. school nurses, bus drivers, paraprofessionals, cafeteria staff).
    - Require IEP teams to advise parents of daily living/hygiene tasks and medical supports that may be included in an IEP for students with significant cognitive disabilities and significant health needs.
    - Require CW worker to work with families to make referrals for special education services for any CW-involved child to the local education agency when the child is perceived to have a disability or special healthcare need.
    - Consider home-based education for all students who are too medically fragile to attend public school and offer related services for home-based education.
- OSDE, DHS, ODMHSAS, and Oklahoma State Department of Health (OSDH) should collaborate to provide training and guidance about making needed referrals, use of medical equipment, and qualifications for performing nursing services.
    - Require schools to obtain a prescription or physician's summary letter with explicit instructions on how to properly feed a child with a G-tube/NG-tube and how to maintain the G-tube.

  - Require annual training for school personnel regarding students with disabilities and school supports.
  - Require schools to address the protocol for feeding the child on days/times when a school nurse is not available.
  - Develop guidance for school-based health services, including school nursing services, to include information on making referrals for disabilities, CW, EPSDT, durable and adaptive medical equipment, home nurse visitation programs, and qualifications for performing nursing services.
  - Provide training to welfare staff on behavioral health services and evidence-based practices from the ODMHSAS.
  - Provide training to mental health professionals on unique needs of children in child welfare.
  - Provide standardized training to all educators related to identifying the signs of abuse and neglect and the legal obligations to report.

- Educate students about self-advocacy, rights and responsibilities.
  - OSDE should distribute print or digital versions of “Rights and Responsibilities” booklet produced by the Developmental Disabilities Council of Oklahoma to every public school student on an IEP.
  - OSDE should provide explicit and age-appropriate instruction in self advocacy skills for all students with a focus on abuse and neglect.

- OSDE and OSDH should collaborate to implement strategies for training and supporting school nurses in facilitating wrap-around services, including screening and making referrals for abuse, neglect, and medical neglect.
  - Train nurses and staff on EPSDT, durable medical and adaptive equipment, utilizing OK ABLE Tech, and home nurse visitation programs.
  - Train nurses on recognizing the signs of, and screening for, abuse, neglect and medical neglect.
  - Train nurses on effective participation in IEP meetings.
- Provide supplemental funding to schools to provide a school nurse to every school site and require school nurses in districts with 1,000 or more students.

BEST PRACTICE

SCREENING

Routine screening for all children who come to the attention of Child Welfare is needed to ensure equal opportunity to receive early care and intervention services. Pennsylvania and Colorado have been identified as model systems in this regard. For example, in Colorado, Child Welfare is required to refer any child under 5 years for developmental screening if the child is a confirmed victim of child maltreatment. If the child is under 2, the Special Education Administration is also required to conduct screening and evaluation to determine eligibility for Part C early intervention services.[5]

SCHOOL NURSING

School nurses are needed at each school site to ensure access to necessary services for all students. While Oklahoma currently has a shortage of school nurses,[6] other states, like Minnesota, require districts with 1,000 or more students to employ at least one full-time licensed nurse.

TRAINING

Michigan utilizes mental health agencies to train child welfare staff on behavioral health services and evidence-based practices. In turn, child welfare staff, foster parents and other child welfare experts train mental health professionals on the unique needs of children in child welfare. This builds capacity among frontline workers to appropriately identify and connect children in need of screening, referrals and services to necessary resources.[7]

ISSUE:
CHILD WELFARE

Legislative, policy, and training changes are needed to support children with disabilities in child welfare.

Proper and timely identification of children experiencing abuse, neglect and medical neglect was not made in the cases reviewed. Because of this, accessing supports on behalf of the child was delayed. Once investigations began, workers often did not complete a full assessment of the needs related to the child's disability and did not recommend appropriate services or follow-up needed to assist in the ongoing care and protection of the child. It was also found in a few of the cases reviewed that children with known developmental disabilities were not immediately referred for a medical exam nor were records received from the child's most recent medical appointments.

