pennsylvania
DEPARTMENT OF HUMAN SERVICES

REPORT ON THE NEAR FATALITY OF:

[redacted]

Date of Birth: 09/13/2013
Date of Incident: 02/09/2017
Date of Report to ChildLine: 02/09/2017
CWIS Referral ID: [redacted]

FAMILY KNOWN TO COUNTY CHILDREN AND YOUTH AGENCY AT TIME OF INCIDENT OR WITHIN THE PRECEDING 16 MONTHS:

Lancaster County Children and Youth Social Services Agency

REPORT FINALIZED ON:
08/07/2017

Unredacted reports are confidential under the provisions of the Child Protective Services Law and cannot be released to the public.
(23 Pa. C.S. Section 6340)

Unauthorized release is prohibited under penalty of law.
(23 Pa. C.S. Section 6349 (b))

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Reason for Review:

Pursuant to the Child Protective Services Law, the Department, through OCYF, must conduct a review and provide a written report of all cases of suspected child abuse that result in a fatality or near fatality. This written report must be completed as soon as possible but no later than six months after the date the report was registered with ChildLine for investigation.

The Child Protective Services Law also requires that county children and youth agencies convene a review when a report of child abuse involving a fatality or near fatality is substantiated or when a status determination has not been made regarding the report within 30 days of the report to ChildLine.

Lancaster County has convened a review team in accordance with the Child Protective Services Law related to this report. The county review team was convened on 02/22/2017 and 03/22/2017.

Family Constellation:

First and Last Name:	Relationship:	Date of Birth
[redacted]	Biological Mother	[redacted]1973
	Victim Child	09/13/2013
	Sibling	[redacted]2004
	Sibling	[redacted]2002
	Biological Father	[redacted]1972
	Sibling	[redacted]2000
	Sibling	[redacted]1997
	*Deceased Sibling	[redacted]1996
	Sibling	[redacted]2006
	Sibling	[redacted]2009
	Sibling	[redacted]1996

* Denotes an individual that is not a household member or did not live in the home at the time of the incident, but is relevant to the report.

Summary of OCYF Child (Near) Fatality Review Activities:

The Central Region Office of Children, Youth and Families obtained and reviewed all current records pertaining to the case to include various medical reports, assessments and case documentation.

Summary of circumstances prior to Incident:

On April 09, 2014 Lancaster County Children and Youth completed a courtesy visit for Perry County Children and Youth for a registered medical neglect of a one year old victim child. The child was born with [redacted] which is very prevalent in the Amish community, however, it is also very serious. The parents did not seek medical attention for the child when the initial symptoms arose. The family had

been working with [redacted] in Lancaster. The family wanted to do a homeopathic approach to the child's illness, and was working with [redacted] to do this. The child needed [redacted] Later the family disagreed with the diagnosis and [redacted] to the child. As a result the child was hospitalized. Perry County Children and Youth opened the case for services and enacted a safety plan. Two different doctors were consulted on the case with both having differing opinions on how to proceed from a medical standpoint. One doctor's focus was to make the child as comfortable as possible and the other doctor [redacted] The family started using new formula mixes and supplements to address [redacted] The child slightly improved as a result of the change in formula but [redacted] would be permanent. The case was unfounded and closed. No additional information could be obtained because the record was expunged.

Circumstances of Child (Near) Fatality and Related Case Activity:

On 02/09/2017, a report was received that the three year old male victim child who was [redacted] at Children's Hospital of Philadelphia [redacted] was in serious condition as a result of a his parents not following the recommended treatment plan. [redacted]

[redacted] indicated that they attempted to work with the family since 01/19/2017. They have sent letters to family and have spoken with both parents [redacted] have instructed the family on giving the child a special formula and specific food to prevent reactions and stabilize the child disorder. [redacted] When the parents were asked about the child's condition they reported the child had a poor reaction to the prescribed diet. The mother indicated that she makes her own formula using unpasteurized cow's milk [redacted] and has been doing this since June 2014. [redacted] As a result of the metabolic disorder, the child is small for his age and not growing. The child is severely developmentally delayed and cannot walk or talk.

The doctor registered the report as a near fatality on 02/19/2017 because of on-going concerns with the child's health. The doctor also decided the child was not critical enough to warrant a hospital stay at that time and the child [redacted] with follow up care instructions [redacted] Lancaster county children and youth services conducted a home visit on 02/20/2017. The meeting was held with the mother and Amish community liaison to discuss a safety plan. The mother said that she understands what the doctors are prescribing but disagrees with the medical plan. [redacted] Lancaster County Children Youth enacted a safety plan that included having an Amish community member supervise the feedings of the child [redacted] The safety plan was monitored by the agency through announced and unannounced visits.

