## North Dakota

### Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>ND</td>
<td>NONE</td>
<td>“Administrative duties of state and county agencies and confidential birth reports for newborns with visible congenital deformities are addressed in NDCC Chapter 50-10.” - <em>Title V</em> grant 2007 application to HRSA.</td>
<td>FROM: NBDPN State Profiles 2009:</td>
<td>“Data from the North Dakota Birth Defects Monitoring System is used to: 1) report incidence and prevalence of birth defects, 2) increase awareness of birth defects and identified risk factors, 3) help researchers and health –care providers learn more about preventing future problems, and 4) assure that children born with birth defects have access to needed health-care and other services.” [emphasis added]</td>
<td>NO</td>
<td>NO</td>
</tr>
</tbody>
</table>

**ND state website reports that NDCC 50-10 was repealed in 2007.**

*State Title V Block Grant Narrative, State: ND Application Year: 2007:*

“The Data Systems Development Program provides data on the health status of CSHCN's in order to provide evidence-based decisions for program development and service delivery. Major activities include State Systems Development Initiative (SSDI) grant administration, birth defects monitoring, needs assessment, performance and outcome monitoring, estimates of chronic disease prevalence, utilization and cost, and data-related publications.”

“Annual birth defects surveillance system: The state has developed a passive birth defects monitoring system. In the past, Title V staff have...”

**23-01-15. Research**
managed the database which is available electronically for program planning purposes. Ranking fell from a 3 to a 2 this year because consistency to obtain data was impacted by turnover in the SSDI Coordinator position. The SSDI Coordinator is responsible for the birth defects surveillance system in ND. Surveillance Registries are a primary focus of the 2007-2011 SSDI grant.//2007//"


“The North Dakota Birth Defects Monitoring System was established in 2003 as a means of identifying an collecting information about babies born with certain birth defects in North Dakota. The North Dakota Birth Defects Monitoring program is a passive surveillance system. Data are collected and linked from three secondary data sources. Because of the low numbers of both resident births and occurrences of individual birth defects in North Dakota, rates for each birth defect are averaged over five consecutive years to improve statistical stability of the data.”

**studies confidential - Penalty. 1. All information, records of interviews, written reports, statements, notes, memoranda, or other data procured by the state department of health, in connection with studies conducted by the state department of health, or carried on by the department jointly with other persons, agencies, or organizations, or procured by such other persons, agencies, or organizations, for the purpose of reducing the morbidity or mortality from any cause or condition of health is confidential and must be used solely for the purposes of medical or scientific research. [emphasis added]**