Additionally, several of the cases reviewed included the death of the child. Many of these cases did not have a scene investigation, medical evaluation, or history review due to the child's previous diagnosis. Upon review by the committee, it was determined there were elements of neglect involving these children and a more thorough review and investigation should have occurred at the time of death. Moreover, reviews for compliance with child welfare practice and policy should be continuous to ensure work is carried out with quality on a consistent basis.

RECOMMENDATIONS

- Assess a child's safety, educational status, developmental functioning and known physical, intellectual, or emotional disabilities.
    - Implement a mandatory question during intake regarding the child's developmental functioning and any known physical, intellectual, or emotional disabilities.
    - Require Adult Protective Services (APS) staff to notify CW if their investigation discovers children in the home where maltreatment allegations were made so an assessment of the child's health and safety can be made.
    - Require documentation of the child's specific disabilities and needs and how the person responsible for the child meets those needs, including the services in place at the time of the investigation and any services recommended by child welfare.
    - Remind CW staff they are required to obtain educational information for all children and to follow up if the child is not receiving any educational services. CW staff should also follow up with the OSDE regarding Child Find when enrollment status is unknown or has changed for an identified child with a diagnosed disability who it is determined is not receiving educational services.
- Require medical providers report when a child with a disability or medical condition does not receive required follow-up care due to missed medical or physical/occupational therapy appointments.
- Enact changes to legislation addressing placement in care facilities and notification of DHS upon the death of a child with disabilities.
    - Require the ME's office to contact child welfare at the time any child's body is received or allow CW access to the vital statistics records.
    - Identify and notify physicians across the state willing to review child deaths without child welfare involvement. Identify a process for those physicians receiving notification of a child death by either vital statistics or the ME's office.
    - Deny higher level facilities, such as hospitals and Acute Psychiatric facilities, the ability to reject inpatient treatment for reasons other than capacity for children who meet Medicaid criteria and have developmental disabilities, behavioral health diagnoses, or intellectual disabilities.
- Implement statewide CW training to build supervisor capacity to identify cases with the potential for poor prognosis and develop regional plans regarding training needs.

- Report fraud to the Social Security Administration when investigations reveal resources for the child are not being provided directly to the child's caretaker. In such cases, Child Welfare should assist the primary custodian in obtaining the resources.
- Partner with Animal Welfare offices across the state to identify children with disabilities living in homes where animals have been removed due to maltreatment. Removal of these children should result in a priority investigation.

BEST PRACTICE

The Oklahoma Department of Human Services (DHS) Child Welfare employs regional teams focused on continuous quality improvement and quality assurance (CQI/QA). The CQI/QA team assists the regional director in reviewing case decisions across all programs in order to identify trends. The information is analyzed and region specific plans are developed regarding specific training needs for individual workers, supervisors, district directors, or an entire district.

This team may also help ensure ongoing review for compliance with child welfare practice and policy necessary to guarantee the work is being carried out on a consistent basis with quality.

ISSUE:
LEGAL CONSIDERATIONS AND INTERVENTIONS

Addressing cases that involve children diagnosed with disabilities poses difficulties for the juvenile deprived system and the individuals who work within it. These professionals are often not educated about the potential complex medical, physical, and therapeutic interventions, adaptive equipment and other needs that may be involved in cases related to a child with a disability. As a result, parents, who are the potential source of the abuse or neglect investigation, are often heavily relied upon to provide information about the child’s disability, diagnosis, and special needs. Not fully taking the developmental age of the child into consideration, caregiver bias, and lack of placement resources appear to have been factors in decision-making about removal in some of the cases reviewed. Targeted approaches should be implemented to limit the impact of these factors.

Many of the cases reviewed by the Committee were addressed solely by DHS, and resulted in no request for court intervention. As such, staffing did not occur outside of the agency to determine if removal of the child was warranted or to assess services specific to a child with a disability. In order to better serve the needs of children with disabilities, additional training, education, and resources are necessary to improve the ability of child welfare workers to appropriately assess imminent risk of harm.

