NATIONAL BIRTH DEFECTS PREVENTION NETWORK

Guidelines for Conducting Birth Defects Surveillance

Chapter 11
Data Presentation

DATA PRESENTATION WORKGROUP AND OTHER TECHNICAL CONTRIBUTORS

Ann Phelps, Chair (TX)
CJ Alverson (CDC)
Carla Becker (NE)
Amy Case (TX)
Janet Cragan (CDC)
Deborah Fox (NY)
Russ Kirby (AL)
James Kucik (CDC)
Peter Langlois (TX)
David Law (TN)
Cara Mai (CDC)
Craig Mason (ME)
Leslie O'Leary (CDC)
Tunu Ramadhani (TX)
Russel Rickard (CO)
Csaba Siffel (CDC)
Shihfen Tu (ME)
Jessica Tencza (CDC)

BATTELLE CENTERS FOR PUBLIC HEALTH RESEARCH AND EVALUATION

Lowell E. Sever, Editor
Joanne Abed, Technical Editor
Shyanika Rose and Kate Blessing, Technical Support

July 2008

Support for development, production, and distribution of these guidelines was provided by the Birth Defects Branch, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Copies of *Guidelines for Conducting Birth Defects Surveillance* can be viewed or downloaded from the NBDPN website at http://www.nbdpn.org/bdsurveillance.html.

Comments and suggestions on this document are welcome. Submit comments to the Surveillance Guidelines and Standards Committee via e-mail at nbdpn@cdc.gov.

You may also contact a member of the NBDPN Executive Committee by accessing http://www.nbdpn.org and then selecting Network Officers and Committees.

Suggested citation according to format of Uniform Requirements for Manuscripts Submitted to Biomedical Journals:∗

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

National Birth Defects Prevention Network, Inc.
Web site: http://www.nbdpn.org
E-mail: nbdpn@cdc.gov

∗International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to biomedical journals. *Ann Intern Med* 1988;108:258-265.

Table of Contents

Figures and Tables

Appendices

11.1 Using Data for Decision-Making

This chapter focuses on the fundamentals of data presentation for a birth defects surveillance program. A birth defects research program will have needs that go beyond what is addressed in this chapter. Readers are referred to the references and technical appendices in this chapter for additional information. The reader may also wish to refer to Chapter 8 (Statistical Methods) of The Surveillance Guidelines *for more in-depth treatment of some of the topics touched upon in this chapter. Finally, the Members Only section of the National Birth Defects Prevention Network (NBDPN) website will be posting materials on more advanced aspects of data presentation as they become available.*

Collecting data for data's sake wastes precious resources. There is no good reason to collect data unless we intend to use them, generally to *inform* someone in a position to *do* something about the story our data tell.

Surveillance data in particular are intended for use in accomplishing the purposes and objectives of the surveillance program. In Chapter 1 of *The Surveillance Guidelines* we discussed the five major purposes of birth defects surveillance and their related objectives, as presented below.

- *Epidemiologic.* Epidemiologic objectives include developing timely baseline birth defects rates, monitoring trends and relationships to environmental factors, performing cluster investigations, and providing a basis for ecologic and etiologic studies
- *Planning and prevention.* Planning and prevention objectives include providing data for services planning, providing a basis for prevention strategies, and evaluating the efficacy of preventive services and programs.
- *Educational and social.* Educational and social objectives include informing the public about public health importance, informing parents about resources and care facilities, providing data for studies of economic impact, and providing data for follow-up studies of long-term effects.
- *Healthcare and human services.* Healthcare and human services objectives include referring children to services and resources and evaluating services utilization.
- *Clinical.* A clinical objective is providing the basis for clinical research.

Of course, not all surveillance programs pursue all of these purposes and objectives, but every program pursues some combination of them, and all collect data as a means to achieve them.

In order to fulfill the objectives of a birth defect surveillance program in all of these core areas, data must be collected in a complete, accurate, and timely manner. They must also be processed and interpreted in a way that ensures the availability of useful information to those with the responsibility to carry out specific activities that meet the program's objectives. Under some circumstances, this is relatively straightforward. For example, if a programmatic objective is to connect babies with specific birth defects and their families with appropriate medical and social services, then data collected on diagnosis and parent contact information immediately provide the information needed to initiate an appropriate referral. Frequently, however, there is a need to aggregate, analyze, and interpret data and subsequently present the resulting information to a variety of partners capable of taking necessary action. It is this latter more complex process that is the focus of this chapter.

11.1.1 The Data-to-Action Continuum

Yet data are, after all, only data. How is it that the data so carefully collected by surveillance program staff are transformed into the many different kinds of actions necessary to achieve their programmatic objectives?

There are two points to consider in answering this question. First, surveillance staff clearly cannot accomplish all of these important objectives without the help of their partners. Second, the transformation of data into action is not a discrete one-time occurrence—such as standing up with your slide presentation in front of a live audience—but rather a complex process involving extended collaboration between surveillance staff and their partners over time. To be sure, it is through presenting data in a clear manner in response to expressed interests of a particular "audience" and in support of an actionable message that this transformation begins to occur. Yet we need to bear in mind that, while the data presentation theories and skills discussed in this chapter can be mobilized in aid of this transformation, they are in fact only one aspect of the larger collaborative process that transforms data into action.

We can conceptualize this transformation as having four stages (see Figure 11.1, the Data-to-Action Matrix), with surveillance program staff and their partners closely involved in each one. Sources are abstracted to obtain *data*. Data are analyzed and interpreted to obtain *information*. Information is communicated to develop *knowledge*. And knowledge is used to inform *action.* Data presentation, then, is one of several skills that support this process, as we convey information to our program partners in order to generate the knowledge needed to embark on actions that meet our shared objectives.

11.1.2 Products of the Data-to-Action Transformation

Figure 11.1 suggests that each stage of the data-to-action transformation results in a distinct "product": data (Stage 1), information (Stage 2), knowledge (Stage 3), and action (Stage 4).

Let's take a moment to clarify these terms. While this chapter is entitled "Data Presentation," we are not really talking about presenting *data*, but rather about presenting the *information* generated from data in the expectation of building *knowledge* for ourselves and our partners. Although the terms 'data' and 'information' and even 'knowledge' are often used somewhat interchangeably, there are important distinctions between them.

Simply put, the purpose of data is to record "something" and the purpose of information is to build knowledge. Data (from the Latin meaning "something given") consist of raw facts or unedited stimuli. They are based on the symbolic recording of something, such as numbers, facts, and figures. Data provide a foundation for and can be developed into information, but they must be combined and integrated with other data before they become useful.

While information includes data, data do not necessarily include information. Information is data with semantic association and is the result of processing, manipulating, and organizing data in a way that adds to the knowledge of the receiver. When augmented by meaning or interpretation, data become information. It is the information developed from data that provides answers to our questions and those of our partners about birth defects, thereby increasing our knowledge.

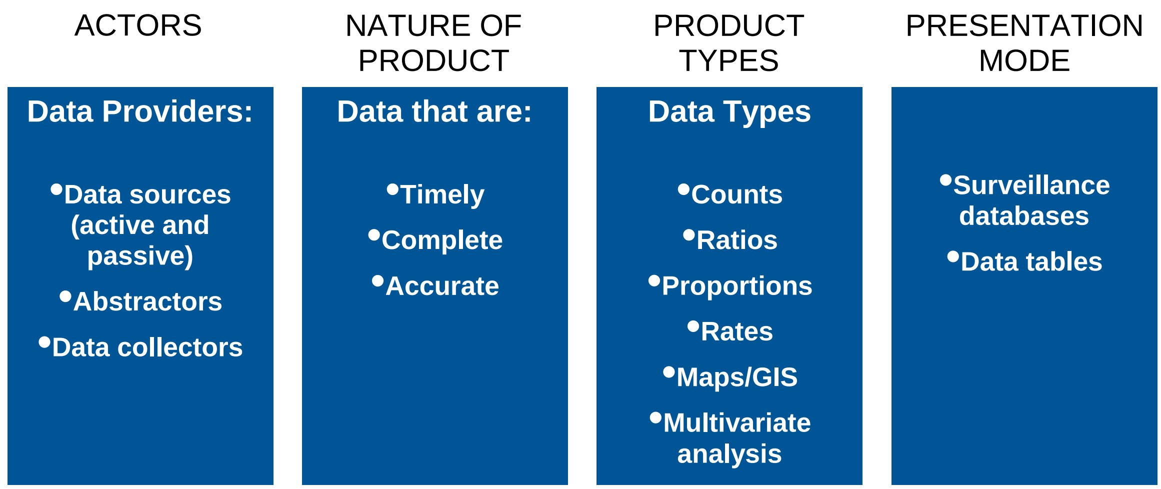
Figure 11.1 Data-to-Action Matrix

	ACTORS	NATURE OF PRODUCT	PRODUCT TYPES	PRESENTATION MODE
DATA	Data Providers	• Timely • Complete • Accurate	• Counts • Ratios • Proportions • Rates	• Surveillance databases • Data tables
INFORMATION	Data Interpreters	• Relevant • Useful • Compares like with like	• Within region • Across regions • Comparisons by population, time, geographic areas, benchmarks	• Histogram • Frequency • Bar chart • Graph • Spot map
KNOWLEDGE	Knowledge Makers	Generated through iterative, multi-directional communication	• Tailored presentations	• Discussion • Written feedback on presentations
ACTION	Action Takers	• Appropriate • Evidence-based • Maximally effective and cost-effective	• Estimating frequencies • Referrals to services • Planning services • Planning interventions • Conducting research • Cluster investigations	• Surveillance reports • Websites • Scientific publications • Policy papers • Guidelines • Intervention protocols • Risk communications • Press releases, media articles and shows

From the perspective of this chapter, our goal is to obtain data from a data provider (Stage 1–Data Provision), analyze and interpret it so that it becomes information (Stage 2–Data to Information), and then present it to and discuss it with one or more potential action takers so that it becomes knowledge that can be used to meet programmatic objectives (Stage 3–Information to Knowledge). It is then the action takers' responsibility to see that the new knowledge is used to meet the specific objectives of the program for which it has been collected and for which it is relevant (Stage 4–Knowledge to Action).

