

NBDPN Standards for Birth Defects Surveillance Data Utilization Assessment Tool

Version 1.0 (v1.0), November 2022 Final

Purpose: Data utilization standards for birth defects surveillance are intended to inform program objectives and surveillance functions, thereby facilitating data use that benefits public health.

Format: The Assessment Tool lists performance measures for data utilization. Each item identifies the level of standards performance as (1), (2), or (3). Performance measures are organized into Monitoring, Public Health Practice, and Research categories.

Definitions - explanations: Each performance measure is followed by a definition that provides clarification on how to interpret the measure and the justification/explanation for the specific measure.

NBDPN Guidelines: These standards (i.e., performance measures) are linked to the NBDPN Birth Defects Surveillance Guidelines Manual (<https://www.nbdpn.org/guidelines.php>). Chapters of the Manual that relate to each measure are specified after the definition. Each performance measure references one or more chapters from the Guidelines Manual. Applicable chapters include:

Chapter 1: Using Data
Chapter 3: Case Definition
Chapter 4: Data Elements
Chapter 6: Case Ascertainment Methods
Chapter 8: Statistical Methods
Chapter 10: Data Collaboration and Dissemination
Chapter 11: Data Presentation

Instructions: This is designed as a self-assessment tool for a birth defects surveillance system. Three performance levels are associated with each indicator:

Level 1: **Basic** level of performance by a surveillance program
Level 2: **Essential** level of performance by a surveillance program
Level 3: **Optimal** level of performance by a surveillance program

Before completing each indicator, be sure to read all performance options.

For each indicator, please check the highest performance level that applies for your birth defects surveillance system.

Before you start, please complete the identification box below.

State	
Name of person completing tool	
Title	
Email	
Date	

Table of Contents

DU1: Monitoring	3
DU1.1. Analysis of birth defects data by person	3
DU1.2 Analysis of birth defects data by place	4
DU1.3 Analysis of birth defects data by time	5
DU1.4 Generation of program-specific birth defect reports for public use	6
DU1.5 Submission of data to external partners/users outside of the program.....	7
DU1.6 Geocoding of birth defects data (address at delivery).....	8
DU1.7 Linkage of registry data to health/service-related databases	9
DU2: Public Health Practice	10
DU2.1 Referral plan for referral to services	10
DU2.2 Type of programs/services referred to	11
DU2.3 Data verification prior to referral	11
DU2.4 Timeliness of referrals	12
DU2.5 Key linkages/data integration for analyzing referral to services outcomes.....	13
DU2.6 Education and outreach materials	14
DU2.7 Outreach/education/prevention plan	14
DU2.8 Prevention efforts targeted at high-risk populations (e.g., NTD recurrence, diabetes, smoking, FAS)	15
DU2.9 Efforts to raise awareness through communication and interaction, regardless of audience	15
DU2.10 Outreach to other birth defect surveillance programs and NBDPN.....	16
DU2.11 Outreach/education/prevention evaluation	17
DU2.12 Community investigations (e.g., ability to assess cluster concerns or respond to new emerging threats)	18
DU3: Research	19
DU3.1 Descriptive studies.....	19
DU3.2 Linkages for follow-up/longitudinal studies (e.g., survival, long-term effects, economic analysis).....	20
DU3.3 Etiologic studies (to get beyond basic descriptive studies)	21

DU1: Monitoring

The intermittent performance and analysis of routine measurements, aimed at detecting changes in the environment or health status of populations – not to be confused with surveillance, which is a continuous process, although techniques of surveillance may be used in monitoring. (Last, 2001: A Dictionary of Epidemiology, 4th ed.)

		Level 1	Level 2	Level 3
Monitoring DU1.1	<p>DU1.1. Analysis of birth defects data by person</p> <p>“Person” attributes include age, sex, ethnicity/race, and socioeconomic status. