

Summary on the Proposed Update to the Nebraska Birth Defect Registry

- The Nebraska Birth Defect Registry was created by the Legislature in 1972 (found at Neb. Rev. Stat. 71-646 – 71-648), but has not been updated in the 46 years following its creation.
- In recent years, the Centers for Disease Control and Prevention (CDC) has undergone efforts to modernize birth defect monitoring. Evaluation of the Nebraska Birth Defect Registry requirements identified shortcomings and the need for the Legislature to update the registry. The following bullet points describe the proposed changes to modernize the registry:
 - The update would redefine the birth defects required for reporting to capture those recognized by the National Birth Defect Prevention Network. A link to the ICD-10-CM and ICD-9-CM codes for the included birth defects can be found [here](#).
 - Due to the amount of birth defects that are commonly identified after the first birthday, and in order to ensure the full capturing of the birth defects described above, the age cutoff for reporting would be updated from one-year of age to six-years of age. 13 states currently require reporting beyond the first year of life of the child.
 - Currently, the Nebraska registry only permits those present at the time of birth to report birth defects. The update would remove the present at birth requirement so that all treating providers are able to report discovered birth defects in a child.
 - Finally, the update authorizes the Department of Health and Human Services (DHHS) to release data from the registry to providers who may be caring for a child reported to the registry. This will ensure optimal support and referrals to various early intervention and support services, as necessary, for affected families.
- DHHS currently includes birth defect data on their vital statistics report. In the past, groups and organizations conducting research have requested birth defect data from DHHS, which the Department has been unable to provide due to the incompleteness of the data that is currently reported. Be assured, the data collected under the updated registry will still be subject to Nebraska medical and health data disclosure laws.
- DHHS stated that reporting for the updated registry will be able to utilize the existing technological infrastructure already in place and in use by providers across the state.

Questions on the proposed update to the Nebraska Birth Defect Registry? Please contact Dexter Schrodtt in the Office of Senator Matt Williams at 402-471-2642 or dschrodtt@leg.ne.gov