Child welfare must work more collaboratively with the education system. Child welfare staff cannot adequately assess the safety and well-being needs of a child without understanding the child's current education situation. The education system may even serve as an additional support to the family of a child with a disability.

While children with disabilities are at an increased risk for abuse, there is no clearly accepted definition of a child with a disability being applied to child welfare cases in Oklahoma. Even the Committee struggled to identify an agreed upon definition. There is also currently no clear tracking by DHS because of the problems associated with identifying and applying these concepts in the field. The death and near-death cases reviewed had to be identified by studying each case over the prescribed time period to determine if the child had a discernible disability.

Abuse and neglect of children with severe disabilities often happens in isolation. In several cases reviewed, the child was not attending school, was not receiving meaningful services to address their disability, and was not being seen regularly for medical care. Public awareness of the duty to report suspected abuse or neglect and the heightened vulnerabilities of children with disabilities is especially important in these situations, particularly when a child is non-verbal. Working to ensure school teachers and the public are educated on what to look for is imperative. Additionally, schools still struggle with implementing the individual duty to report. Continued training for educators and school districts to ensure policies are in place that conform with the law are imperative.

Knowing the signs of abuse and neglect in children with disabilities is also an issue for DHS. Child welfare workers may not have any experience until they are called out to investigate a case. Complex medical information can be intimidating and difficult to understand for a lay person. Ensuring medical needs and diagnoses' are communicated in such a way that a social worker can understand and then can be related back to the safety threats associated with that child is critical. Disability advocates, medical professionals, and other disability experts could work with DHS to draft information guides that give child welfare workers information about specific disability diagnoses or medical conditions common among children involved with child welfare. This guide could be created based on the child's disability and include a checklist for ensuring investigative information has been gathered, service referrals made, adaptive equipment obtained, parental support groups identified, and other potential programs for the child are made available.

Additionally, “heinous and shocking abuse” and “heinous and shocking neglect” are both terms defined by statute and denote the specific level of abuse or neglect in a DHS finding. Although a “heinous and shocking abuse/neglect” finding gives rise to pursue immediate termination of parental rights, it is a stand-alone finding. The legal definitions and policy considerations are not joined, however there appears to be a linkage in application. In some cases, the child who suffered the abuse or neglect died and was also an only child. If the statutory definition is met, the CWS finding should still be “heinous and shocking abuse or neglect”. Clarifying instructions to staff regarding assessing a pattern of chronic abuse or neglect as it relates to a child with a disability is vital.

RECOMMENDATIONS

- Improve assessment of imminent risk of harm for children with disabilities.
    - Implement specific protocols for information gathering during the investigative phase, including a requirement to report for Medicaid billing, which includes a listing of all medical services billed for the child, be obtained in all cases involving a child with a disability. This provides a tool for DHS to assist in identifying medical service providers, aid in verifying parental reports regarding attendance and follow-up with medical appointments, and compliance with recommendations.
    - Expand DHS policy (CWS Numbered Memo 18-06) to require a consultation or staffing with the CWS nurses when the child is diagnosed with a disability, particularly in instances when the child is unable to communicate, to ensure the worker understands the needs of the child. This would assist in determining what services or medical care may be needed and the associated risks.
    - Ensure CWS nurses receive ongoing training in assessing the complex medical needs of children with disabilities, as well as an appreciation and understanding of child welfare policy and the legal and policy definitions related to deprivation.
    - Develop experts in local areas who have specialized training or skill in the investigation of abuse and neglect of children with disabilities. Workers could be incentivized through pay differentials for completing additional training used for consultation and assistance in local offices, acting as mentors, staffing investigations and cases involving children with disabilities, assessing risk for children with disabilities, and specialized interviewing techniques and protocols for children with disabilities.
- Provide services when substantiated findings are determined.
    - Create a specialty court docket for medical neglect cases to ensure follow-up with necessary medical care.