This chapter discusses each of the stages in the model in turn. We spend less time on the first and fourth stages, as both are thoroughly discussed elsewhere in *The Surveillance Guidelines*. Stage 4 (Knowledge to Action) is discussed further in Section 1.4 of *The Surveillance Guidelines* (Uses of Surveillance-based Birth Defects Data), and most of the rest of *The Surveillance Guidelines* address Stage 1 (Data Provision).

11.2 Stage 1 – Data Provision



With respect to the ability of surveillance data to provide useful information, the old axiom from statistics "garbage in, garbage out" holds true. Before a surveillance staff member can begin to think about how to present data, knowing what data to present and feeling confident that the data are accurate and reliable is paramount.

In fact, the value provided by the information developed using birth defects surveillance data depends heavily on the quality of those data and the completeness and accuracy with which they are collected. The majority of the technical content of *The Surveillance Guidelines* is directed toward helping to ensure completeness and accuracy of the data that are collected and their resulting validity.

From an epidemiologic perspective, when we refer to ***data validity*** we are concerned with whether the data regarding cases in a study or surveillance program accurately reflect the numbers and characteristics of the cases that occur and that are eligible for inclusion in the data set. When we are attempting to determine or measure the occurrence of birth defects in a population, it is essential that we include all of the cases that meet the established case definition (completeness). For cross-sectional or case-control studies, while completeness is important, in the absence of including all cases validity is driven by whether the cases that are included accurately reflect all the cases that occurred in the study population (population at risk) with respect to epidemiologic variables related to characteristics of person, place, and time.

In the next section we discuss some of the analytical and interpretative issues involved in turning surveillance data into information.

11.3 Stage 2 – From Data to Information

ACTORS	NATURE OF PRODUCT	PRODUCT TYPES	PRESENTATION MODE
Data Interpreters: •Data managers •Epidemiologists •Statisticians •Public health staff	**Information that is:** •Relevant •Useful •Compares like with like	**Information Types** •Within region •Across regions •Comparisons by population, time, geographic areas, benchmarks	•Histogram •Frequency •Bar Chart •Graph •Spot Map •Area Map

In *The Surveillance Guidelines*, we follow the Centers for Disease Control and Prevention (CDC) definition of ***surveillance*** as established in Chapter 1. The key themes of the CDC definition of surveillance are the integration of data collection, analysis, interpretation, dissemination, and application. It is in moving from analysis to interpretation that data are converted to information.

Some aspects of birth defects lead to potential confusion or ambiguity in reporting information about them and their distribution. In this section we discuss a number of analytical and interpretive issues that should be considered when developing and presenting birth defects data. These include:

- Providing contextual information (person, place, and time)
- Missing or unknown data
- Importance of comparison
- Approaches to measuring occurrence (prevalence versus incidence)
- Level of focus (which in part arises from the complex etiology and comorbid nature of many birth defects)
- Risk factors and the importance of timing with respect to exposures
- Privacy and data suppression (see also Appendix 11.1)
- Using Geographic Information Systems (see also Appendix 11.2)

11.3.1 Providing Contextual Information—Person, Place, and Time

When presenting data, it is useful to consider the key epidemiologic constructs of *person*, *place*, and *time*. What population is reflected in the data? From what location were data collected? And on what time period are the data based? One must be able to accurately and precisely answer these questions for the findings to be relevant. For example, a presentation may report very interesting results based on a sample that was collected in a very disorganized and biased manner, making it impossible to define exactly what population is reflected in the data set. Unfortunately, these results would be of limited value because it is impossible to define to whom the findings are relevant.

Similarly, whenever variation by person, place, or time occurs, analyses should examine possible differences or trends. If a sample includes multiple ethnic groups, are there differences between these groups? Or if data were collected over a decade, were trends seen over time? A presentation should acknowledge that such trends were examined and differences reported if observed.

In the actual presentation, it is often useful to present data grouped on the basis of person, place, and time. When doing so, it is important to be mindful of widely accepted groupings inside or outside your organization. For example, *person* characteristics such as age, race, and ethnicity can be grouped based on Office of Management and Budget classifications. Audience members will be familiar with such groupings and, more importantly, they will be better able to relate the findings to their own data based upon these common groupings than they would if the presenter organized the data in some idiosyncratic manner. Similarly, *place* can be presented in a variety of ways, including aggregating based on town, county, zip code, or census tract.

Information collected over *time* can lead to more complex issues, such as the decision to report raw curves or a moving average. The complexity of time-varying data requires that one be clear on both the time period and method used in presenting such information.

11.3.2 Missing or Unknown Data

An aspect of data presentation often overlooked is the importance of providing information about the extent of missing/unknown data for study variables. Information that is missing or unknown can be just as important to understanding results as is the available information. This is especially true when the amount of missing information is more than minimal. Missing or unknown information can be reported in such data displays as tables, histograms, and pie charts by including a category labeled ‘unknown’ (e.g., maternal age $\leq$ 34, maternal age 35+, and maternal age unknown). If the way the information is being presented does not allow for a row/column/line/bar/slice to be designated as ‘unknown’, a footnote should be added to the data display informing the audience about the extent of the unknown data. Maps based on geocoded data, for example, could add a footnote with the “percentage of data that was not geocoded” to the geographic resolution presented.

11.3.3 The Importance of Comparison

Epidemiologic data tend to be numeric and presented either as counts, ratios, proportions, or rates. In addition they are usually presented as information specific to the epidemiologic parameters of person, place, and time. Information presented in this manner provides a way of making meaningful comparisons between different populations and different periods of time. Note: the points made below are of particular importance when one will be comparing data collected at different levels (local, state, regional, national) or by different programs.

Fundamental to epidemiology are the principles of comparisons:

- Between areas/populations
- Within an area/population over time

These comparisons often involve consideration of epidemiologic variables such as sex, plurality, race/ethnicity, pregnancy outcome, maternal age, etc. Comparisons are also usually of some measure of occurrence, in the case of birth defects *prevalence* of a specific malformation or groups of malformations. Increasingly, there is interest in making comparisons between some health status indicator at the local or state level and a benchmark, such as a Healthy People 2010 objective or an agency-developed objective.

For comparisons to convey useful information, it is essential that **like be compared with like**. When comparative data are presented, the audience must know if this holds. In terms of birth defects data, there are at least four points that need to be clearly established if meaningful comparisons are to be made:

- What is being counted? Are the outcomes—case definitions—comparable? (see Chapter 3)
- How are cases ascertained? Were similar methods of case ascertainment used? (see Chapter 6)
- Are the pregnancy outcomes from which the cases were ascertained comparable?
- Are comparable measures used to summarize data?

Each of these is worth considering with respect to the information that can be provided based on surveillance data.

What Is Being Counted?

Comparability of outcomes revolves around disease coding, classification, and the aggregation of cases. At the most general level, if we refer to "the occurrence of birth defects," we need to be clear about what is included in that term. In the past, birth defects were usually considered to be synonymous with congenital malformations and referred to diagnoses with ICD-8 and ICD-9 codes 740.0 to 759.9. Some surveillance programs, however, may follow the much more general March of Dimes definition of birth defects that includes metabolic and functional abnormalities as well. When comparing data between programs that use different definitions of the term 'birth defects', there are likely to be sufficient differences between what programs are counting as to make comparisons difficult, if not meaningless.

Even programs that use the same definition for the term 'birth defects' may vary in terms of what they include (and count) under a specific group of birth defects. One example of this relates to the reporting of studies of neural tube defects. In the past it was common to see reference to the occurrence of "central nervous system (CNS) malformations." Anencephaly and spina bifida might make up the majority of the cases, but cases of hydrocephaly and microcephaly would often be included as well. Clearly, comparing the results of a study that reported on the occurrence of all CNS malformations with one that consisted only of cases of anencephaly and spina bifida would be inappropriate.

Programs may also differ in the ways they define a specific birth defect. For example, most surveillance programs do not include preterm babies with atrial septal defects as cases. The Metropolitan Atlanta Congenital Defects Program (MACDP), for one, does not include infants of less than 36 weeks gestation at delivery among their reported cases of this defect (Correa et al., 2007). Therefore, if a program does not establish a gestational age criterion for atrial septal defect as part of the case definition, then comparison of their prevalence data with those of MACDP would be misleading.

How Are Cases Ascertained?

The second key aspect to data comparability relates to how the surveillance program ascertains cases. For example, some have expressed concern that surveillance programs relying on the reporting of cases by hospitals (passive case ascertainment) may identify a smaller percentage of the true cases that occur than will programs that send abstractors from their staff out to hospitals to actively search records for potential cases (active case ascertainment). Such differences may be more perceived than real, depending on the individual surveillance programs involved.

Perhaps a better example of potential differences in completeness of ascertainment based on methods of case identification would be an attempt to compare data from a program that identifies cases only from vital records (birth and fetal death certificates) with data from a program that identifies cases based on medical record review. Several studies have identified serious problems with under-reporting of malformations on vital records (Watkins et al., 1996).

Are the Pregnancy Outcomes from Which Cases Were Ascertained Comparable?

Another issue with respect to comparisons relates to the populations from which cases are identified. While some surveillance programs are able to identify prenatally diagnosed cases that result in pregnancy termination and include them in their numerator, many are not. This difference is particularly important for defects such as anencephaly and spina bifida, which are being diagnosed prenatally with increasing frequency. In one of the first studies conducted by the NBDPN, prevalence data over time were presented separately for programs that did (9 states) and did not (13 states) ascertain prenatally diagnosed and electively terminated pregnancies where a fetus with anencephaly or spina bifida was identified (Williams et al., 2002b). Figures included in this paper clearly show the potential effects of inappropriately comparing prevalence from programs that do and do not include cases from terminated pregnancies in their data.

