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Among the most tragic victims of alcohol and substance abuse are the children born with the needlessly compromised destinies that accompany fetal alcohol syndrome. Our failure to prevent such impairments has many causes. The paper by Miller, et al. points to the deficiencies of our surveillance systems, systems that could facilitate a relatively neglected part of our public health agenda: the prevention of birth defects.

Birth defects are an important public health problem: the leading cause of infant mortality, the fifth leading cause of years of potential life lost, and a leading cause of morbidity in childhood and disability throughout the lifespan (1,2,3). Fetal Alcohol Syndrome alone is a leading cause of mental retardation and other disabilities (4,5). And it is preventable. Despite a quarter century of efforts, adequate research and effective prevention and intervention strategies remain largely unrealized for fetal alcohol syndrome and for most other birth defects categories.

While population-based birth defects registries do exist in some form in 26 states, of those which have used active case-finding methods only three (those maintained by CDC and the states of California and Iowa) have been sustained over extended periods. Even these three programs frequently have limited funding and little has been done to exploit their public health potential. Occasionally, as Miller describes, substantial effort has gone into building effective state surveillance systems and the development of experienced staff. Unfortunately, while such efforts are to be applauded and can result in valuable new information, they are frequently not sustained, their potential wasted.

Why have public agencies and policy-makers continued to undervalue these systems, and more importantly, what can be done to build effective programs? At the core of this complex problem has been the failure of the clinical, research, and public health communities to make a compelling argument for a larger investment of

resources. And so we stumble upon a circular system of defeat: Without adequate surveillance systems to learn the scope and impact of fetal alcohol syndrome and other birth defects, we cannot generate meaningful estimates of the health, educational, or human services needed, nor make compelling arguments; and without the compelling arguments, we cannot fund surveillance systems or evaluate the effectiveness of interventions.

Another part of the problem may lie with the public health community itself. For the most part, public health officials are not well-informed on birth defects or on medical genetics in general and have tended to view birth defects surveillance as a private responsibility rather than as a part of a broader public health agenda. There is also the general perception that birth defects and genetic conditions are rare events, and not subject to prevention or intervention. Yet recent advances in genetics (through the Human Genome Project and other genetics research programs), molecular biology and teratology offer substantial evidence to the contrary, and have extraordinary implications for preventive health care, including birth defects prevention (6).

Thus it is not surprising that enthusiasm for birth defects surveillance is modest. Surveillance too narrowly focussed (e.g. on fetal alcohol syndrome alone) accentuates its limits. Fortunately, several themes have now emerged nationally which offer the possibility that this culture of indifference or reluctance may change.

- Birth defects surveillance systems are technically possible and exist in several other countries, providing valuable information about the causes and impact of these conditions (7).

- Our ability to collect, analyze and communicate complex data sets has improved enormously. Information networks are now widespread and a cadre of knowledgeable birth defects epidemiologists is available.

- A comprehensive children's health care data set, under development in some states, federal agencies, and private organizations has recognized value (8,9,10).

- Expanding knowledge about human diversity and health risk factors from the Human Genome Project and other genetics research, shows that detailed biologic and clinical knowledge of individuals and whole populations will be needed to resolve causality and to design sound therapies and preventive strategies for common disorders of health.

- Congress, too, evinces interest in promoting programs to understand the causes, methods of prevention

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and treatment of birth defects. Congress asked the Institute of Medicine to study the problem of fetal alcohol syndrome (11). A bipartisan Birth Defects Prevention Act (12) would expand birth defects epidemiology at CDC and regional prevention research centers. Additional appropriations may enhance birth defects and genetics programs.

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- Direct clinical services are likely to be increasingly privatized in the future. For public health the challenge will be to ensure access to care for all, while re-directing resources to the "core public health functions," i.e. assessment, assurance, and policy formulation, (13) none of which can be accomplished without an enhanced health surveillance and tracking system.

Does the public health community have the discipline and energy to respond: to learn a new body of information, to reallocate resources, and to design and implement this component of the public health infrastructure? Steps now will allow birth defects prevention efforts to become an integral part of the public health agenda of the 21st century. Not easy, but the alternative

is an outmoded and unresponsive system, eroding public confidence and support, and thousands of children living needlessly compromised lives.

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