February 14, 2017

Re: Supplementary Testimony from the Office of the Child Advocate, see February 7, 2016 hearing.

Dear Distinguished Chairs and Members of the Children's Committee,

The purpose of this correspondence is to more fully respond to questions raised by members of Children's Committee during the February 7, 2017 public hearing testimony of the Office of the Child Advocate (OCA). The OCA wishes to specifically address two areas of concern that were raised during the hearing, (1) reliability and utility of the child fatality data produced by the OCA and (2) the scope of the problem the OCA termed a "crisis" faced by certain families who have children with complex developmental disabilities and/or significant mental health treatment needs.

1. Child Fatality Data

As part of the OCA's testimony in support of proposed Senate Bill 396, *An Act Concerning Child Fatality Review Procedures*, the OCA referenced the fact that it has fielded recent questions regarding the number of child fatality cases where the family had recent involvement with the Department of Children and Families (DCF).[1] In response to those requests, OCA included in its testimony a brief overview of statistical data and manner classification of children's death. This data did not, by description, provide analysis of the quality of state supervision, custody or intervention with regard to the child and his or her family. OCA stated that the child deaths summarized in the testimony may or may not have been the result of maltreatment. OCA would like to offer the following additional information, responsive to questions and concerns raised during the hearing:

- **Maltreatment Deaths**
  Though one may conclude that only deaths that are classified as "Homicide" or "Suicide" may require rigorous review or maltreatment investigation, OCA would respectfully like to clarify that suspicions of maltreatment may exist across any of the five manners of death for children. Those manner classifications include: (1) Natural (2) Accident (3) Undetermined (4) Homicide and (5) Suicide.

  As co-chair of the State Child Fatality Review Panel (CFRP), OCA sees child maltreatment deaths in *all* manner classifications. We have attached our 2014 Infant and Toddler report for your review. This report provides an example of in-depth analysis regarding the deaths of the state's youngest

[1] Requests for information came from the Office of Legislative Research as well as an aide to the Children's Committee, requesting the following: "a breakdown of the number of DCF involved children who have died, by year, since the agency was created." OCA responded to both requests for inquiry by indicating that we were able to produce quantitative data only, broken down by manner of death as classified by the Office of the Chief Medical Examiner. OCA included the requested information as part of our testimony regarding a related child fatality bill.

children, ages birth to three.[2] This report examined all manner of death for infants and toddlers in 2013, including deaths classified as Accidental or Undetermined that were suspicious for or deemed the result of child maltreatment.[3]

- **Sudden Unexplained Infant Death/Undetermined**
  Historically, the Office of the Chief Medical Examiner (OCME), referred to the sudden death of an infant where no medical cause or obvious findings of abuse, neglect, or disease, were identified as the underlying cause of death, as SIDS and such deaths were typically classified as being due to "natural" causes. As national research has evolved regarding these child fatalities and state practices with regard to comprehensive death scene investigations including scene reenactment, the classification of these deaths as SIDS/Natural has significantly declined. These untimely deaths of infants are now classified as Sudden Unexpected Infant Deaths (SUID) and the manner is most often categorized as either Undetermined or Accident (no longer classified as *Natural*). These infant deaths are now understood to most often correlate with unsafe sleep environments, including sleeping in an adult bed, at times with an impaired or intoxicated parent, sleeping with blankets, pillows, and other things in the sleep environment. These deaths are therefore deemed preventable and an important subject for review and public health intervention. Some of these cases may also be suspicious for child maltreatment.

  In 2014, OCA and CFRP published a public health alert regarding Un-Safe Sleep Related deaths. The alert cites research that "families under child protective services supervision are three times more likely to have a Sudden Infant Death than those that are not."[4] Again, this research finding does not mean the quality of DCF intervention in all such child fatality cases was poor. Rather, the significance of the finding is to ensure awareness regarding risk factors for sudden infant death, and to assist in the development of strategic communications and interventions for prevention.