Are Comparable Measures Used to Summarize Data?

Once it is decided what to count and how to collect the data on what is being counted, it is important to ensure that the measures used to present the resulting information are the same. If the presenter is calculating the measures from base data, the same measure (e.g., birth prevalence expressed as cases per 10,000 live births) should be used for each of the different population groups, areas, or time periods. However, if the presenter is compiling or comparing already calculated measures, it is prudent to understand how these were calculated. For example, several surveillance programs within the NBDPN have presented birth prevalence as cases per 1,000 live births, while others have used cases per 10,000 live births. This difference should be quite evident in most instances. Less evident is the fact that surveillance programs in the NBDPN tend to use only live births in the denominator (see Chapter 8 Statistical Methods), whereas reports from other groups, such as the International Clearinghouse and EUROCAT, may include spontaneous fetal deaths and/or pregnancy terminations in the denominator. While the inclusion of these outcomes in the denominator will not have the same impact as if they are included in the numerator, it will result in slightly lower prevalence values (Sever, 2006).

When comparing groups within a population it is also good to ensure that specific birth prevalence is being calculated, i.e., that both the numerator and denominator are restricted to the same population. Occasionally, we find prevalence figures where the denominator is based on the whole population and the numerator comes from a subgroup. The above issues can be checked by carefully reviewing the Methods section of the reports from which data are being drawn.

11.3.4 Approaches to Measuring Occurrence—Prevalence Versus Incidence

Birth defects arise developmentally within the first few weeks after conception. As a result, many affected embryos (i.e., cases) will spontaneously abort before a woman is aware she is pregnant. Consequently, in epidemiologic terms, it is impossible for one to reliably assess the *population at risk*, as the number of pregnancies that reach the critical gestational phase where a given birth defect can arise is unknown. In addition, it is unknown how many of these affected pregnancies result in spontaneous abortions. As discussed elsewhere, it is not possible to accurately estimate the *incidence* of a birth defect—the number of new cases of a defect occurring in a population at risk during a specific time period—because one cannot establish the number of new cases of the birth defect nor the population of conceptuses that were viable (and thus “at risk”) at the relevant point of development (Mason et al., 2005). Most epidemiologists in the field suggest that data be presented and discussed in terms of prevalence, often reported as *prevalence at birth* or *birth prevalence*.

As noted, in reporting the occurrence of birth defects, prevalence estimates are often calculated so that the numerator includes cases that do not appear in the denominator. For example, while the denominator commonly consists of the number of live births, if data are available, it is generally preferable to include birth defects observed among fetal deaths and induced terminations in the numerator. The resulting prevalence is a ratio, which generally includes a multiplier—typically 10,000—so that the reported prevalence of most defects will have at least one unit to the left of the decimal point. Numerically 1.6/10,000 is the equivalent of 0.16/1,000. For further detail see Chapter 8 “Statistical Methods.”

Birth prevalence provides a method of expressing the occurrence in a population in a way that supports comparisons. When the number of live births is used as the denominator, to be meaningful it should represent the same geographic and temporal “population at risk” that the birth defects cases come from. For example, in Missouri in 1989–1995 there were 193 cases of tetralogy of Fallot delivered statewide. This provides the numerator for the calculation of prevalence. The 532,592 live births delivered statewide in 1989–1995 are the denominator. The number of cases (193) divided by the number of live births (532,592) times the multiplier of 10,000 yields a prevalence of 3.62 case per 10,000 live births.

11.3.5 Level of Focus

Different types of birth defects can have different causes and arise through several different biologic pathways. Moreover, an individual child can have defects in multiple organ systems. This creates another fundamental issue, which can be thought of as the choice of level of focus: whether the focus is on individual (specific) birth defects or on individuals with birth defects. When the focus is on *individual birth defects*, the occurrence of specific birth defects is of interest. In contrast, when the focus is on *individuals with birth defects*, one is interested in the issue of how many people have birth defects.

How one chooses between these approaches depends on the question being asked or how the data will be used. If one is interested in identifying possible teratological effects of environmental contaminants, for example, the focus may shift from a single birth defect to the occurrence of any potentially related birth defect. This may involve examining the potential association between various chemicals and the occurrence of all types of birth defects.

Many scientists argue that analyzing all birth defects together rather than examining specific defects is of limited value. Importantly, how different types of defects can be aggregated in a biologically meaningful way is an issue of interest. Just as reports on infectious disease do not look at infectious diseases as a group, but present information on specific diseases (measles, shigella, AIDS, syphilis, toxoplasmosis, malaria, etc.), birth defects should be examined in the same way. For example, the epidemiology and causes of outcomes such as neural tube defects, gastroschisis, and Down syndrome are different so the logic of lumping them together may be questionable. Nevertheless, approaches for grouping defects in biologically and etiologically meaningful ways are being pursued.

In addition, it is important to recognize that many times a child will have more than one type of birth defect. For example, 58% of children in the Texas registry have more than one birth defect. Therefore, reporting the numbers of cases of individual types of birth defects, without informing the audience of the extent of multiple diagnoses, may unintentionally lead to an overestimation of the number of individuals in the population with birth defects. Furthermore, many audiences may be specifically interested in the number of persons with birth defects, since this information can be relevant for advocacy and health planning purposes.

11.3.6 Risk Factors and the Importance of Timing with Respect to Exposures

Surveillance programs often collect limited data on risk factors for birth defects, as well as on cases. However, there are important distinctions between those types of data routinely collected and those obtained as part of special studies (such as cluster investigations) or in conducting epidemiologic research. This discussion focuses on risk factor data that are often collected routinely and their presentation.

Exposures known to be risk factors for birth defects are quite limited, one of the issues that makes additional epidemiologic studies so important. Examples include *maternal metabolic imbalances* (such as diabetes) and *viral infections* (such as rubella), as well as a small number of *drugs* and *occupational/ environmental chemicals*.

Three sociodemographic variables for which data are routinely available can potentially be considered risk factors for some birth defects. These are maternal age (date of birth), maternal race and ethnicity, and maternal education. As discussed in Chapter 4 (Data Variables), the first two of these are considered as core variables, while the last is a recommended variable.

In presenting data on these variables, *maternal age* is usually grouped either into quinquennia (≤19, 20–24, 25–29, 30–34 and ≥ 35) or into two age groups (<35 and ≥35). The latter grouping is used as it is particularly relevant to Down syndrome risk and prevalence. As discussed in Chapter 4, *race and ethnicity* should be presented in categories that are comparable with the federal standards in current use. If data on *maternal level of education* are collected, then they should be presented in the same categories used on the birth certificate. Following these recommendations in presenting data on the above sociodemographic variables allows information on cases to be compared with that from the certificates of live births for the at-risk population.

A final type of risk factor information to be considered here is *maternal place of residence* (address). This, too, is considered a core variable and is basic to the use of geographical information systems, a topic discussed later in this chapter. In terms of presenting data on residence, cases are usually aggregated into some geopolitical unit (such as counties) or into administrative units (such as health regions), for which information on live births is available. How these aggregated data are presented to the public or to data users other than surveillance program staff is considered below in the discussion of data suppression.

While perhaps not pertinent to the way data are presented in a general sense, the issue of maternal residence as a risk factor raises an important point about presenting information in epidemiologic studies. Particularly with the increasing utilization of GIS, the location of the mother's place of residence is sometimes used as a surrogate for exposures in studies of risk factors associated with the ambient environment (Sever, 1997). In considering residence as a surrogate for exposure in studying birth defect risk factors, it is important to know the location of the mother's residence at the time in gestation when relevant developmental events are occurring. Periods of sensitivity are well known for many organs and structures and, for the most part, these are during the embryonic period, early in pregnancy (Mortensen et al., 1991).

Unfortunately, most surveillance programs collect only information on the mother's address at the time of delivery, when it is residence during embryogenesis that is biologically relevant. This is important in assessing possible risks related to the ambient environment because several studies have shown that a large percentage of women move between conception and delivery (Canfield et al., 2006). Residence at delivery, therefore, is not only limited in its usefulness as a surrogate for exposure, but in many cases it does not reflect biologically relevant exposure, since it does not represent where the woman lived when crucial events in embryogenesis were taking place. This limitation should be noted when data on maternal residence are presented as part of epidemiologic studies of environmental reproductive hazards.

11.3.7 Privacy and Data Suppression

Specific birth defects are often rare events (sometimes extremely rare) leading to yet another set of issues that must be considered when presenting birth defects data. The public health professional must balance the potentially conflicting goals of information dissemination with protection of the privacy of persons in the community. When the number of cases in a diagnostic category within a group or stratum (such as race or sex) is small or the population from which the cases are determined is small, the risk of allowing a specific individual to be identified may be deemed too large to be acceptable. In such cases, steps must be taken to protect an individual's privacy. In addition to protecting privacy, prevalence information is often suppressed when concerns exist regarding possible statistical unreliability of estimates that are based on small numbers.

The most common method of preventing the identification of specific individuals in tabular data is through *cell suppression*. This means not providing counts in individual cells where doing so would potentially allow identification of a specific person. Cell suppression can also be done by combining cells from different small groups to create larger groupings that reduce the risk of identifying individuals. While there are also more sophisticated data perturbation methods that use statistical noise to mask sensitive information, these are generally more suitable for use with economic or financial data than with public health data.

In general, the more restrictive a suppression rule, the less information a given table or report will provide. The weaker a suppression rule, the greater the potential threat of revealing confidential health information. It is a question of balancing the threat to individual privacy with the public health value of presenting the data.

Overall, deciding when and how to suppress birth defects information is more a social, political, and legal issue than a technical one. The technical aspects are quite straightforward, but the contextual and procedural/policy issues are likely not to be. These all need to be considered and balanced in the local context before informed decisions can be made to suppress or not to suppress data in program reports or other documents.

