



Fact Sheet

State Birth Defects Performance Measures

AMCHP's Role

AMCHP works with partners at the national, state and local levels to promote healthy birth outcomes and to strengthen and support the systems and services for children and youth with special health care needs to help children reach their full potential. Promoting effective state models for the use of birth defects surveillance is an important component of this work.

ACKNOWLEDGEMENT:

This publication was supported by Grant number 5U38H000523-03 from the Centers for Disease Control and Prevention's National Center for Birth Defects and Developmental Disabilities. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

The Association of Maternal & Child Health Programs (AMCHP) reviewed the Title V Information System in the winter 2011 to identify states that have adopted performance measures related to birth defects surveillance with the aim of highlighting innovative and effective ways that State Title V agencies utilize birth defects surveillance systems to improve maternal and child health (MCH). Birth defects registries serve as essential tools in understanding the rates and types of birth defects in order to enhance policies and programs to improve birth outcomes.

According to the National Birth Defects Prevention Network, the term birth defect "encompasses a diversity of conditions including physical malformations, sensory deficits, chromosomal abnormalities, metabolic defects, neurodevelopmental disorders, and complications related to prematurity and low birth weight." Birth defects surveillance systems monitor the number and types of these congenital abnormalities that negatively affect health and development in a particular population.

Birth defects surveillance systems, and the data they yield, can be used to study and address a variety of issues in MCH populations, including:

1. Epidemiologic (monitor trends, improve diagnostic rates)
2. Planning/Prevention (inform programs, evaluate efficacy of services)
3. Educational/Social (raise social awareness, develop parental support, evaluate economic impact on communities and government)
4. Health care (monitor service utilization and referral system)
5. Health system (promote interagency collaboration)
6. Clinical (improve diagnosis, reduce the long term impact of health issues through early identification)

State Performance Measures

Forty-five states and territories have either an operational or a planning birth defects surveillance program. According to the Centers for Disease Control and Prevention (CDC), 48 percent of these state birth defects programs receive funding from Title V/MCH. Some of the Title V programs have developed performance measures to utilize the data from and further develop surveillance and intervention efforts. In 2010, 11 states and territories had adopted at least one state performance measure related to birth defects surveillance: Georgia, Idaho, Missouri, Montana, New Jersey, North Carolina, Northern Mariana Islands, Ohio, Puerto Rico, Utah, and Wyoming. These performance measures relate to the goals and priorities of the birth defects surveillance program in each state. The measures vary from widening the scope of the surveillance system to abstracting, analyzing and applying data on a particular health issue. The state performance measures and their objectives are summarized below.



**Association of Maternal
& Child Health Programs**

2030 M Street, NW, Suite 350
Washington, DC 20036
MAIN (202) 775-0436
FAX (202) 775-0061

AMCHP.ORG

ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

State	State Performance Measure	Objective/Intent
Georgia	Percent of women of reproductive age who consume an appropriate amount of folic acid prior to pregnancy.	<ul style="list-style-type: none"> Reduce the occurrence of neural tube defects and spina bifida in Georgia. Uses Georgia Pregnancy Risk Assessment Monitoring System (PRAMS).
Idaho	Percent of women 18 and older who regularly (4 or more times per week) took a multivitamin in the month prior to getting pregnant.	<ul style="list-style-type: none"> Increase the number of women who regularly take a multivitamin in the month prior to getting pregnant. Uses Idaho Pregnancy Risk Assessment Tracking System.
Missouri	Percentage of women with a recent live birth who reported taking a multivitamin or a prenatal vitamin four or more times per week in the month prior to pregnancy.	<ul style="list-style-type: none"> Increase the proportion of preconceptional use of folic acid among women of childbearing age. Reduce occurrence of neural tube defects.
Montana	The percent of children with cleft lip and/or palate receiving care in interdisciplinary clinics.	<ul style="list-style-type: none"> Increase number of Montana children who are identified with cleft lip and/or palate who receive available in-state services. Provides interdisciplinary team care to families and individuals, beginning shortly after birth and continuing until the physical growth of an individual has been completed – around 21 years of age.
New Jersey	Percent of live children registered with the BDARS who have been referred to NJ's Special Child Health Services Case Management Unit who are receiving services.	<ul style="list-style-type: none"> Adds case management module to the Birth Defects and Autism Reporting System (BDARS), which allows units to receive registrations in real time, and allows for faster family contact and assists registered children in gaining access to appropriate health and education services.
North Carolina	Percent of women of childbearing age taking folic acid regularly.	<ul style="list-style-type: none"> Increase the proportion of pregnancies begun with an optimum folic acid level. Includes periodic use of Carolina Behavioral Risk Factor Surveillance System (BRFSS) Folic Acid Module.
N. Mariana Islands	Input information on infants with a diagnosis at birth into the Birth Defects Registry within 6 months.	<ul style="list-style-type: none"> Develop birth defects registry to improve work in early identification, intervention, and tracking.
Ohio	Maintain/enhance the Ohio Connections for Children with Special Needs (OCCSN) birth defects information system to improve use of data for surveillance, referrals to services and prevention activities.	<ul style="list-style-type: none"> Improve data utilization for analytical studies and to drive program activities. Builds on statewide birth defects surveillance system to increase utilization of birth defects data for prevalence and trend analyses, referrals to services and prevention activities.
Puerto Rico	<p>The prevalence at birth of neural tube defects (NTDs).</p> <p>The proportion of women of childbearing age consuming folic acid.</p>	<ul style="list-style-type: none"> Evaluate effectiveness of preconception campaign to create awareness of the benefits of daily folic acid supplementation, and address prevention messages for known NTD risk factors such as obesity and diabetes. Increase the proportion of women who begin pregnancy with the recommended folic acid intake.
Utah	Percent of women of reproductive age (18-44 years) who report that they take a multivitamin pill or supplement containing at least 400mcg of folic acid daily.	<ul style="list-style-type: none"> Increase the percent of women of childbearing age taking multivitamins with optimum level of folic acid. Utah Behavioral Risk Factor Surveillance System (BRFSS) conducts a folic acid module biannually.
Wyoming	Percent of postpartum women reporting multivitamin use four or more times per week in the month before becoming pregnant.	<ul style="list-style-type: none"> Assess self-reported data on a state based sample of recently postpartum women.