### District of Columbia

#### Birth Defects Surveillance System

<table>
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<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>
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| DC    | NO LAW FOUND | **Deneen Long-White:**

“Over the past ten years, birth defects has climbed to be the second leading cause of death among District of Columbia infants. In an effort to address this issue, the Department of Health (DOH) began the District of Columbia Birth Defects Prevention and Surveillance Program (DCBDPS).

To ensure coordinated comprehensive activities, one key feature was required - the integration of this new surveillance system with current MCH surveillance and program activities. In response, DOH looked to an existing Title V program, the Hospital Discharge Planner Program, and the integrated Universal Newborn Infant Tracking System (UNITS) to fill these requirements.

**Deneen Long-White:**

“So whoever is accessing the system can see all this at once for a particular child. And we have our universal newborn infant tracking system, or UNITS, that actually houses all of this information for a particular child.”

**Deneen Long-White:**

“Yeah, actually this is just one integrated system. We have—through our SSDI grant, we have a much larger system which is more of a research type system where all this information is dumped. And it links to the immunization, but we also want to try to get that ‘cause we want to follow these children through 24.”

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<th>Consent Required?</th>
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<tbody>
<tr>
<td>NO</td>
<td>YES (…but No)</td>
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Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008.

Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature.

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Integration occurs at multiple levels from data collection, database linkage, program planning and implementation, to referral and follow-up services. Key examples of integration include, at the data collection level, Discharge Planners funded through the Title V program and placed in hospitals are responsible for identifying infants with birth defects, collecting specific data, and beginning the process of linking the families to the State Title V Children with Special Health Care Needs (CSHCN) Program. The CSHCN Program is responsible for ensuring linkage of the family to needed services.

All information is housed in UNITS, an integrated database, which includes results of newborn hearing and metabolic screens, birth defects surveillance, lead screening, care coordination and Discharge Planner data reports.

Unidentified Speaker: What do you do about families that deny any services?

Deneen Long-White: Um, we note that they deny the services, but we still track them. [emphasis added]

The DCBDPS is an excellent example integrating surveillance of a smaller population into larger MCH surveillance. In addition, it serves as a model for utilizing public/private partnerships to effectively and efficiently conduct surveillance and monitoring.” – Dec 13, 2005 presentation, American Public Health Association,

Deneen Long-White (Chief, Data Collection and Analysis Division, DC Department of Health) made the comments during MCHB Conference Webcast, AMCHP 2004, E4-Making Connections: Linking Birth Defects Surveillance Systems, Newborn Screening and Title V(CSHCH)—3/1/2004,

http://apha.confex.com/apha/133am/techprogram/paper_117619.htm