Surveillance program administrators and technical staff should be aware that standards used to suppress data may already be set in state laws or in departmental or institutional rules and regulations. It is the responsibility of surveillance staff and administrators to be aware of these standards and practice within their limits. If standards are not established, it behooves a surveillance program to establish rules that will be followed consistently. This is best accomplished with the assistance of an advisory committee, an institutional review or privacy board, or a similar body.

Appendix 11.1 reviews the basic methods, issues, strengths, and vulnerabilities of cell suppression.

11.3.8 Geographic Information Systems (GIS)

The application of Geographic Information Systems (GIS) methods has become an integral component of aggregating, analyzing, evaluating, and displaying health data. The current practical applications of GIS in epidemiologic studies range from descriptive statistics (i.e., plotting data on a map) to evaluation of spatial relations between environmental exposures and health outcomes.

Several definitions exist for geographic information systems. One of the most recent, as found in *Healthy People 2010*, defines GIS as “powerful tools combining geography, data and computer mapping” (U.S. Department of Health and Human Services, 2000). Software packages available today, such as ArcMap and MapInfo, integrate many GIS functions. These include (1) database management, (2) data manipulation and analysis, and (3) data presentation (i.e., displaying data on a map). To be included in GIS, the data should have some kind of geographical or spatial component that can be translated into digit maps. Appendix 11.2 contains a brief introduction to GIS mapping along with a list of suggested references.

11.4 Stage 3 – From Information to Knowledge

ACTORS	NATURE OF PRODUCT	PRODUCT TYPES	PRESENTATION MODE
Knowledge Makers: •Data providers •Data interpreters •Action takers	**Knowledge that is:** Generated through iterative, multi-directional communication between collectors, interpreters, and users of data	**Knowledge Types** •Presentations tailored to information needs and backgrounds of various audience types	•Discussion •Written feedback on presentations

As mentioned previously, the key themes of the CDC definition of ***surveillance*** are the integration of data collection, analysis, interpretation, dissemination, and application. In the previous section we spoke of moving from analysis to interpretation, whereby data are converted to information. In this section we are more concerned with dissemination of information with an eye toward application, whereby information is converted to knowledge capable of informing action. We now turn to some of the more technical, as opposed to the more philosophical or theoretical aspects of data presentation. In the broadest sense, we are here concerned with the clarity of the information presented and a lack of ambiguity in the message to be communicated.

We can conceive of the process of communication as having five major components—the sender (presenter), the medium, the message, the objective(s), and the receiver (audience). It is important in the development of a data presentation to keep all of these components in mind. It is also important to realize that communication is not simply a linear process of conveying the message from the sender to the receiver, but rather often involves a loop from the sender to the receiver, back to the sender, and back to the receiver.

In general, we suggest working backward through the communication sequence when designing your presentation. That is, instead of beginning with yourself (the sender) and what you want to tell the audience, begin by thinking about the audience (the receiver) and its information needs. Beginning with the audience will help you determine the objectives of the presentation, formulate the message, and select the best medium to use in conveying that message. Below we walk you through the process of developing a data presentation by (a) accurately characterizing the audience and understanding its needs, (b) establishing the purpose or objectives for a given presentation, (c) developing the content of and ensuring the clarity of the message, (d) selecting the most appropriate medium for the message, and (e) being aware of biases you as the presenter may have. We do not mean to suggest that consideration of elements a-e must be undertaken sequentially. However, all need to be considered carefully in the context of the presentation as a whole, even if some are apparent “givens”. For example, if you are told you must prepare a report for the Governor on x topic, then you know the audience and the medium as well as the overall objective of the report, namely “to provide information on x.” Still you would do well to learn more about why the Governor is interested in x, what specific information is being sought, and how the information will be used before developing the report.

11.4.1 The Receiver—Understanding the Audience and Its Information Needs

Know your audience! One of the central tenets of any presentation is identifying the audience being addressed and recognizing the information needs of its members. This includes taking into consideration the audience members' backgrounds, interests, and bases of knowledge. For example, a presentation to epidemiologists may include detailed information on complex analyses, yet these should be presented only as a summary to an audience of policy makers. The former may expect—and insist on—a presentation including numerical estimates of standard errors, confidence intervals, etc., while the latter will respond better to straightforward graphical displays that illustrate the key points. Even in an apparently homogeneous audience there can be significant heterogeneity. For example, a presentation to a parent group may include both highly informed individuals who have extensively researched a particular birth defect, as well as new parents who may be wholly unfamiliar with the field.

If the nature and level of expertise of your audience is not clear to you, do not hesitate to talk to someone in a position to know more about the audience and why the presentation has been requested or arranged.

11.4.2 The Objective(s)—Determining the Purpose of the Presentation

The type of information an audience is interested in and the questions posed can vary considerably, which in turn will influence your objectives in developing the presentation. An audience consisting of policy makers may be hoping to learn about population trends and attributable risk. Researchers may be interested in the prevalence of cases based on various demographic variables, while service providers may be most interested in the geographic distribution of cases and services. These differences lead to different types of questions that will require different analytic approaches and may lend themselves to different formats of data presentation. In Appendix 11.3 (the Data Users Matrix) we characterize a number of possible audiences for a birth defects surveillance presentation in terms of their likely information needs and presentation approaches that might meet those needs.

In sum, one must be prepared to use different approaches to audiences that differ in current levels of knowledge regarding the topic, as well as in having different interests, objectives, and information needs. The questions of interest to a particular audience will drive both the analytic approaches and the medium or format selected for presentation.

11.4.3 The Message—Developing Content and Ensuring Clarity

Having meticulously collected, cleaned, and analyzed a surveillance program's birth defects data, the proud owner of neatly tabulated findings may well wonder, why it is necessary to also express these findings in graph or chart form. Shouldn't the numbers speak for themselves?

The answer is yes, of course, the researcher should be able to verbally convey the most important results and to summarize succinctly characteristics of the data. In addition, it is certainly helpful to make complete tabular data available to the consumer of epidemiologic results (i.e., the audience). However, while individual learning styles differ, most people are primarily oriented to interpreting visual information as opposed to tabular data (Spence, 1990) and can more easily make judgments about that information based on a limited number of simple cues: smaller/larger, brighter/darker, increasing/diminishing. Therefore, a graphical display increases the efficiency with which your audience processes your information (Legge et al., 1989). Remember, too, that data presentation is aimed at meeting a specific purpose; whether stated or not, you have an objective and a message to convey, and your audience needs to understand it.

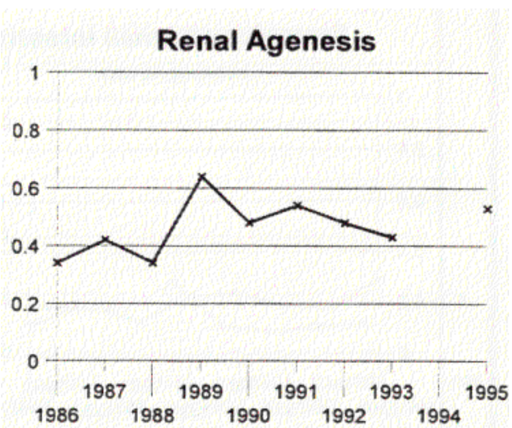
In this section we discuss graphical representations (such as graphs and charts), concluding with tips for you to keep in mind as you develop a data presentation. We then offer guidance on how to choose the appropriate format for displaying a given type of data, with further detail provided in Appendix 11.4. We conclude this section with a discussion of the characteristics of a clear, informative table.

Graphs and Charts

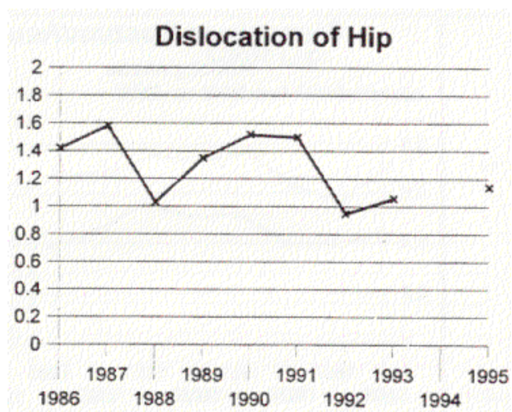
The discussion below will enable you to create graphical representations of your data that meet the following requirements:

- Convey results accurately
- Allow for efficient interpretation
- Engage the interest of the audience

Conveying results accurately. Essentially, all of the information conveyed through graphs and charts allows for comparison and answers a single question: which is larger? This is a question of proportionality. Therefore, it is important that visual elements reflect the same proportions as the data they represent. For example, Sample Figures 1A and 1B demonstrate cases per 10,000 live births for a specific birth defect, but the figures use a different range of values on the y-axis. This practice distorts the actual differences in proportion making it appear as if the rates of these two defects are quite similar, when in fact dislocation of the hip is about twice as common in this population (Muscatello et al., 2006).

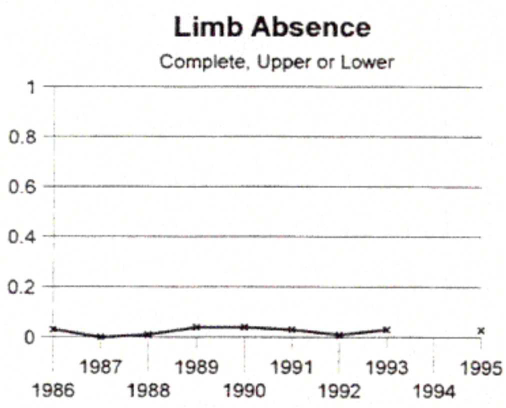


Sample Figure 1A. Cases per 10,000 live births 1986–1995



Sample Figure 1B. Cases per 10,000 live births 1986–1995

However, it is not always desirable to use the same scale for all charts. Sample Figure 1C demonstrates cases per 10,000 live births using the same scale as Sample Figure 1A, but since absence of limbs is so much rarer than renal agenesis, it is difficult to detect any difference among years for Limb Absence. Therefore, it is important to weigh the essential information you want to convey before deciding on scale (as well as other features); in this case, which is of primary concern: between-defect comparisons or illustrating a trend for one particular defect?