- **Quantitative/Manner Classification vs. Investigative Data on Child Fatalities**
  As requested, OCA provided data regarding the "number of DCF involved children who have died, by year, since the agency was created."[5] OCA testified that the fact that a child dies while under DCF

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[2] Section II of this report provides an analysis of 24 infant and toddler deaths where the family had DCF involvement prior to or at the time of the child's death. For these cases prior history with DCF ranged from 1 previous report to as many as 14 previous reports of suspected maltreatment. Seven of the 10 children who died in the manner classified at Undetermined, had a caregiver with a documented history of substance use or who admitted using alcohol or substances prior to going to sleep with or near the baby. Report by the OCA found here: http://www.ct.gov/oca/lib/oca/Final_OCA_Infant_Toddler_Fatality_Report.pdf. See discussion regarding Undetermined Deaths, beginning on pg. 12.

[3] Example would be a child that drowns in the bathtub with an intoxicated parent; or a child that dies in an unsafe sleep environment with a parent who is using drugs/alcohol.

[4] OCA/CFRP Public Health Alert found here:
http://www.ct.gov/oca/lib/oca/PublicHealthAlert_Safe_SleepApr_7_FINAL__docx_%282%29.pdf citing Putnam-Hornstein E. Schneiderman JU. Cleves MA. Magruder J. Krous HF. A Prospective Study of Sudden Infant Death after Reported Maltreatment. *Journal of Pediatrics. 164(1):142-8, 2014 Jan.* Recognition of the increased risk for un-safe sleep related deaths among families with child protective service histories or contemporary CPS concerns also contributed to the development of DCF's "safe sleep" practice policies, published in 2014. Connecticut Department of Children and Families, "Standards and Practice for Safe Sleep Environments: Assessing the Safety of an Infant's Sleep Environment," Practice Guide to be used in conjunction with DCF Policy 34-12-8 (2014).

[5] Email from a legislative aide to the OCA, January, 2017. OCA explained in a phone conversation that we are not able to produce data as far back as when DCF or OCA was created.

supervision does not mean that the quality of state supervision or intervention was poor. OCA deeply appreciates the interest of committee members in having such an important determination made as to each child death, ever year. However, that type of finding is not only *qualitative*, but *investigative*, and necessarily the product of rigorous and extensive review of the circumstances leading to an individual child's death.[6] The proposed bill by Senator Fasano acknowledges the limited resources within the OCA and Child Fatality Review Panel[7] to investigate such circumstances in all child fatalities each year and therefore the proposed bill seeks to enhance resources for the production of such investigative and qualitative findings. The OCA respectfully proposes that the Committee may find it helpful to ask DCF for redacted copies of its internal/ "special" reviews of child fatalities and critical incidents in which DCF has concurrent or recent involvement with a family and conducted a subsequent review of its practice.

Comparison of states' child maltreatment fatality data is difficult.

While OCA appreciates the Committee Chair's reference to statistical information regarding the number of child maltreatment deaths that occur in Connecticut and how such information compares to other states, OCA respectfully refers the Committee to a portion of OCA's testimony, pg. 4, Note 3, citing a recent United State Government Accountability Office Report:

> **Unfortunately most states under-report maltreatment fatalities and comparisons from one state to another are difficult, if not impossible, to conduct. A 2011 United States Government Accountability Office report found that because of challenges in child death investigation, reliance on child welfare agency reporting and a lack of uniformity regarding determinations of abuse and neglect, state data submissions regarding maltreatment fatalities are 'only a proportion of all child fatalities caused by abuse or neglect.' Report by the United States Government Accountability Office, *Child Maltreatment: Strengthening National Data on Child Fatalities Could in Aid in Prevention*, found on the web at, http://www.gao.gov/new.items/d11599.pdf, pg. 9.**

The information above does not mean that Connecticut is not worthy of recognition for its efforts to promote children's health and well-being, but for the purpose of providing additional clarifying information to the Committee as it considers important proposals regarding child fatality review. In sum, the OCA acknowledges the complexity of child death review and the importance of such work to the state's public health initiatives to support child survival. The OCA strongly supports the intent of Senator Fasano's proposed bill which would further enhance the ability of the OCA to produce qualitative and investigative information regarding this important public health issue. The OCA would welcome further opportunities to speak with Committee members regarding the child fatality review process and the reports the OCA and CFRP have produced in recent years.[8]

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[6] See Report of the OCA regarding Deaths of Infants And Toddlers, published July, 2014, *supra* n. 2.

[7] The CFRP is an advisory committee made up of professionals. The OCA has one Full Time Employee dedicated to staffing the Child Fatality Review Panel.

