

## Birth Defects Surveillance Programs Overview

Birth defects are the leading cause of death in children less than one year of age, affecting one in every 33 births.<sup>1</sup> Birth defects affect overall health, development, and function, often requiring special medical care throughout the lifespan. The most common birth defects are heart defects, cleft lip and cleft palate, Down syndrome, and spina bifida.<sup>2</sup> By conducting birth defects surveillance, states are able to identify children in need of services and ensure appropriate referral, evaluate service utilization by referred families, and improve services in areas where these conditions are prevalent.<sup>3</sup>

Forty-three states, the District of Columbia, and Puerto Rico currently track birth defects, with 42 of these programs based in state public health agencies. How birth defects are tracked and detected varies depending on funds available to the state or territory. Surveillance programs utilize a number of different funding sources; the CDC currently funds 65 percent of existing birth defects surveillance programs, and only 15 states are funded by CDC to maintain birth defects registries. A study by the Trust for America's Health found that state and territorial health officials want to expand their birth defects registry programs but do not have the resources to do so.<sup>4</sup>

One potential avenue toward expanding the capacity of birth defects surveillance systems involves birth defects programs and their partners coordinating resources to enhance health information exchange activities. Increased data sharing would enable state and territorial programs to strengthen their overall impact by expanding the number of information sources they tap into and the types of birth defects conditions they monitor. By strengthening their connections to data sources and partners and creating more efficient and effective two-way data exchange systems, state programs could potentially increase their funding support, increase their number of data sources, and improve the overall birth defects surveillance system.

The following fact sheets outline the results of a 2009 ASTHO online survey of 43 state and territorial birth defects programs. The survey assessed state approaches to birth defects surveillance and tracking, including the following information:

1. Data sources.
2. Funding.
3. Personnel.
4. Data sharing.
5. Data exchange.
6. Data use and dissemination.

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<sup>1</sup> "Update on overall prevalence of major birth defects – Atlanta, Georgia, 1978-2005." Morbidity and Mortality Weekly Report. 2008. 57(01):1-5. Available at [www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm). Accessed 1/23/2013.

<sup>2</sup> March of Dimes. "Birth Defects Research." Available at [www.marchofdimes.com/research/faq\\_researchcommonbirthdefects.html](http://www.marchofdimes.com/research/faq_researchcommonbirthdefects.html). Accessed 12/26/2012.

<sup>3</sup> Sever, LE (ed). *Guidelines for Conducting Birth Defects Surveillance*. Atlanta, GA: National Birth Defects Prevention Network, Inc. 2004.

<sup>4</sup> Trust for America's Health. *Birth Defects Tracking and Prevention One Year Later: One Step Forward. Two Steps Back?* Washington, DC: Trust for America's Health. 2003.