

Birth Defects Surveillance Program Data Sources

State-based birth defects surveillance programs use case ascertainment strategies to identify birth defects cases. Case reporting is a passive strategy in which programs receive reports from one or more data sources, requiring programs to provide detailed instructions to data sources to ensure accurate and consistent reporting.¹ Case finding is more proactive and uses trained staff to conduct systematic investigations to find, identify, and register birth defects cases.² Despite the differences in these approaches, comparable results can be obtained.

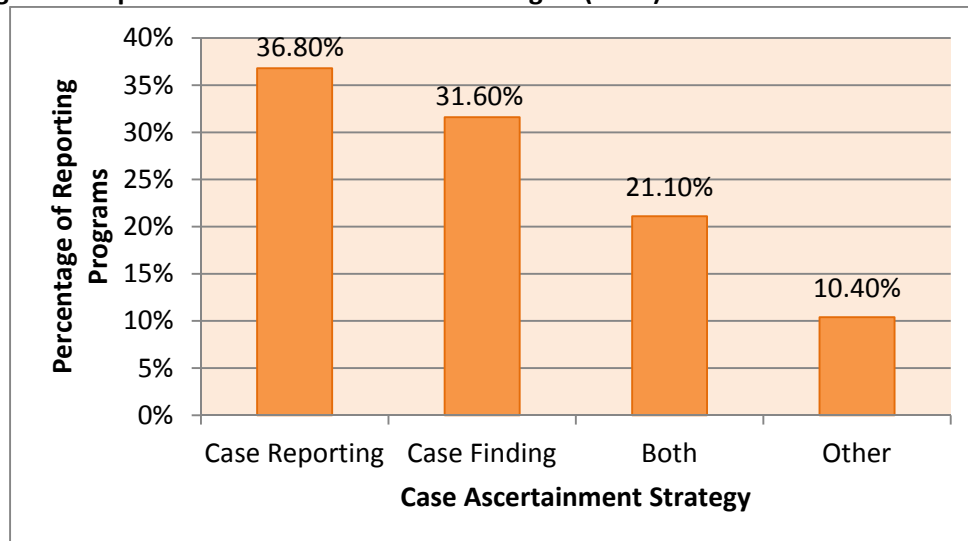
Birth defects surveillance programs monitor major defects (i.e., conditions present at birth that cause structural changes in one or more body parts) that affect a baby's health, development, and functional ability.³ With inadequate resources, programs may be forced to limit the number and types of conditions they monitor, reducing their overall impact.

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Methods and Results

In 2009, ASTHO conducted an online survey of 43 state and territorial birth defects programs to assess their approaches to birth defects surveillance and tracking. State-based programs identified whether they used case reporting, case finding, or a combination of both to determine the prevalence of birth defects (Figure 1). Case ascertainment strategies are determined by the program's objectives and the data sources they can access with their available resources.

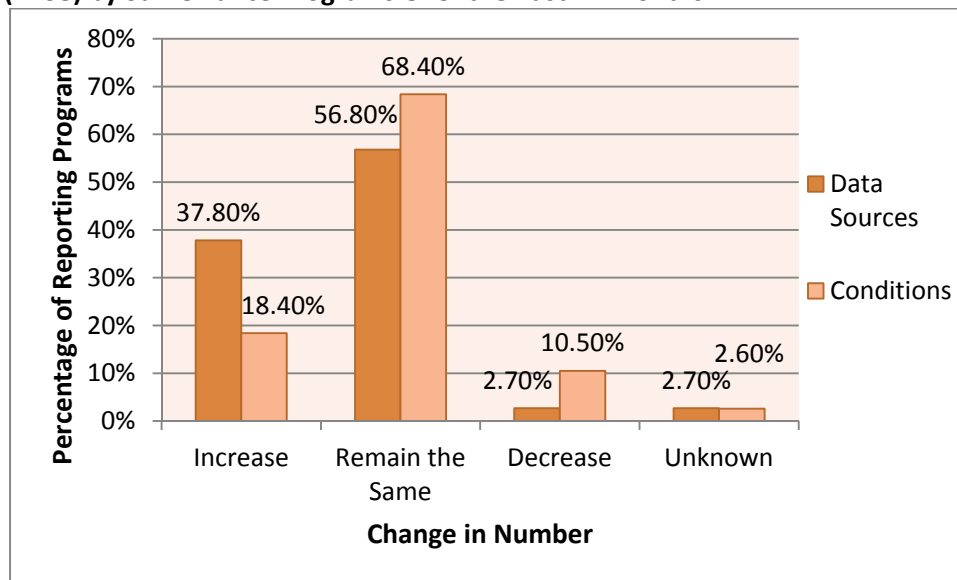
Figure 1. Reported Case Ascertainment Strategies (n=38)



Prenatal diagnosis is evolving as an important data source in birth defects surveillance. Since prenatal diagnosis provides the option for women to electively terminate affected pregnancies, using prenatal diagnostic data to identify birth defects in fetuses or embryos provides valuable information for identifying risk factors. While more than half of the reporting programs (55.6%) indicated they used prenatal diagnosis, many (41.7%) indicated they were doing so with limited capabilities.

State-based birth defects surveillance programs often have limited funding, influencing the number of data sources used to identify children with birth defects and the number and types of conditions monitored. Figure 2 shows changes in both the number of data sources and number of conditions screened by responding programs over the past two years.

Figure 2. Change in Number of Data Sources (n=37) and Reported Conditions (n=38) by Surveillance Programs Over the Past 24 Months



Future

Despite funding challenges, many states anticipate that the number of data sources they use for birth defects surveillance will either increase (16 states) or remain the same (16 states) over the next two years (2010-2011). While only eight states expect to see an increase in the conditions monitored, 22 states foresee no changes in the conditions covered by their programs in the next 24 months. Given the known budgetary constraints, this may indicate that states are beginning to utilize data sharing or data exchange to enhance or maintain their current surveillance systems in a more cost-effective and efficient manner. Consistent surveillance activities will allow states to look at trends or relationships in the data and determine the effectiveness of birth defects prevention programs over time.

To increase the quantity of data available and strengthen the overall impact of birth defects surveillance, state-based programs should continue to expand the number and types of data sources used in identifying cases by specifically targeting data that would likely be missed by other sources. Survey results indicate that nearly 30 percent of respondents are looking to target prenatal diagnosis in the future. This will provide valuable information for estimating prevalence rates and identifying birth defects risk factors.

¹ Sever, LE (ed). *Guidelines for Conducting Birth Defects Surveillance*. Atlanta, GA: National Birth Defects Prevention Network, Inc. 2004.

² Ibid.

³ Ibid.