

90-Day Summary Report for Child Death, Serious Injury or Egregious Incident

Reports submitted to the Division of Safety and Permanence (DSP) that do not include all of the required information will be returned to the agency for proper completion. Do not identify individuals by name when completing this report. Individuals may be referenced by relationship or position; e.g., mother, father, child, sibling, physician, detective, etc.

Case Tracking Number: 111117DSP-Monr-166 **Agency:** Monroe County Dept. of Human Services

Scope of DSP Review of Incident

- No Review. The information contained in this report was provided by the agency.
 90-Day Review

Child Information (at time of incident)

Age: 5 months Gender: Female Male

Race or Ethnicity: Caucasian

Special Needs: Severe Combined Immunodeficiency

Date of Incident: 11/17/11

Description of the incident, including the suspected cause of death, injury or egregious abuse or neglect:

A medical professional committee reviewed the infant's diagnosis of Severe Combined Immunodeficiency and treatment plan, and indicated that he required a bone marrow transplant. Reportedly, the Amish child was near death and the family declined necessary treatment. On the same day the report was made to the agency, the child was pronounced deceased. The father explained that they had taken the infant to the family physician, and that he had provided them with two treatment options; care at home or a bone marrow transplant. After consultation, discussion, and prayer, the parents decided to provide care at home under the direction of the primary care physician. The parents felt that with the treatment provided by the physician and prayer, the infant had a chance of getting better and living a quality life. On 10/18/2011, the parents took the infant to the doctor for respiratory distress and were prescribed antibiotic medication, the parent's administered the medication and the infant's cough went away and he was doing better. On 11/14/2011, the family consulted with the physician over the infant's decreased appetite, and health decline. It was determined by the physician that the infant was near death and the physician prescribed pain medication to provide end of life care. The infant passed away on 11/17/2011, the physician signed the death certificate and listed Severe Combined Immunodeficiency related illness as the cause of death. No other concerns about the family were noted during the initial assessment. No criminal charges were filed in connection with the infant's death.

Findings by agency, including maltreatment determination and material circumstances leading to incident:

The agency unsubstantiated neglect to the infant by his parents. There are eight other children in the care of the biological mother and father, and these siblings were determined safe in the couple's care. The infant was born with a genetic disorder, Severe Combined Immunodeficiency (SCID), and had been under the care of a primary care physician. The physician had counseled the family about possible treatment options including care at home, and had answered the parent's questions about bone marrow transplant. The family took the infant to the physician when he displayed signs of respiratory distress, and administered the prescribed medication. Later the physician provided in house care and started palliative care. The physician felt the family's course of action was appropriate. The parents have had two other children that have died of SCID related illnesses as infants, one of whom never left the hospital after birth.

It appears there is great divide in the medical community over treatment of Severe Combined Immunodeficiency (SCID). The primary care physician felt this family's course of action was appropriate and it was not a case of medical neglect. The physician stated that he has been speaking with the Clinic for Special Children in Pennsylvania, which works heavily with the Amish in Lancaster County, PA. They have indicated to the physician that his approaches would be recommended, not a "heavy handed approach" of forced transplantation. In addition, the Children's Hospital of Wisconsin indicates that besides bone marrow transplant, other treatment options for SCID include "giving the child injections to help boost the child's immune system, and treating each infection very promptly and accurately." Documentation states that "Specific treatment for SCID will be determined by your child's physician based on: child's age, overall health, and medical history; extent of disease, child's tolerance for specific medications, procedures or therapies; expectations

Child's residence at the time of incident: In-home Out-of-home care placement

Complete the appropriate following section (A. or B. based on the child's residence at the time of the incident).

A. Children residing at home at the time of the incident:

Description of the child's family (includes household members, noncustodial parent and other children that have visitation with the child and/or in the child's family home):

The infant resided with his biological parents and his eight siblings.

Yes No **Statement of Services:** Were services under ch. 48 or ch. 938 being provided to the child, any member of the child's family or alleged maltreater at the time of the incident, including any referrals received by the agency or reports being investigated at time of incident?

If "Yes", briefly describe the type of services, date(s) of last contact between agency and recipient(s) of those services, and the person(s) receiving those services:

N/A

Summary of all involvement in services as adults under ch. 48 or ch. 938 by child's parents or alleged maltreater in the previous five years: (Does not include the current incident.)

None

Summary of actions taken by the agency under ch. 48, including any investigation of a report or referrals to services involving the child, any member of the child's family living in this household and the child's parents and alleged maltreater at the age of 18 years or older. (Does not include the current incident.)

(Note: Screened out reports listed in this section may include only the date of the report, screening decision, and if a referral to services occurred at Access. Reports that do not constitute a reasonable belief of maltreatment or threatened harm may not be screened in for an initial assessment, and no further action is required by the agency.)

None

Summary of any investigation involving the child, any member of the child's family and alleged maltreater conducted under ch. 48 or ch. 938 and any services provided to the child and child's family since the date of the incident:

The agency unsubstantiated neglect to the deceased infant. His siblings were determined safe in the care of the biological mother and father. The deceased infant had been diagnosed with a genetic condition and was under the care of a physician; his siblings do not share his medical diagnosis. The family was offered information regarding counseling; however they declined the information and stated that their community has been very supportive. The agency closed the case upon completion of the initial assessment.

B. Children residing in out-of-home (OHC) placement at time of incident:

Description of the OHC placement and basis for decision to place child there:

Description of all other persons residing in the OHC placement home:

Licensing history: Including type of license, duration of license, summary of any violations by licensee or an employee of licensee that constitutes a substantial failure to protect and promote the welfare of the child.

Summary of any actions taken by agency in response to the incident: (Check all that apply.)

- | | |
|---|--|
| <input checked="" type="checkbox"/> Screening of Access report | <input type="checkbox"/> Attempted or successful reunification |
| <input type="checkbox"/> Protective plan implemented | <input type="checkbox"/> Referral to services |
| <input checked="" type="checkbox"/> Initial assessment conducted | <input type="checkbox"/> Transportation assistance |
| <input type="checkbox"/> Safety plan implemented | <input checked="" type="checkbox"/> Collaboration with law enforcement |
| <input type="checkbox"/> Temporary physical custody of child | <input checked="" type="checkbox"/> Collaboration with medical professionals |
| <input type="checkbox"/> Petitioned for court order / CHIPS (child in need of protection or services) | <input type="checkbox"/> Supervised visitation |
| <input type="checkbox"/> Placement into foster home | <input type="checkbox"/> Case remains open for services |
| <input type="checkbox"/> Placement with relatives | <input checked="" type="checkbox"/> Case closed by agency |
| <input type="checkbox"/> Ongoing Services case management | <input type="checkbox"/> Initiated efforts to address or enhance community collaboration on CA/N cases |
| | <input type="checkbox"/> Other (describe): |

FOR DSP COMPLETION ONLY:

DEPARTMENT OF CHILDREN AND FAMILIES

Division of Safety and Permanence

Summary of policy or practice changes to address issues identified during the review of the incident:

None - No DSP Review

Recommendations for further changes in policies, practices, rules or statutes needed to address identified issues:

None - No DSP Review

Yes No Not Applicable This 90-day summary report completes the Division of Safety and Permanence (DSP) review of this case.

If the case review was not completed within 90 days, the DSP will complete and submit the final summary report within 6 months.

The agency must submit an electronic copy of the completed 90-Day Summary Report to PaulaL.Brown@wisconsin.gov