

*Monday, February 23, 11:00AM-11:45AM
Plenary Session*

Standards for Birth Defects Surveillance

Moderator: Carol Stanton, Colorado Dept. of Public Health and Environment, Denver, CO

Putting It Together: the Pillars of Birth Defects Surveillance in the Context of Public Health Practice

Lowell E. Sever, Battelle Centers for Public Health Research and Evaluation, Seattle, WA

Surveillance programs are an important cornerstone of public health practice. In this presentation I suggest that we look at birth defects surveillance in this context and that of the core public health functions of assessment, policy development, and assurance. These core functions are relevant to our desire to improve the quality of surveillance programs, through developing standards which support our efforts to improve the health of babies and children.

The NBDPN logo includes three important functional terms: surveillance, research, and prevention. This can also be conceptualized as an iterative loop, with each of these broad areas being linked with the other, similar to the linkages between the core public health functions.

The key value of surveillance standards relates to improving the consistency of quality data. In the recently-released Guidelines chapter on data presentation we developed a data-to-action continuum and I would argue that the entire process rests on a base of high quality data.

There are a number of ways to organize the component objectives of birth defects surveillance programs into categories. Last year at this meeting we introduced the concept of surveillance “pillars” representing three broad functional goals and the basic requirements for each. These are epidemiology/monitoring, research, and linking to services. What the move to establishing standards does is to take that an important step forward. One can think about this from the perspective of the guidelines saying what a program should do and the standards setting out what programs must do ensure that their data are of consistent quality to support each of the three categories we are calling pillars. Each of these pillars can be characterized as a category of “action” in the data-to-action continuum and the standards for each include dimensions that relate to assuring the completeness, accuracy and timeliness of surveillance data.

The pillars provide support for the ultimate public health practice objective of prevention. In this presentation I define prevention and discuss it in the public health context, integrating the surveillance pillars with the core functions of public health described earlier. The presentation closes by emphasizing the usefulness of standards to improving data quality.

Draft Standards for Birth Defect Surveillance

Bradley D. McDowell, Iowa Registry for Congenital and Inherited Disorders, Iowa City, IA

Lowell Sever described how the goals of birth defect surveillance programs can be organized under three pillars: epidemiology/monitoring, research, and linking to services. These three pillars ultimately support actions directed toward prevention. Members of the Surveillance Guidelines and Standards Committee (SGSC) have drafted sets of surveillance standards specific to each pillar. These three sets of standards are presented within a common organization of six “dimensions”: data variables, classification and coding, case ascertainment, case definition, data quality management, and data management and security.

The Guidelines Evaluation Workgroup wants your opinion on these standards! Please go to <http://www.nbdpn.org/current/resources/standards.html> to let us know what you think.