The family decided they wanted a second opinion regarding the child's ongoing medical treatment. On 02/27/2017, the child was seen [redacted] in Washington DC at the National Children's Health Center. The mother reported to the doctor that [redacted] and as a result, the child has decreased his bottle intake from 10 down to 7-8 bottles per day. The mother reported the child was dehydrated and constipated but sleeping well. [redacted] It was recommended the family follow up with the primary care physician that has treated the child for the disorder over the past three years. The primary care physician recommended the family rotate the different types of milk (goat, buffalo, cow milk) to meet the child's supplemental needs. The primary care physician will be used to address any acute medical concerns that might require recommendations for hospitalization. The family has agreed to continue long term follow up care with the Nation Children's Center in Washington DC. The mother was also looking to take the child to another doctor [redacted] in Norristown, PA for another opinion. During the course of the investigation the child was receiving formula as well as spring water for his food and hydration. The family was cooperative and allowed home nursing to visit regularly to ensure the wellbeing of the child. There were no additional hospitalization during the investigation. Lancaster Children and Youth lifted the safety plan on April 7, 2017 and the case was closed as unfounded.

At the beginning of the case, the agency submitted a referral to the Pennsylvania State Police for follow up. There were no criminal charges against the parents and the police closed the case.

County Strengths, Deficiencies and Recommendations for Change as Identified by the County's Child (Near) Fatality Report:

- Strengths in compliance with statutes, regulations and services to children and families;
  - An immediate response tag was assigned to the case.
  - The Agency was prompt with its investigation, meeting all required timeframes. There were no other child welfare concerns for this family.
  - All individuals involved with the family were interviewed.
  - The Caseworker requested all medical records for [redacted] and consulted with all treating physicians.
  - The Agency developed a Safety Plan to meet the needs of the children and ensure their safety, and was able to preserve the family and avoid placement.
  - The caseworker and mother engaged in a conference call with the treating physician to discuss the child's disease and created a treatment plan to ensure that everyone understood the treatment plan for the child.
  - The child will be referred [redacted] for screening as per CAPTA regulation.
  - Agency contacted the Amish Bishop to follow through with mother and family to assure the safety of the child.
  - The case returned to the MDT the following month to provide an update to the committee and discuss additional recommendations.

- Deficiencies in compliance with statutes, regulations and services to children and families;
  - None noted

- Recommendations for changes at the state and local levels on reducing the likelihood of future child fatalities and near fatalities directly related to abuse;
  - None noted

- Recommendations for changes at the state and local levels on monitoring and inspection of county agencies; and
  - None noted

- Recommendations for changes at the state and local levels on collaboration of community agencies and service providers to prevent child abuse.
  - The caseworker will explore with the parents if other members of the extended family have been diagnosed [redacted] Early detection of the disease can significantly reduce permanent brain damage by changing the diet of the child.

Department Review of County Internal Report:

The Central Region Office of Children, Youth and Families received the Lancaster County Child Near Fatality Team Report on 05/19/2017. The report content and findings are representative of what was discussed during the meeting on 2/22/2017. Lancaster County Children and Youth continued to investigate the case

beyond the Act 33 meeting. The county held a follow up multi-disciplinary team meeting on 03/22/2017.

Department of Human Services Findings:

- County Strengths:
  - The county demonstrated appropriate collaboration with law enforcement and medical professionals throughout the investigation.
  - The agency worked quickly to assure the safety of the child by enacting a safety plan for feeding the child.
  - Due to the high population of Amish families in the county, the agency continues to work diligently on maintaining and building rapport with elders and Amish community members.

- County Weaknesses: and
  - None found

- Statutory and Regulatory Areas of Non-Compliance by the County Agency.
  - None found

Department of Human Services Recommendations:

Given the child's diagnosis is permanent and the family has already been referred to two different county and youth agencies, there is a high likelihood additional referrals will be made regarding how the family is proceeding with the child's medical care. Additional referrals regarding the family not meeting the child's medical needs may result in need to remove the child from his home.

The Department agrees with Lancaster County Children and Youth that early detection of the disease in children can significantly reduce permanent brain damages by changing the child's diet. If this metabolic disorder is more prevalent among certain populations, targeted educational campaigns could be done to help educate parents on the disorder.