    - Create a Regional Disability Family Centered Services Worker position in each region, specifically for prevention cases involving children with a disability. Disabilities, CWS and Disability Advocates could collaborate to determine the qualifications of these positions and partner to identify and ensure appropriate training opportunities for these specialized workers.
    - Dedicate resources to ensure the Regional Disability Family Centered Services Worker receives holistic training in assessing the full range of services available, as well as understanding the unique needs of parents of children with disabilities.
    - Extend the "services follow-up" time period in Child Welfare Policy 340:75-3-520 from 60 days to 120 days for all cases with a substantiated finding or a finding that the child is unsafe when it involves a child with a disability. These cases could be referred to the Regional Disability Family Centered Services Worker for follow-up, including EPSDT referrals.
- Improve safety plans:
    - Amend policy for cases with safety plans to increase the amount of face-to-face contact required with the child who has a disability, including in the child's home, with even more contact required for children who are unable to communicate or who have behavioral issues associated with their disability.
    - Ensure a safety plan monitor fully understands the specific needs and demands related to the child's disability, and has full disclosure, at the onset.
    - Implement safeguards to ensure safety plan conditions are provided in writing and clearly understood by the safety plan monitors and the parents of the child(ren), including clearly articulating the duration of a safety plan. Although policy may address these issues, it does not appear to be carried out in a consistent and meaningful way.
    - Provide additional opportunities and resources for respite care for children with disabilities.
- Expand the use of select court petitions to increase protective interventions.
    - Expand the use of "Out of Custody" Petitions to allow children to remain in the home and provide court oversight of follow-up with the necessary care and treatment of the child.
    - Use the "In Need of Special Care and Treatment" provision of the deprived statutes as a basis for filing a Petition and allow the Court the necessary oversight to monitor compliance with medical care, treatment and other necessary services for children where removal may not be warranted but there is a pattern of medical neglect and lack of follow-up by parents of children with complex medical needs.
    - Train the Judiciary and District Attorneys regarding the use of court intervention in cases where children have not been removed from the

home, as well as the unique needs of children with intellectual and developmental disabilities.

- Assess safety and link children and caregivers services using a multi-disciplinary model:
    - Expand existing Multi-Disciplinary Team (MDT) process to staff cases involving children with disabilities, even when removal is not requested.
    - Include representatives from the Office of Client Advocacy and a Disabilities representative on the MDT Team for staffing of these cases. If Regional Disability Family Team Services Worker positions were created those individuals could also be part of the MDT Team.
    - Ensure workers are aware of the ability to request review at the Children's Hospitals in Oklahoma City and Tulsa or to request a medical review.
    - Law enforcement could receive additional training and staffing support for these cases as an MDT participant.
    - Ensure courts know they can order additional services and utilize disability advocates, such as the Office of Client Advocacy, Special Advocacy Program to assist families with linking to services and supports.
    - Connect the Court Appointed Special Advocates (CASA) program and other children's disability advocacy and parent groups in order to recruit CASA volunteers with expertise in developmental, educational and physical disabilities and advocacy.
    - Target judicial training so Judges are aware of advocacy resources and contacts in order to better utilize them in their communities.
- Findings, Definitions and Policy considerations:
    - Clarify instructions to staff regarding assessing a pattern of chronic abuse or neglect as it relates to a child with a disability and provide specific examples.
    - Make clear that a pattern of failure to obtain medical care and treatment can rise to the level of "heinous and shocking neglect" based on the unique needs of the child. Parents may move to another State and/or subsequently have other children or become persons responsible for the care of a child. It is critical that the extent of the abuse or neglect be clearly apparent for future reference.
    - Clearly require in DHS policy a Priority One investigation and immediate response when a child with disabilities is removed from care facilities and/or hospitals against medical advice. This is especially critical for children with complex medical needs.
    - Ensure safeguards could be put in place to improve the process for unattended deaths, including the interface between the Medical Examiner's Office, local law enforcement and DHS to ensure these deaths are properly investigated and appropriate protocols are in place when the ME's office defers to local law enforcement.