Sample Figure 1C. Cases per 10,000 live births 1986–1995

Chart design characteristics that can distort proportions when changing scales across multiple graphs include:

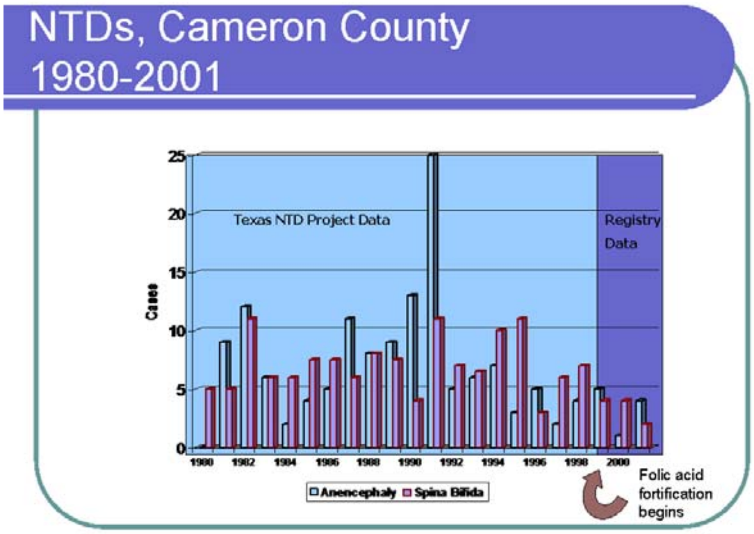
- Two different graphs examining the same outcome, but based on different time periods or different lengths of time.
- A bar graph of several time-based groups, where the groups correspond to different lengths of time.
- Graphs of statistical functions, such as regression lines, that extend beyond the range of values observed in the data.
- Use of three-dimensional graphical elements.

Allowing for efficient interpretation. To support efficient interpretation of data an important principle to follow is the *ink-to-data ratio*. Simply put, try to minimize the proportion of "ink" (or what would be ink on a printed page) that is employed in actually representing data. This means eliminating extraneous graphical elements that do not convey additional meaning, such as slide backgrounds, clip art, animations, and other elements of what is often referred to as "chart junk."

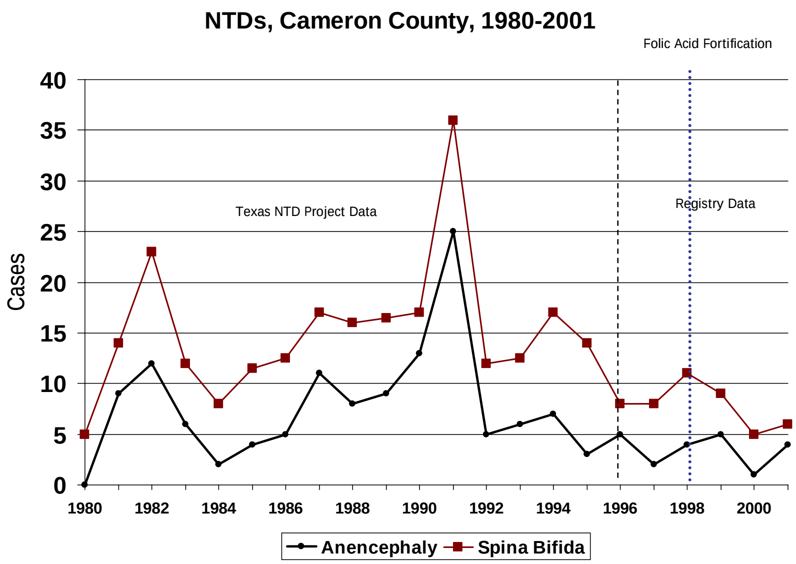
Chart junk can appear in two varieties. The first is extraneous material unrelated to the actual data. This type of junk is relatively easy to eliminate as it tends to be under the control of the person using the graphing software. So resist the temptation! In cases where the junk is generated by the graphing software, do not hesitate to edit it out wherever possible.

The second form of chart junk involves certain graphic styles that require a large amount of space to convey a small amount of data. In this regard, the key is to focus on the data themselves, rather than the data "containers." Data containers are shapes used to reflect data, such as bars and line markers, and minimizing their size can be particularly helpful if one is presenting a large volume of data.

For example, consider which of the figures below is easier to understand, Sample Figure 2A or 2B. *Hint:* See how many instances of chart junk you can identify in Sample Figure 2A.[1]



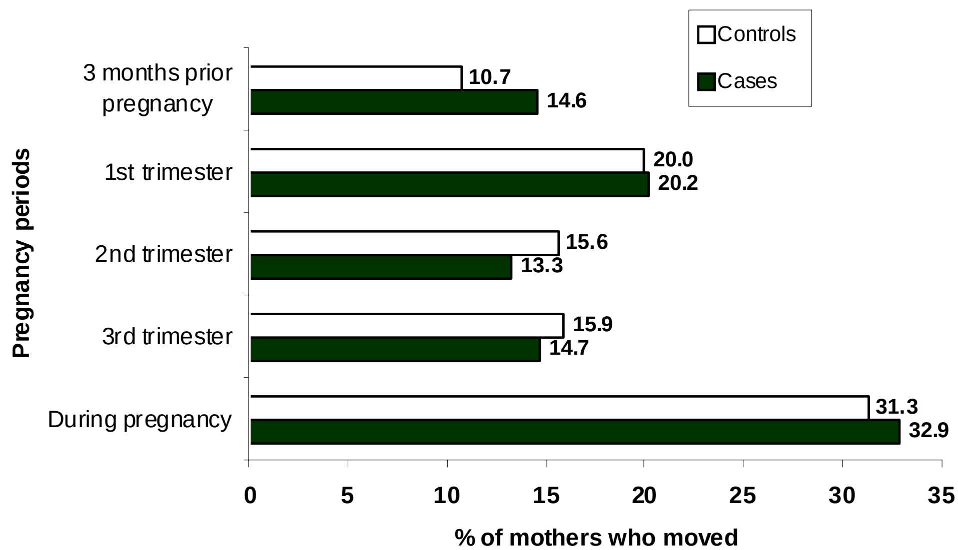
Sample Figure 2A. Example of excessive "ink:data" ratio



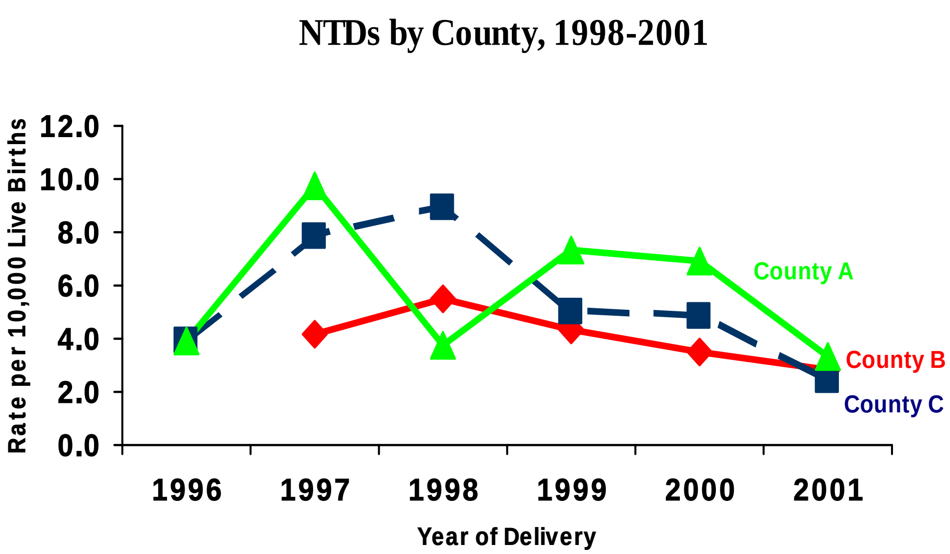
Sample Figure 2B. All "ink" conveys essential information

[1] In Sample Figure 2A, the differing color backgrounds, the slide design elements, and the stylized arrow, combined with 3D bars, employ a great deal of "ink" to convey the same information as conveyed in Sample Figure 2B.

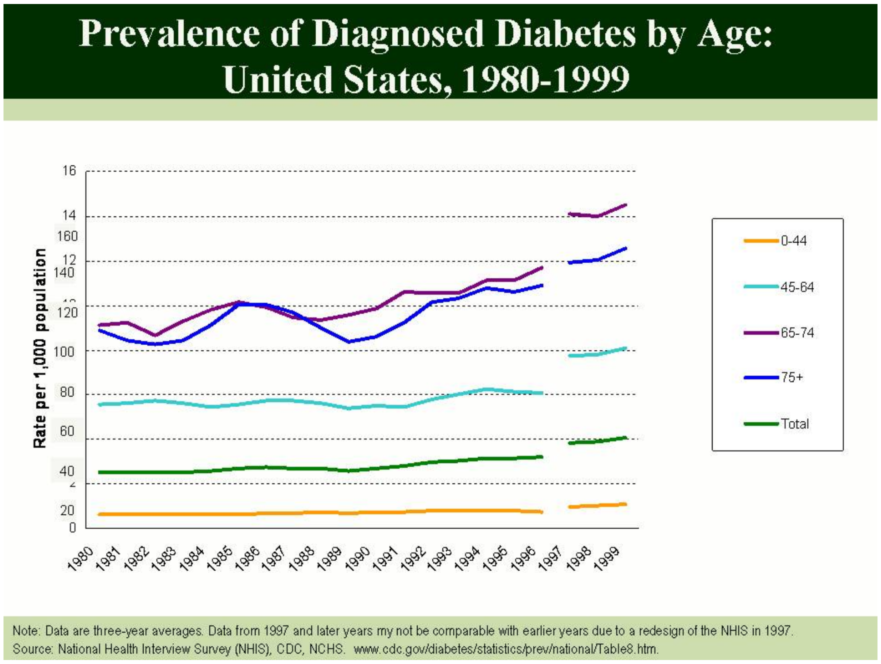
Sample Figures 2C through 2F present further techniques to reduce the amount of "ink" in a chart or graph. In 2C, adding data labels to the bars allows you to eliminate additional "ink" in the form of gridlines, while allowing the viewer to accurately assess the value of each bar. Horizontal orientation allows category labels to be spelled out rather than abbreviated. Sample Figure 2D contains no legend; rather each data series is labeled directly, with color coding used to ensure correct pairing of label with series. Sample Figure 2F (versus 2E) also uses direct labeling instead of a legend, and changes X axis scaling to every other year, which is sufficient for these data.

