**Section 661.110 Early Hearing Detection and Intervention (EHDI) Registry**

a) The Department will *maintain a registry of cases*. The Department will *maintain a registry documenting screening, diagnosis, and intervention of cases of positive hearing screening results, including information needed for the purpose of follow-up services.* (Section 15 of the EHDI Act).

b) *Physicians, advanced practice registered nurses, physician assistants, otolaryngologists, audiologists, ancillary health care providers, early intervention programs and providers,* parent support, *parent-to-parent support programs, the Department of Human Services, and the University of Illinois at Chicago Division of Specialized Care for Children shall report all hearing testing, medical treatment, and intervention outcomes related to newborn hearing screening or newly identified hearing loss for children birth through 6 years of age to the Department,* including newborns, infants and children born out-of-state and in need of follow-up services in Illinois. *Reporting shall be done within 7 days after the date of service or after an inquiry from the Department.* (Section 10 of the EHDI Act). *Reports shall be submitted to the Department in a format determined by the Department*.

c) Medical care facilities shall submit the following for every newborn, infant or child to whom a newborn hearing screening test is administered:

1) Newborn, infant or child's name (first, middle and last);

2) Newborn, infant or child's date of birth;

3) Nursery, i.e., NICU, SCBU, well baby;

4) Newborn, infant or child's gender;

5) Newborn, infant or child's birth order;

6) Newborn, infant or child's place of birth;

7) Unique identification number assigned to newborn, infant or child's;

8) Full legal name of both parents;

9) Full legal name of legal guardian or caregiver, if applicable;

10) Date of birth of both parents;

11) Date of birth of legal guardian or caregiver, if applicable;

12) Time, date, screening technology and individual-ear screening results for each screening session;

13) Any risk factors for hearing loss;

14) Follow-up plan of care;

15) Medical care facility to where the newborn, infant or child is transferred, date of transfer and reason for transfer, if applicable;

16) Date of death for newborns, infant or children who expire prior to discharge, if applicable;

17) Name of the facility or physician submitting the test results; and

18) Address of facility or physician submitting the test results.

d) Medical care facilities shall submit the following for every newborn, infant or child who does not pass the final hearing screening prior to discharge:

1) Residential address and telephone number, including street address, city, county, state and ZIP code of newborn or infant;

2) Residential address and telephone number, including street address, city, county, state and ZIP code of both parents, legal guardian or caregiver, if different from residential address and telephone number of the newborn, infant or child;

3) Interventions administered, if any;

4) Support services referrals, if any; and

5) Name and address of primary healthcare provider who will care for the newborn, infant or child after discharge.

e) EHDI service providers

1) EHDI service providers shall submit the following information:

A) Provider, location and type of hearing testing; ear specific information; diagnosis; treatment plan; and recommendations;

B) Broken or re-scheduled appointments;

C) Follow-up services;

D) Part C and non-Part C intervention services, supports and enrollment status for the newborn, infant or child and the newborn, infant or child's family, legal guardian or caregiver; and

E) Parent, parent-to-parent or EHDI-related support services.

2) Service provider submissions shall include, at a minimum, the following:

A) Newborn, infant or child's name (first, middle and last);

B) Newborn, infant or child's date of birth;

C) Newborn, infant or child's gender;

D) Newborn, infant or child's primary healthcare provider or clinic;

E) Newborn, infant or child's birthplace, if available;

F) Residential address and telephone number, including street address, city, county, state and ZIP code of newborn, infant or child;

G) Residential address and telephone number, including street address, city, county, state and ZIP code of both parents, legal guardian or caregiver, if different from residential address and telephone number of newborn, infant or child;

H) Primary language spoken in the home of the newborn, infant or child, if available;

I) Name, address and credentials of service provider; and

J) Any known risk factors for hearing loss, if available.

f) The Department of Human Services, Bureau of Early Intervention or their designee shall submit the following minimum information:

1) Enrollment status of any newborn, infant or child with a confirmed or suspected hearing loss;

2) Dates of service to include at minimum referral, enrollment, and exit dates for early intervention services;

3) Early intervention service coordinator, early intervention audiologist, and early intervention services listed on the individualized family service plan (IFSP); and

4) Reason for record closure when applicable.

g) *For the purposes of documentation and coordination of medical care or intervention services,* federal reporting, systematic monitoring and evaluation to promote quality standards *the Department may share identifiable newborn hearing screening information with medical care facilities, health care providers, early intervention programs and providers, local health departments, the Department of Human Services, the University of Illinois at Chicago Division of Specialized Care for Children,* parent support, parent-to-parent support organizations and the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC). (Section 23(a) of the Illinois EHDI Act).

h) *Except in cases of willful or wanton misconduct, no health care provider, hospital, or medical facility acting in compliance with this* Section *shall be civilly or criminally liable for any act performed in compliance with this* Section, *including furnishing information required according to this* Section. (Section 23(c) of the federal EHDI Act).