

Office of the Inspector General Report to the Governor and General Assembly (Jan. 2024)

OIG2024 #157

Child No. 157	DOB: 05/2017	DOD: 06/2023	Natural
Age at death:	6 years		
Cause of death:	Hypernatremia due to respiratory infection due to type 1 spinal atrophy		
Reason for review:	Open intact family services case at time of child's death; one unfounded and one indicated child protection investigation within one year of child's death		
Action taken:	Investigatory review of records		
<u>Narrative:</u> Six-year-old medically complex child died in the hospital 11 days after he was found unresponsive in the care of his stepfather. After an MRI revealed minimal brain activity, his mother and stepfather agreed to withdraw care. Child had been diagnosed with spinal muscular atrophy, a chronic kidney issue, and hypotonia. He required a wheelchair for mobility, a g-tube for feeding and a breathing machine. Upon admission, the child had two different viruses, subdural hematomas, and very high sodium levels which doctors reported indicated dehydration. The child's mother, stepfather, and home health nurse reported his formula was changed two weeks earlier and he had been sick with a cold for approximately one week. All three denied concerns that he missed feedings. The mother stated the child appeared to be doing well on the new formula, but the nurse noted the child had been asking for water in the week prior to his hospitalization. She stated the mother called the child's pediatrician to discuss his increased thirst, but the pediatrician's office had no notes in the child's file about the child's cold or thirst. The state's attorney declined to file criminal charges. DCFS indicated the child's mother and stepfather for death by neglect (#51). DCFS unfounded the investigation for head injuries by abuse (#2), and for substantial risk of physical injury/environment injurious to health and welfare by neglect (#60).			
<u>Reason for Review:</u> In August 2022, DCFS received a report that the family's pediatrician sent the child's then 6-month-old sister to the hospital for low weight, and medical staff determined her weight was due to improper feeding. The mother had also missed 2-month and 4-month checkups for the baby. The CPI met with the mother at the hospital, who reported she fed the sister, but the baby had been spitting up a lot, so she thought she was feeding her too much. The mother explained she missed some appointments because of lack of transportation. She reported she had five children at home, including the then 5-year-old child, who had special needs. The CPI learned the family agreed to in-home nursing care. The hospital released the sister to the care of the mother after the family agreed to in-home nursing care. The mother later reported the sister's doctor placed her on a new formula and feeding schedule. The mother agreed to intact family services and noted they would need to find new housing soon because their landlord planned to sell their home. Throughout the investigation, the sister continued to gain weight and her pediatrician reported she was growing and developing well. DCFS indicated the child's mother and stepfather for failure to thrive (#81). DCFS opened a high-risk intact family services case. The intact worker met weekly with the family at their home. In March 2023, the mother reported they were given a five-day eviction notice and she was looking for new housing and employment. She stated the family would stay at a hotel if they did not locate a new apartment in time and the intact worker made a referral for Norman funds. One week later, DCFS received a report that the then 5-year-old child did not receive appropriate follow-up medical care, including missed appointments with pulmonology and missed treatment injections. The CPI saw the family at home and noted the child was seen sleeping on the couch, hooked up to his g-tube, and he showed no outward signs of abuse or neglect. The mother and the DSCC worker reported the child received his injection one week earlier and had additional appointments scheduled. The parents reported they were still looking for a new home. In May 2023, the CPI observed the family in their new home and noted the home was appropriate. The reporter informed the CPI the family had attended all appointments since the hotline call. The CPI also spoke with the DCFS nurse, who noted the child had a terminal condition and his mother had a right to refuse the injections. The child's pediatrician stated she did not believe the child was medically neglected. Before the investigation closed, the mother reported she was getting back on track with finances, they had a new home and new car, and they received in-home nursing services five or more days per week. DCFS unfounded the investigation for medical neglect (#79).			

The intact case remained open at the time of the child's death.