

Introduction: Birth Defects Surveillance in the United States

F. JOHN MEANEY

Department of Pediatrics, College of Medicine, Arizona Health Sciences Center, Tucson, Arizona 85724

State programs for the surveillance of birth defects now provide data on the vast majority of the nation's births. The number of state programs has increased dramatically in the late 1990s with the passage of the Birth Defects Prevention Act of 1998 and the subsequent funding of 26 cooperative agreements between states and the Centers for Disease Control and Prevention (CDC). As of the end of 2000, 45 (87%) of the states, DC, and Puerto Rico, have existing programs for monitoring birth defects (Larry Edmonds, personal communication).

The purposes for conducting surveillance for birth defects have not changed in the past two decades. States have increasingly diversified in the extent to which they address these purposes, which may conveniently be grouped into three categories: 1) epidemiological, 2) preventative/planning, and 3) social/ educational, as suggested by Reed and Meaney ('88).

The articles appearing in this issue of *Teratology* encompass the full breadth of purposes for doing surveillance. This introduction will attempt to summarize the papers using the aforementioned categories, with one slight deviation, in that the second and third categories are combined. Only two of the articles fell into the grouping of two categories and the issues each of these articles addresses overlap the two categories considerably. This is done for the convenience of the reader, and the categories should in no way be construed as the definitive way to view the purposes/rationale for surveillance programs. If anything, reports on the results of surveillance programs will exhibit considerable overlap and implications, potential or actual, for the categories Reed and Meaney suggested more than a decade ago.

The majority of articles in this issue fit within the epidemiological category for purpose of surveillance. Rasmussen and Moore provide a useful review of coding issues and problems specifically for birth defects surveillance. The authors' use of specific examples of the effects of inaccurate coding in studies of birth defects is particularly effective in demonstrating why this aspect of surveillance deserves our utmost attention. The paper will be a major resource for the chapter on coding in the Surveillance Guidelines and Standards Manual that is in progress through the efforts of the committee by that name of the National Birth Defects Prevention Network (NBDPN).

Several papers address what might best be termed program evaluation aspects of birth defects surveillance. Hobbs, Hopkins, and Simmons provide another example of an approach that has implications for national guidelines and standards. Data were used from the most recently published birth defects surveillance report of the NBDPN (NBDPN, 2000) to examine how prevalence rates might be influenced by variation in surveillance methods among the reporting states. More descriptive than analytical, the paper nevertheless provides a framework for future, more analytic assessments of this problem. In a decidedly more analytical approach, Orton, Rickard, and Miller use record reviews and capture-recapture methodology to assess the prevalence rate of Down syndrome in Colorado, which from a previously published report (Flood et al., '94) was higher than in other reporting state registries for birth defects. The methods were useful in identifying the problems of false-positive and inconclusive reports of Down syndrome cases and estimating a revised prevalence rate that is comparable to those observed in the other sites. Finally, Forrester and Merz evaluate what impact the inclusion of early fetal deaths has had on the birth defects surveillance program in Hawaii. A 12-year secular trend of an increasing proportion of cases for which early fetal deaths accounted is used to support the inclusion of these outcomes in surveillance programs as well as prenatal genetic services as data sources. Two additional papers under the category of epidemiology describe, respectively, a developing surveillance program and changes in a system that has existed for more than two decades. Pershyn-Kisor and co-authors describe efforts to implement surveillance of birth defects in U.S. military populations and the issues unique to this activity. The Department of Defense Birth Defects Registry has the goals of improving health care to military families and contributing to improved birth defects surveillance and research on a national basis. For almost twenty years, the New York Department of Health has operated a birth defects registry, initiated in response to the Love Canal crisis in the late 1970s. Druschel, Sharpe, and Cross detail efforts towards streamlining the existing system and reducing the burden on the hospitals that currently report cases. The article contributes an important discussion of the principles of birth defects surveillance programs and the issues that were confronted by one program in attempting to "change the system."

The final two papers relate primarily to the second and third purposes of surveillance in Reed and Meaney's original scheme. The paper by Tilford, Robbins, and Hobbs is an attempt to examine the economic burden to families of children with birth defects beyond the usual health care costs. It focuses attention on the costs of additional caretaker time and family burden, both of which have not received much attention from the standpoint of birth defects. The issues addressed in this paper provide a basis for further work, but they also reflect cultural differences between the perspectives of the public health and disability advocacy communities.

In the last paper in this issue, Montgomery and Miller describe the Colorado Responds to Children with Special Needs (CRCSN) program that has been serving as the monitoring program for birth defects, developmental disabilities, and children at risk for developmental delay since 1988. Since 1990 the program has implemented an objective for prevention of secondary disabilities by connecting children with these condi-

tions and their families with local, community-based services. This state program is called the Community Notification and Referral Program (CNRP). Family responses to a survey indicate that almost two-thirds learn about services of which they were previously unaware, demonstrating that the follow-up program could have even more impact if the funding for local services were more widely available. The philosophy and methodology of the CRCSN and CNRP both serve as model system components for other state programs that wish to use birth defects surveillance beyond its epidemiological objectives.

LITERATURE CITED

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