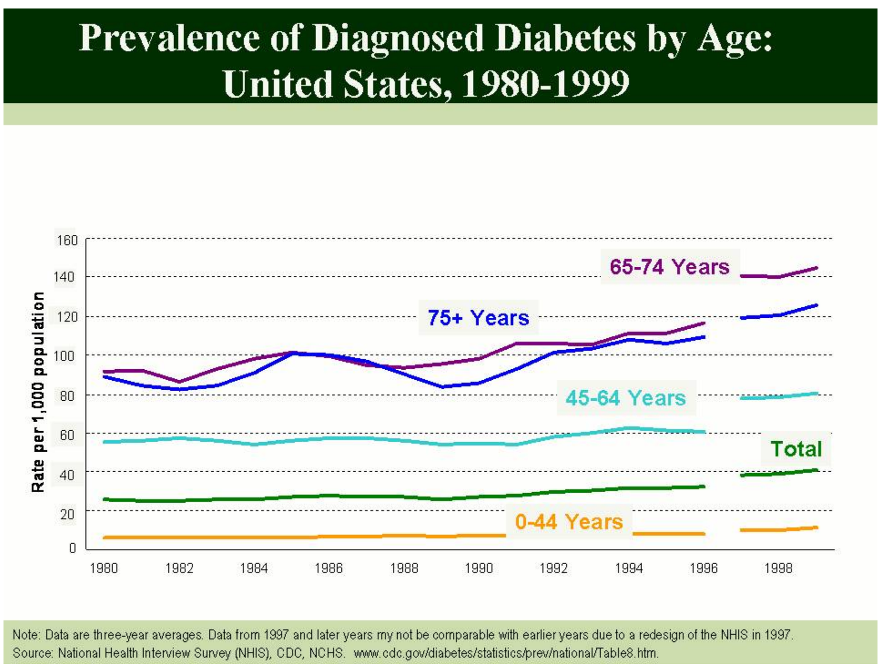


Sample Figure 2C. Use of data labels to eliminate additional "ink" in the form of gridlines. Horizontal orientation allows category labels to be spelled out.



Sample Figure 2D. Direct labeling of data series rather than legend. Use of color coding to ensure correct pairing of label with series.



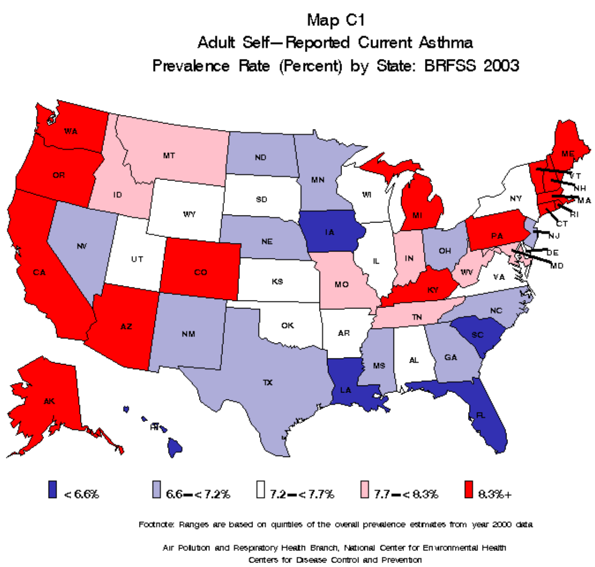


Sample Figures 2E and 2F. Note that Figure 2F uses direct labeling rather than a legend, and changes X-axis scaling to every other year.

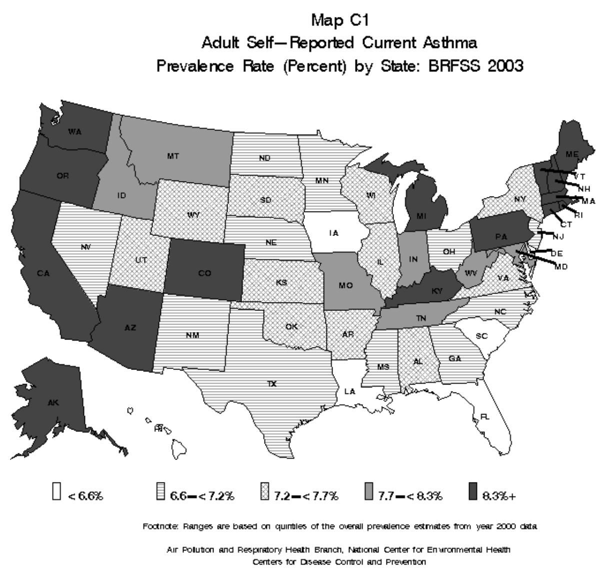
As a general rule, an intelligent reader/observer should be able to clearly interpret a chart or graph without referring to supplemental text or materials. If a figure will be used in a live presentation, the information presented visually can be minimized to the extent that it will be supplemented orally. However, copies of an oral presentation or figures used in formats without benefit of augmentation by a presenter should contain sufficient information to stand alone yet still be understood.

Engaging audience interest. While tabular data lend themselves to accurate interpretation, especially by those accustomed to working with numbers, they nevertheless require more time to process (Spence, 1990), are tedious to follow in a slide presentation, and are less accessible to non-technical audiences. A compromise suggested by Tufte (2003) is to use handouts, including the actual data tables, in lieu of the standard 2x3 printed version of slides.

Cautions about chart-junk notwithstanding, certain visual elements can improve audience engagement. For example, color can be an effective means of increasing visual interest and adding clarity to a figure (compare the differing impact of Sample Figures 3A and 3B). Color can also be used to portray increasing data density (the amount of information conveyed relative to the size of a figure) or to add an additional level of information to a figure. For example, the size of a dot may indicate the number of babies born at a hospital, while the color of the dot indicates the percentage of births who spend more than 24 hours in a neonatal intensive care unit. However, avoid too much color, as well as combinations of colors that may distract, confuse, or mislead readers.



Sample Figure 3A. Example of a map using color codes



Sample Figure 3B. Example of same map in gray scale

Understated, subtle backgrounds, textures, and other graphical elements can be eye-catching but can also easily be over-used. Furthermore, no amount of visually stimulating material on a chart can take the place of a presenter whose tone of voice, bearing, and engagement with the audience bespeak a clear understanding of and excitement about the information being presented. Table 11.1 below contains some summary tips for graphical data presentation.

Table 11.1 Summary Tips for Graphical Data Presentation

General Tips
▪ Remember that the default graphing settings on your software package (e.g., PowerPoint) are rarely the best for creating an effective graph. If you do not have the time or interest to customize your own slides, consult an expert in your organization. ▪ Use a clear and simple font (e.g., a sans serif font such as Arial). ▪ Use footnotes to explain acronyms and methods (Muscatello et al., 2006). ▪ Restrict the use of abbreviations to those that will be known to everyone in a potential audience or readership, or provide a list of the less well-known abbreviations used, keeping them few in number and usage. ▪ Indicate the units that are being used (e.g., age in days, weight in grams).
Analytical Tips
▪ Emphasize differences between groups—identical patterns across groups can be stated and/or expressed in a bullet point and do not need to be portrayed in a figure. ▪ Avoid comparisons across multiple figures.
Visual Tips
▪ Avoid the use of background pictures, or additional pictures, lines, or shapes that are added solely to “beautify” a figure. ▪ Avoid the use of unnecessary or heavy gridlines. Use white spaces with a bar instead of a grid line. ▪ Eliminate 3-D bar graphs, which add lines and shading while providing no additional information. Furthermore, two-dimensional charts are generally interpreted more quickly and accurately than those in 3-D (Hughes 2001). ▪ Eliminate unnecessary legends. Legends—if absolutely needed—can be placed inside the plot area for a graph. This increases the maximum size of the graph. Rather than a legend, use direct labeling if possible. ▪ Simplify labeling (Muscatello et al., 2006). For example, a time series on the X axis need not always have every year listed—it is implied that 1995 is the point between 1994 and 1996.
Staying on Message
▪ Remember your core message and do not present irrelevant data (e.g., detailed methodological information if not a methodological study). ▪ For certain audiences (e.g., lay persons or policy makers), consider wording the title as a plainly stated question that guides interpretation of the graph (Muscatello et al., 2006). For example, “Is gastroschisis more common among babies born to younger mothers?” rather than “Patterns of prevalence of gastroschisis by age of mother” ▪ Show your charts and tables to someone unfamiliar with the data and ask them how they interpret the “bottom line” message from each. Revise to improve clarity.

What Type of Graph or Chart Should I Use?

Appendix 11.4 contains information on some of the more common types of graphs and charts along with suggestions on how to choose a type appropriate to the data you are planning to display.

Before making your final decision, however, you should also ask yourself two questions that relate less to the nature of your data and more to your own personal preferences and the needs/interests of your audience:

- *Am I comfortable explaining this graph or chart?* If the answer is no, find an alternative format with which you are more comfortable.
- *Given my audience, should I sacrifice detail for clarity, or clarity for detail?* For example, an audience of foster parents would probably benefit from clarity with less detail, whereas an audience of epidemiologists will readily comprehend your meaning and will rather be looking for additional detail about methods or sample characteristics.