BEST PRACTICE

Oklahoma is currently piloting the START Program, a specialized program for children with both a disability and a history of behavioral problems. Training and education about the START program and expanding availability state-wide would be extremely beneficial.

- Clarify DHS investigative findings in child neglect cases to allow for a determination that the parent's actions or inactions caused or contributed to the child's death instead of relying on the ME's report that frequently lists the child's underlying medical condition as the cause of death and does not address "quality of care" issues. In such cases it is particularly difficult to link the child's death causally to the parent in cases in which a disabled child has died as a result of neglect.
- Expand the definition in Title 10A Section 1-1-105 to include:
  - "Child with a disability" means any child who has a physical or mental impairment or complex medical needs which substantially limits one or more of the major life activities of the child, or who is regarded as having such an impairment by a competent medical professional." This clarification of the definition of a "child with a disability" will strengthen safeguards created through the Quinton Douglas Wood Act of 2014.
  - "Suspected disability" in the DHS policy ("child with a disability or a suspected disability") to ensure necessary protections kick in at the on-set of an investigation.
- Educational neglect and identification of children with disabilities
  - Pursuant to federal law (IDEA) school districts are currently required to identify children with disabilities within the school district. This requirement is not limited to children who are attending school. Much work could be done to partner with the education system to find ways to improve services for these children and to ensure notification when a child with a disability is not attending school or has been dis-enrolled from school.
  - Identify ways to fill gaps in the system to ensure children do not fall through the cracks:
    - Develop partnerships between DHS, Disabilities, disability advocates and the State Department of Education to improve processes.
    - Address absences of children with disabilities in the same way as children without disabilities in courts with truancy programs.

COMMITTEE MEMBERS

Kathryn Boyle Brewer, J.D.
Ms. Brewer is the appointee of the Speaker of the House, Charles McCall. She currently serves as the Assistant Executive Coordinator for the District Attorneys Council. She has spent the bulk of her career focused on the welfare of Oklahoma's children, both in her role as a long-time prosecutor and as the Advocate General for the Office of Client Advocacy at the Oklahoma Department of Human Services. She became an advocate for children with disabilities through her involvement with the administrative review of the death of Quentin Douglas Wood, and has continued to fight to uphold and protect the rights of children and adults with disabilities.

The Honorable L. Elizabeth Brown

Judge Brown is the appointee of the Chief Justice of the Oklahoma Supreme Court. She has served as the Associate District Judge for Adair County since 2002. She received her B.S. from Northeastern State University and her J.D. from Oklahoma City University, School of Law in 1997. She is a member of the Oklahoma Bar Association and is admitted to practice in Oklahoma, the Western and Eastern Districts of Oklahoma and the United States Supreme Court. In 2014, she was appointed by the Chief Justice of the Oklahoma Supreme Court to serve on the Juvenile Justice Oversight and Advisory Committee, comprised of nine judges from across the state whose docket responsibilities include juvenile cases. The committee advises the Supreme Court on matters relating to the administration of justice for children. She also serves on the Office of Juvenile Affairs' Interstate Council on Juvenile Supervision. She also serves on the board of the Adair County Boys and Girls Club.

Joe Dewey, J.D.

Mr. Dewey was appointed to the Special Committee by the Advocate General of the Department of Human Services. He has worked as an Assistant General Counsel with the Oklahoma Department of Human Services for the past four years. At DHS he works closely with several program areas including Medicaid, the Developmental Disability Division, and the Office of Client Advocacy. He is also the agency attorney assigned to the Community Services Worker Registry, which lists Disabilities client caretakers with confirmed findings of abuse and neglect. Previously he was an Assistant District Attorney in Oklahoma County where he worked in the Juvenile Division for eight years, prosecuting both delinquent and deprived juvenile cases.