[8] Recent reports from the OCA/CFRP include: Five Year Review, published 2016; Public Health Alerts regarding Youth Suicide and Unsafe Sleep Deaths; Child Fatality Investigative Reports regarding *Londyn Sack*, *Zaniyah Calloway, Infant-Toddler Deaths: 2013, The Shooting at Sandy Hook Elementary School*, as well as annual reports from the OCA regarding child fatality data, and annual submissions by the OCA to the Children's Report Card. All reports can be found on the OCA website: http://www.ct.gov/oca/site/default.asp.

2. **OCA's concern regarding the crisis faced by families of children with complex developmental disabilities and mental health treatment needs—Reference Proposed Bill 6297: An Act Concerning Voluntary Placement in the Custody of the Department of Children and Families and Parental Rights**

During the February 7th testimony regarding Proposed Bill 6297,OCA spoke of the recent experience of a father who had called the OCA to seek help for his 10 year old son, diagnosed with Autism and presenting with acute behavior health issues. OCA sought to share with the Committee the anguish felt by many families that contact OCA when they cannot access necessary care for their child. There are regular calls to our office from parents, grandparents and professional providers/hospitals reaching out for such help. The case example was provided solely to demonstrate how a family's crisis can lead them to fear the possibility of the loss of parental custody or rights as they become increasingly unable to manage their child's complex needs at home.

For your convenience and review, OCA respectfully offers the following highlights from previous testimony and information provided by this Office regarding this issue:

- On February 18, 2016, OCA offered the following testimony to the **Appropriations Committee**:

  OCA responds to hundreds of citizens' calls for help regarding children annually; often children with significant developmental, intellectual and emotional disorders who cannot access required supports. Their families are often in crisis; their child stuck in the emergency room for days on end, or languishing in an inpatient psychiatric unit waiting for services that are not available. Lack of access to appropriate (or sometimes, any) services unnecessarily results in harmful and unsafe circumstances for children and their families. Connecticut remains challenged in its ability to timely identify and address evolving child and family needs to circumvent family crisis. Systems of care are often fractured and ineffective, rendering families desperate and hopeless.

- In May of 2016, OCA conducted an internal examination of concerns received during the previous 12 months, regarding children with developmental disabilities, with or without unmet mental health treatment needs. OCA's review found the following:

  During the period under review, **OCA opened for advocacy and investigation well over 100 children's cases where a primary concern was the provision of appropriate mental health, family support or special education services *for a child with a developmental disability***. Where the concern was focused on access to community/mental health supports, approximately half of the calls came from professionals (mental health, medical, education), the average age of the child was 12 and most of these children were boys.

  While the state has been taking important steps to increase access to critical services for children with complex needs, including recent Medicaid expansion to cover services for children with Autism Spectrum Disorders, many families still cannot yet access the care they need in a consistent, reliable, and timely manner. OCA supports all state efforts to increase access to care for vulnerable populations and appreciates the work of all branches of government to recognize and respond to urgent problems described herein.

- In 2016, the legislature passed House Bill 5587, *An Act Establishing a Council to Make Recommendations Concerning Services for Children and Young Adults with Developmental Disabilities*, and merged this group with the state's Medicaid Oversight Committee. The OCA is a member of this new working group where the urgent problems and crisis that many families with vulnerable children experience is currently being discussed. OCA is eager to share information regarding these important matters

with members of the Children's Committee, and we hope you consider us a resource in developing solutions that can assist families and children.

The OCA provides this information to assist the Children's Committee as it considers proposals regarding the procedures by which some families may feel they are forced to lose custody of their children to a state agency in order to access appropriate care.

The OCA was created by this legislature, along with the Child Fatality Review Panel, after the death of a child involved with DCF. The OCA was charged with a critical function in state government, primarily as an advocate for children, but also for families, and other concerned citizens. OCA is a champion for transparency and accountability with regard to the delivery of publicly-funded services to children. We recognize the tensions that OCA's investigative work can produce. OCA is grateful that there are many good things happening for children in our state, but OCA's charge is to report regarding gaps in our current child-serving systems. We welcome a respectful dialogue and discourse about any issues related to children, and we want to assure the Children's Committee that OCA will continue to do it's very best to provide accurate, timely, researched, and reasoned information for your consideration. Thank for your review of the supplementary information provided by the OCA. Please do not hesitate to contact me with any further questions.

Sincerely,

Sarah Eagan, Esq.

Child Advocate, State of Connecticut