Tables

Despite the usefulness of graphical data presentation formats such as those just described, there will be times when a table is still the ideal choice. Tables display data in a systematic way and help readers locate specific information readily. Simple tables can stand alone in a slide presentation or be used as a supplemental handout when presenting summary data in graphical format.

Good tables have (see Sample Table 1):

- A table number
- A table title that clearly identifies the data displayed
- Column and row headings
- At least 3 horizontal lines (below the title, column headings, and data fields)
- Decimal alignment
- Expanded forms of abbreviations used in the tables, generally as footnotes
- Additional explanatory footnotes as needed

Sample Table 1. Counts of selected birth defects cases and maternal country of birth, 2004

	Maternal country of birth							
	U.S.-born*		Mexico/CA**		Others***		Missing	
	count	%	count	%	count	%	count	%
Controls	539	48.4	498	44.7	68	6.2	8	0.7
Heterotaxia	63	36.6	97	56.4	11	6.4	1	0.6
Omphalocele	42	48.3	44	50.6	0	0.0	1	1.1
Gastroschisis	58	43.3	63	47.0	12	9.0	1	0.7
Oral clefts	49	52.1	38	40.5	7	7.4	0	0

CA=Central America
* 50 U.S. States, Puerto Rico, Virgin Islands (U.S.)
** Mexico, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama
*** Algeria, Argentina, Bolivia, Brazil, Others

11.4.4 The Medium—Ensuring Its Appropriateness

Now that you have considered your audience and its needs, established the purpose for communicating your data, and developed the content and clarity of the message, it is necessary to select the most appropriate medium for the message so that it reaches the right people in a way that will help them to understand, interpret, and use the information. The selection of an appropriate medium, or communication channel, varies depending on the format of your message and the audience's access to the medium.

Communication channels can be active or passive. *Active channels* require the audience to engage with the information; *passive channels* require less interaction. Interpersonal communication, print readership, and Internet communication are examples of active channels, while passive channels include television and radio. A study comparing media type and source of information with the personal context of health-oriented attitudes and behaviors (Dutta, 2007) has demonstrated that health-oriented individuals sought active channels as primary sources of information. Non health-oriented individuals were more likely to obtain information, such as prevention messages, through passive entertainment-education channels.

Information might reach your intended audience directly, via publications, or more indirectly, such as through interpersonal communication by a social service professional relaying information to a family affected by birth defects. As you communicate information through one channel, consider how the data will be interpreted as they flow through other channels (Valente et al., 1996). Below we briefly discuss some of the more common communication channels used for the presentation of birth defects data.

- Reports and publications
- Professional presentations
- Mass media
- Websites
- Community outreach

Reports and Publications

Birth defects data are commonly presented in reports, including internal documents, working papers, and scientific publications. Use guidelines from journals for content and format. The level of detail should be based on the audience and its needs. Follow the principle of *tell 'em:* "Tell 'em what you're going to tell 'em, tell 'em, and tell 'em what you told 'em" (Collins, 2004a). Summarize the key points of the report in an abstract or executive summary, highlight your message clearly, and conclude with a summary. A well-written abstract should be able to stand alone without reference to the article or report being summarized and should concisely outline all relevant topics while excluding unnecessary detail, generally in 200 words or less.

Within the report, pay careful attention to describing explanatory table headings and figure legends. A review of graphical presentations published in *Journal of American Medicine* and *Annals of Emergency Medicine* (Cooper et al., 2002) identified few indicators of poor quality graphs: lack of definition of symbols, internal errors, contradictions with the text, numeric distortion, lack of visual clarity, nonstandard graphic conventions, or extraneous decoration. However, 31% of graphs were not self-explanatory, meaning the reviewers could not unambiguously interpret the graph despite reading the study design and legend of the graph. Additionally, 48% of graphs did not illustrate the underlying distribution and 48% did not depict important covariates.

Professional Presentations

At professional meetings, data are generally presented as poster presentations or platform presentations.

Poster presentations. A poster presentation is a visual display that summarizes your research or programmatic project. The display is mounted on a poster board provided at the meeting. The display includes visual aids such as data tables, charts and photos, along with a limited amount of text presenting the highlights of your topic. Conference participants should be able to quickly understand the work you are presenting including, as appropriate, your central research question or hypothesis, your research approach, and your results. After reviewing your poster, many participants will ask you questions and share their observations. Poster presentations can be an ideal way to:

- Provide a limited amount of information to a diverse audience
- Start productive conversations with new colleagues
- Summarize work you have recently completed
- Obtain useful feedback in developing the study further or in developing a manuscript
- Advertise your work to colleagues or potential employers

Poster presentations provide key opportunities for scientists to network and discuss shared interests with colleagues.

Successful posters tell an interesting story and are visually appealing, logically organized, and easy to read. Visually appealing posters are simple, uncluttered displays that use a variety of tools to convey information (e.g., data tables, figures, photographs). Color adds interest, but be conservative about the number of colors you use. Bright colors can be disconcerting. Judicious use of underlines, boldface type, and bullets can succinctly highlight important information. “White space” is critical to creating an uncluttered look. A poster printed on a single large (8’ x 4’ or 4’ x 4’) sheet of paper is the easiest to view and mount on the poster board.

When constructing figures, charts, or tables, focus the viewer’s attention on the data by reducing or eliminating chart “junk” such as non-essential lines or redundant percent symbols (%). Limit the number of decimal points presented. When you can, label data directly rather than referring the reader to a legend. If possible, convert tabular material to figures that are easy to understand. (See Section 11.4.3 for further discussion of charts and graphs.)

Logically organized posters start with a banner title across the top with the authors listed below, followed by their institutional affiliations. Poster content—text and visuals—should be organized so that they begin in the upper left corner of the poster and end in the bottom right corner. Readers will look at the poster from the top down and from left to right. The layout should follow the format of your conference abstract: generally covering the topics introduction or background, methods, findings, and conclusions. Many posters include the abstract as the initial block of text. Each section should have a brief heading, and sections should be separated by a little “white space.” The text should be condensed to key points and grouped into blocks of no more than 50–75 words. Avoid abbreviations or acronyms that may be unfamiliar to your viewers.

Posters that are easy to read use fonts that are legible from a distance of 3–5 feet. For the poster title, use a very large font (84 point or larger). Author name and affiliation information can be displayed in 72 point.

For other elements of the poster, consider these guidelines:

- Headings and subheadings – at least 32 point
- Text, figure legends, and tables – at least 18 point

Keep the font style for similar content consistent throughout. Be sure that format headings and text of the same level of importance use the same font size. Avoid upper-case or "ALL CAP" fonts. Dark letters on a light background are easiest to read.

Some people may ask that you "walk" them through your poster. Avoid reading it! Instead, summarize the big picture of what you did and why. Use the poster's graphics to illustrate your major findings and support your conclusions. Presenters often provide a condensed version of their poster for interested viewers (e.g., a PowerPoint handout). You might also consider handing out additional information, such as supplemental data tables. *Always include your contact information.*

Platform presentations. Platform presentations are delivered through a structured talk or lecture, commonly using presentation visual aids, such as MS PowerPoint. Effective PowerPoint presentations *support*, rather than replace, the delivery of your presentation. Do not be tempted to read directly from your slides. The quality of the presentation depends on the quality of the presenter's communication of the information and not entirely on the quality of the visual aids (Collins, 2004a).

As with any public speaking activity, speaking softly, unclearly, or in a monotone voice; using excessive hand gestures; and speeding through slides without giving the audience a chance to digest the information will not communicate your message well. Pay attention to the pace and timing of your talk, allowing pauses but also following time limits. Prepare your presentation for compatibility with any computer, bring back-up copies of your presentation and, most importantly, rehearse. Rehearsing, especially in front of a representative audience, will help you become comfortable with your presentation, provide an opportunity to clarify any points that are potentially confusing, and enable you to assess the presentation's natural and logical flow (Collins, 2004b). It will also give you another chance to proofread for potentially embarrassing errors.

When preparing your visual aids, follow principles of clarity, readability, and simplicity. For clarity, design your slides with only a few key points per slide. A standard recommendation is the "rule of six": 6 lines per slide and 6 words per line (Collins, 2004b). Use contrasting background and text colors so your words are readable, but avoid hard-to-read color combinations such as red/green, brown/green, blue/black. Font sizes should be at least 24 pt for text and 36–40 pt for titles, but also consider the size of the room you are presenting in to ensure the people furthest from the screen can read the slide. Setting the entire text in bold can also increase readability.

In terms of simplicity, emphasize the most critical point on each slide. Include pictures and graphs for visual interest when they are relevant, but choose them wisely to minimize distraction from the main point. Tables can be difficult for audiences to read and interpret; look for other ways such as graphs or text to communicate the same information more clearly. If you do choose to use a table, be sure to make use of white space so that the audience can easily see the most salient points without sifting through clutter (Ryder, 1995).

Finally, remember that it is not the topic or data alone that creates a meaningful presentation. Strategic communication of understandable information is the key to successful delivery of data through the professional presentation medium (Thompson et al., 1987).

Mass Media

Dissemination of birth defects data to the general public occurs through many channels: printed news material, television, radio, and websites are just a few examples. Since these media have a broader reach than presentations at professional conferences, the audiences will be more heterogeneous. It is important to integrate the target audience's cultural values into the strategy when selecting the appropriate communication channel, but the ethical challenges of communicating information accurately through mass media are difficult to avoid (Guttman, 1996). A review of 10 years of health content in the media concludes that "popular media is not likely to facilitate understandings helpful to individuals coping with health challenges" (Kline, 2006). The topic of birth defects tends to be misrepresented in the media, generating unnecessary public anxiety (Marks, 1993). If mass media is chosen as a communication medium, think about how the public understands and interprets risk, so that it is not interpreted inaccurately (McComas, 2006).

