

Questions & Answers about Data Collection

LONG-TERM FOLLOW-UP FOR CHILDREN WITH NEWBORN SCREENING CONDITIONS

Why does the Minnesota Department of Health (MDH) gather information about children with conditions included in Minnesota Newborn Screening?

We use the information that we gather to know if children and their families get the support and resources they want and need. We work with parents, health care providers, educators, local public health nurses, community-based organizations, and others as needed to connect families to resources, services, and support. Services may include those that support growth and development, such as early intervention, public health, and medical care. These resources and services give families information to think about as they make decisions. We work to make services available, easy to use, and helpful for families. We also strive to understand and improve outcomes for children over time. Information that we collect helps us monitor overall trends and shows us what is and is not working.

How does MDH learn of a child's diagnosis?

After the child's health care provider diagnoses the condition, they report it to MDH [[Minn. Stat. § 144.125, subdivision 1\(b\)](#)].

What information does MDH collect about children related to these conditions?

We collect demographic data and may collect information about screening, diagnosis, services and supports, interventions, and outcomes during childhood. For more detailed information on the information we collect, please contact the MDH Children and Youth with Special Health Needs program at 1-800-728-5420.

Who has access to this information?

Only designated MDH staff and contractors have access to this data. MDH takes privacy very seriously. Strict laws on data privacy protect this information ([Minn. Stat. § 13](#)). Staff and contractors have all completed data privacy training. Information in the database is carefully protected. It is not public. In addition, we only report information in aggregate. This means that numbers are combined and summarized for a group and that personally identifying information, such as names and birth dates, are not included.

QUESTION & ANSWERS ABOUT DATA COLLECTION

PO Box 64975
St. Paul, MN 55164-0975
800-728-5420
health.cyshn@state.mn.us
www.health.state.mn.us

December 2022

To obtain this information in a different format, call: 800-728-5420.