Wanda Felty

Ms. Felty was appointed to the Special Committee by the Minority Leader of the House of Representatives. She is a parent of a child with significant developmental disabilities and life limiting medical condition. She is the Community Leadership and Advocacy Coordinator for the Center for Learning and Leadership which is Oklahoma's federally recognized University Center for Excellence on Developmental Disabilities. She is also a Core Faculty mentor for the Oklahoma LEND (Leadership Education in Neurodevelopmental Disabilities and related conditions) program at the University of Oklahoma Health Sciences Center.

Debra Knecht

Ms. Knecht is the Interim Deputy Director of Programs in Child Welfare Services for the Department of Human Services (DHS) where she oversees Child Protective Services, Permanency Planning, Family Centered Services, Therapeutic Foster Care Services, Specialized Placements and Partnerships, Project Management, Community Mental Health Collaboration, Child Welfare Training, and Policy. She has been with DHS since 2001. She has a Bachelor's Degree in Sociology from Oklahoma State University and a Master's of Social Work from the University of Oklahoma. She has worked closely with the Child Death Review Board, Domestic Violence Fatality Review Board, and the Oklahoma Drug Endangered Children Committee during her tenure.

Todd Loftin

Mr. Loftin is the appointee of the Superintendent of Public Instruction. He has worked in the Special Education Services Division at the State Department of Education since 2012. He previously worked as a special education teacher at Moore High School.

Janet McBride Irwin

Ms. Irwin holds a BSN RN from Northwestern State University in Natchitoches, LA. She began her career at the LSU Medical Center on the General Pediatric floor where she was instrumental in starting the first Pediatric ICU at the hospital in 1984. She later worked in the PICU at UT Health Science Center in San Antonio and as a Pediatric Specialty nurse at Santa Rosa Children's Hospital, now Christus Santa Rosa. In 1988 she recovered the 1st titanium rib implant from surgery, now known as VEPTR. Since 1999, she has worked at OUMC-The Children's Hospital. She is currently the Clinical Coordinator for TCH, where she coordinates all the admitting areas of the hospital, staffing for all the clinical areas and addresses all patient care at the hospital. She has always been an advocate of quality patient care and family advocacy.

Jason Nelson

Mr. Nelson is the appointee of the Attorney General. He served eight years in the Oklahoma House of Representatives where he authored and supported policy changes to protect vulnerable children, including children with disabilities.

Mary Ellen Stockett, MD

Dr. Stockett has served as Chair of the Special Committee and is the appointee of the Governor. Dr. Stockett is a Child Abuse Pediatrician and Assistant Professor at the OU Health Sciences Center Department of Pediatrics. Dr. Stockett is board-certified in Pediatrics and Child Abuse Pediatrics by the American Board of Pediatrics. She has 20 years of experience in teaching and providing clinical services to maltreated children in Florida and now in Oklahoma. Dr. Stockett is a faculty member of the Interdisciplinary Training Program that educates students about child maltreatment. These students include law, social work, psychology, medical and public health students. She is also involved in multidisciplinary training of individuals involved in child maltreatment assessment throughout the state of Oklahoma. Her duties at OUHSC include the training of medical students and residents regarding child maltreatment as well as evaluation of suspected child victims of maltreatment. She teaches community medical providers to complete medical evaluations of child victims of maltreatment through a grant funded by Victims of Crime Act.

Erin Taylor, Ph.D.

Dr. Taylor was appointed to the Special Committee by the Speaker of the Oklahoma House of Representatives. She is the mother of five children including Henry who has an intellectual disability and a life limiting diagnosis. She is a recent graduate of the Leadership Education in Neurodevelopmental Disabilities program at OUHSC and of the Georgetown Academy on Intercultural Competence. She works on public policy at the Developmental Disabilities Council of Oklahoma and leads a nine-month disability advocacy class called Partners in Policymaking. She is one of the parent facilitators for the state legislature’s Waiting List Caucus.

SOURCES

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[7] Center for the Study of Social Policy. (2018). Opportunities to strengthen developmental screening for children involved in child welfare systems. Retrieved from https://www.cssp.org/policy/2018/Developmental-Screening-FINAL.pdf.