

Birth Defects Surveillance Program Data Sharing

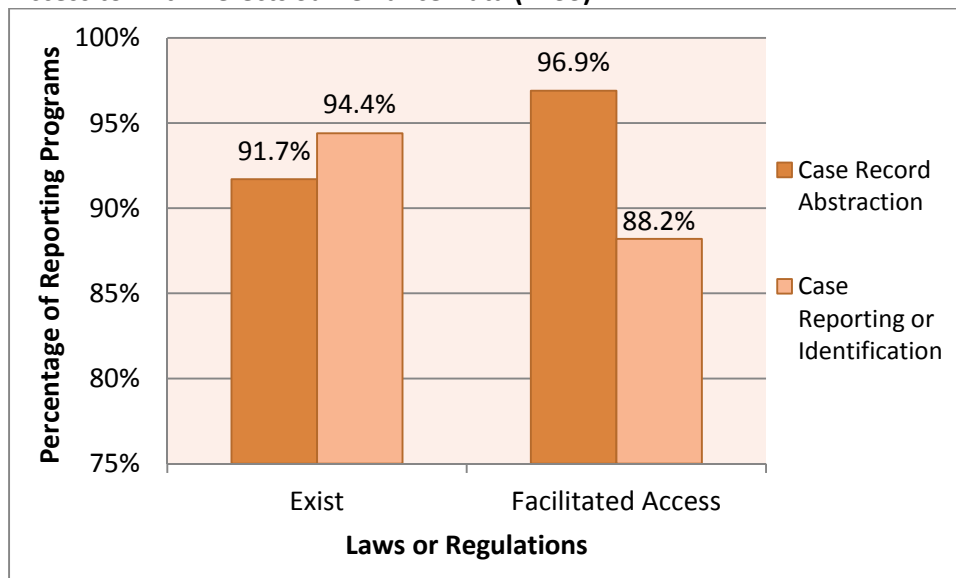
Partnerships play a significant role in state-based birth defects surveillance programs' success. Access to data from resources and partners is often determined by state legislation or regulations that support and facilitate birth defects surveillance program activities. With the appropriate laws and regulations in place, data sources (e.g., medical records, hospital discharge data, or other medical information) containing pertinent information can be shared with the state's birth defects program, increasing the overall effectiveness of the surveillance system.

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. States were asked to assess any laws or regulations, both in existence and in development, which may have affected their program's ability to access certain birth defects data. A majority of respondents reported that their state did have laws or regulations in place addressing both case record abstraction (91.7%) and the reporting or identification of birth defects cases (94.4%), which either directly or indirectly affected their programs (Figure 1). States also reported that the overall effect of the laws or regulations facilitated birth defects case record abstraction (96.9%) or the reporting and identification of birth defects (88.2%).

Only 12 states reported that they had laws or regulations that require vital records to share fetal death data or death certificates with the birth defects program.

Figure 1. Percentage of Programs Reporting Laws or Regulations that Impact Access to Birth Defects Surveillance Data (n=33)



States also assessed the existence or development of laws or regulations that require data sharing between potential partners or data sources and their birth defects surveillance program. Table 1 summarizes the most commonly reported (>50% of states) partners or data sources affected by laws or regulations requiring data sharing with the birth defects program.

Table 1. Most Common Partners or Data Sources with Data Sharing Laws or Regulations (n=34-36)*

Partner or Data Source	Yes	In Development	Not Working on One	N/A**
	Delivery Hospitals: Chart Review	74.3%	0%	14.3%
Delivery Hospitals: Discharge Records	71.4%	0%	20.0%	8.6%
Physicians Reports	65.7%	0%	25.7%	8.6%
Pediatric/Tertiary Care: Specialty Outpatient Clinic	62.9%	2.9%	25.7%	8.6%
Prenatal Diagnosis Clinic/Facility	62.9%	0%	28.6%	8.6%
Pediatric/Tertiary Care: Other	61.8%	0%	29.4%	8.8%
Other Laboratories	54.3%	2.9%	34.3%	8.6%

*Note: Categories are not mutually exclusive; not all states responded to all partner or data source categories.

**N/A indicates that the state does not have the corresponding program (e.g. does not have local health departments).

Only 12 states reported that they had laws or regulations that require vital records to share fetal death data or death certificates with the birth defects program. In addition, fewer than 15 percent of reporting programs had laws or regulations requiring WIC (five states) or third-party payers (Medicaid [five states] and HMO/private insurance (two states)) to share their data. More than half of the programs indicated that no work was being done to establish laws or regulations with these key partners.

The absence of facilitating laws and regulations can be partially offset by an effective memorandum of understanding (MOU) between the partner or data source and the birth defects program. Table 2 presents the most commonly reported (>50% of states) partners or data sources that states identified as having existing MOUs or for which MOUs were not necessary (e.g., both the partner/data source and the birth defects program are part of an integrated data exchange system).

Table 2. Most Common Partners or Data Sources with MOUs (n=33-36)*

Partner or Data Source	Yes (or not needed)	In Development	Not Working on One	N/A**
	Birth Certificate	97.3%	0%	2.7%
Delivery Hospitals: Discharge Records	94.6%	0%	2.7%	2.7%
Delivery Hospitals: Chart Review	88.6%	2.9%	2.9%	5.7%
Vital Records: Death Certificates	86.1%	2.8%	11.1%	0%
Vital Records: Fetal Death	83.3%	2.8%	8.3%	5.6%
Pediatric/Tertiary Care: Specialty Outpatient Clinic	77.8%	2.8%	11.1%	8.3%
Pediatric/Tertiary Care: Other	75.0%	5.6%	11.1%	8.3%
Children with Special Health Needs	73.0%	5.4%	18.9%	2.7%
Early Hearing Detection and Intervention (EHDI)	69.4%	11.1%	16.7%	2.8%
Metabolic/Newborn Genetic Screening	69.4%	11.1%	19.4%	0%
Physician Reports	63.9%	2.8%	16.7%	16.7%
Prenatal Diagnostic Clinic/Facility	60.0%	5.7%	14.3%	20.0%

*Note: Categories are not mutually exclusive; not all states responded to all partner or data source categories.

**N/A indicates that the state does not have the corresponding program (e.g. does not have local health departments).

While many programs indicated that MOUs were in place or not needed with potential partners/data sources, several exceptions did exist. One-third or fewer of reporting states indicated having MOUs with environmental data (12 states), community health centers (12 states), Medicaid (10 states), WIC (nine states), the National Death Index (four states), regional health information organizations (three states), and HMO/private insurers (two states). Several states did indicate that they were in the process of developing agreements with Medicaid (five states) and WIC (four states). Implementing data sharing agreements with these key partners will allow for more accurate state birth defects surveillance data in the future.

Future

A majority of states indicated that laws or regulations have been passed that facilitate the process of birth defects case abstraction, reporting, and identification. However, more work may be necessary to allow access to specific data sources (e.g., fetal death records). While MOUs have some limitations, as they are not legally binding documents, states should explore these agreements as an opportunity to expand their surveillance systems in the absence of or pending the development of formal legislation or regulations.

By implementing laws and regulations that enable data sharing within a state, birth defects surveillance programs can continue to grow and expand their capacity. This is especially important as programs often face budgetary constraints. Increased data sharing will enable programs to strengthen the overall impact of their surveillance system by expanding their number of sources and the types of birth defects conditions that are monitored.