While there is no method that will match all needs for knowledge, understanding the needs of potential users will help determine if mass media channels are appropriate as well as the best way to tailor the message through the medium (Williamson, 2005). Communication strategies should consider the audience's access to information channels, motivation for information, literacy and numeracy, likelihood of interpreting complex data, and cultural context.

Websites

Using websites to convey information about birth defects to the public is becoming increasingly common as health-oriented individuals actively seek knowledge, but these individuals' trust in the information source is paramount. Analysis of data from the Health Information National Trends Survey (Rains, 2007) shows that "trust in information-oriented media, entertainment-oriented media, and one's health care provider all predicted Web behavior and perceptions." Users of the Internet as a source of information are most likely to be women who have high knowledge about resources, regardless of format, and are likely to discuss the information they find with health care providers (Warner and Procaccino, 2007). These women typically have a higher level of education and socioeconomic status (Pandey et al., 2003).

Websites are also useful for disseminating data to research, surveillance, program, and policy users. For all audiences, the website should be clearly laid out, interactive, tailored to the audience, and regularly maintained and updated for current information.

Community Outreach

Another way to communicate birth defects data to the public is through community outreach. Think about creative ways of disseminating information in addition to more traditional routes; look beyond PowerPoint, posters, and reports. Your audience could be someone affected by a birth defect who may or may not attend conferences, read journals, or look at websites. As mentioned earlier, non-health oriented individuals may not actively seek information, especially if they have low literacy or numeracy skills, and consequently low health literacy skills. The attributes of health literacy are "reading and numeracy skills, comprehension, the capacity to use information in health care decision-making, and successful functioning as a healthcare consumer" (Speros, 2005). Over 50% of Americans have limited literacy and numeracy abilities according to a 1992 National Literacy Survey so health materials should be written in simple terms to increase understandability. The health literacy approach is not "dumbing down" data, but simplifying it into reader-friendly plain language so the message is communicated clearly (Stableford and Mettger, 2007).

Some examples of community outreach strategies include:

- Strategically disseminating materials (brochures, posters and pamphlets) in public locations,
- Delivering information at community events or health fairs,
- Connecting with key community gatekeepers such as health promoters who share birth defects information through interpersonal communication.

Understanding the local context is imperative for developing appropriate communication strategies for community outreach.

Remember: "A word of caution that can't be repeated often enough: The medium does NOT replace the message, be it Morse code or interactive video-on-demand. The principal objective remains to choose the right message, for the right people, at the right time and to ensure that it gets through in the most efficient and effective manner" (Chamberlain, 1996).

11.4.5 The Sender—Being Aware of Biases

Finally, as a presenter, one rarely faces an audience without having one's own personal interests and objectives. These may range from seeking funding to promoting a particular theory or model and may or may not align with the objectives and interests of the audience. We should nevertheless strive to present information in as impartial and balanced a manner as possible. This includes not omitting or minimizing contrary information, or choosing or manipulating figures or statistics in order to support a given objective.

11.4.6 Pulling It All Together

What are the factors that drive data presentation at the stage when you are transforming information into knowledge? As stated previously, when planning a data presentation, it is important that you as presenter, and catalyst in the transformation, pay attention to all the other elements of the communication process. That is, that you (a) understand the audience and its needs, (b) establish the objective(s) for the presentation, (c) determine—based on earlier analysis and interpretation—what the message is and how most clearly to present it, and (d) decide upon the communication medium. That is, the elements listed below must all be suitably "matched" in a data presentation:

- Audience and its needs
- Objective(s)
- Message (information being shared)
- Communication medium

The three case studies presented below demonstrate how these elements of a presentation must be coordinated and addressed.

Informing the Public about Birth Defect Prevalence	
Audience	The public
Objective	To inform the public about the frequency of a birth defect in an area, e.g., a state or public health region
Message	The observed prevalence of birth defects during a specified time or trends over time
Communication Medium	Tables or graphs that are clearly labeled, with the terms and categories defined so that they are intelligible to the intended audience. The medium could be a published report; a press release, with supporting technical documentation; or a document on the surveillance program's website.

Informing Policymakers about Birth Defects Issues	
Audience	Legislators or policy makers
Objective	To support efforts to increase health services or justify continuation of funding for the surveillance program itself.
Message	The magnitude of a problem or the resources needed to maintain a surveillance program.
Communication Medium	Clear, succinct bulleted text with supporting graphs and tables.

Responding to Community Members about Birth Defects Clusters	
Audience	Community members
Objective	To respond to concerns about birth defects clusters
Message	Relationship (if any) between birth defects clusters and environmental hazards
Communication Medium	Established state protocols for dealing with this issue and including description of how information regarding the cluster and its investigation is communicated to concerned stakeholders. Important to communicate information to the community, both during the investigation and at its conclusion, using clear and simple messages (Williams et al., 2002a).

11.5 Stage 4 – From Knowledge to Action

ACTORS	NATURE OF PRODUCT	PRODUCT TYPES	PRESENTATION MODE
Action Takers	**Actions that are:**	**Action Types**	
•Data reporting staff •Surveillance staff •Policymakers •Decisionmakers •Intervention designers/ implementers •Health care providers •Media •Families •Community members •Fellow scientists/ researchers	•Appropriate •Evidence-based •Maximally effective and cost-effective	•Estimating frequencies •Referrals to services •Planning services •Planning interventions •Conducting research •Cluster investigations	•Surveillance reports •Websites •Scientific publications •Policy papers •Guidelines •Intervention protocols •Risk communication •Press releases, media articles and shows

As mentioned earlier, the key themes of the CDC definition of *surveillance* are the integration of data collection, analysis, interpretation, dissemination, and application. In the previous section we spoke of dissemination of information with an eye toward application, whereby knowledge capable of informing action is developed. In this section, we speak of application or the undertaking of action(s) in order to achieve programmatic objectives. To illustrate this stage, we present a vignette of a surveillance program as it moves through different developmental phases (nascent, developmental, mature) and how the data produced at each phase of a program's development can be mobilized to inform action.

The stage of development of a registry or surveillance program has important implications for data presentation. The following vignette describes the experiences of one program director in this regard. The text is in the first person to reflect the program director's appraisal of the events surrounding the presentation of data to different audiences at different developmental stages of the program and with different types of action likely to result.

> *In my experience, the quality of our data increased dramatically from our initial data set to the second and has increased incrementally thereafter. We are continuously evaluating our methods and data, with the goal of being more complete, more accurate and reducing bias. Nonetheless, I believe all of our data have had some value and were worth presenting to selected audiences.*
>
> *I received our first data set the day I was asked to take responsibility for the State of Contentment's birth defects surveillance program. I was handed a flexible folder that in essence*

was the registry. In it were a couple floppy disks, several sheets of paper with diagnoses listed on them, and a couple of envelopes containing various parts of copied discharge sheets. Not an ideal data set, but it was the result of a pilot project where hospitals in one region of the state reported their birth defects cases from one year to the department of health. The regional perinatal center had prepared a formatted Excel spreadsheet for the project data, but they were the only hospital to use it. While not standardized and not complete, these were the best data we had at the time.

We compiled the data into a table based on the tables of birth defects in the NBDPN annual report and presented them at a meeting organized by the local chapter of the March of Dimes. The meeting coincided with the March of Dimes' annual legislative lobbying day. It was a relatively informal meeting, and we provided handouts of the data to a mixed audience made up primarily of March of Dimes volunteers; a number of neonatal intensive care unit (NICU) nurses, geneticists, and neonatologists also attended the meeting. The March of Dimes was particularly interested in the data, as they had lobbied the legislature to establish a birth defects surveillance program, legislation which included authorization of the pilot project. The presentation was informal, accompanied by a warning that the data were very messy and likely to be incomplete. Nonetheless, the audience was enthusiastic. The volunteers asked a lot of questions, as did the professionals who also offered a good deal of advice. Among other things, I recall learning the importance of using standardized case definitions; the number of cases of patent ductus arteriosus was likely inflated because there was no control for low-birth-weight infants. The presentation was followed by a reception for the legislators whom the March of Dimes had lobbied earlier that day.

Following the meeting, I developed a plan to use data from our Hospital Discharge Data System linked with the Birth Certificate Data System to identify birth defect cases. This provided a state-wide population-based assessment. We did the extractions and linkages for a one-year birth cohort, the same year's data that were used in the pilot study. At the next March of Dimes annual meeting we presented the overall state data, along with a comparison of the regional pilot study data and the linked data. Once again there was a lot of give and take, and it was readily apparent that the linked data were more complete and accurate. With the birth certificate linkages, we also had considerable data on the characteristics and conditions of the birth population, the denominator for the calculation of strata-specific prevalence estimates. Once again the presentation was followed by a reception with the legislators. A year later a number of the legislators who attended the reception voted to provide funding for our plan to establish a state-wide birth defects surveillance program. The data were not perfect, but they clearly had value.

In the meantime, the single-year data were also submitted for the NBDPN annual report and presented at the opening of a state American College of Obstetricians and Gynecologists (ACOG) meeting. The ACOG meeting was formal with a PowerPoint presentation and the audience, primarily physicians and nurses, was very interested and inquisitive. The data showed specific birth defects rates that appeared high relative to national rates and differences among regions of the state. Much of the discussion following the presentation was on the possible reasons for the observed differences. Some of the hypotheses involved potential artifacts in the data, whereas others involved regional differences in behaviors and populations. Once again the interaction was informative for the presenter as well as the audience.

Subsequently we have given presentations at two American Public Health Association annual meetings; one presentation focused on a plan to evaluate the hospital discharge data, using active case/control reviews, and the other on risk factor analyses using the linked birth certificate and hospital discharge data. To date the program has compiled six years of population-based statewide surveillance data using the linked birth-hospital discharge data and two years of active *case/control reviews. A linkage of the two data sets and their evaluation should be completed soon and will likely provide greater depth and information than any of the previous presentations. The key point is that each of the above-mentioned data sets had both informative and intrinsic value when presented to the appropriate audience, along with clear warnings regarding the data's potential limitations.*

11.6 References

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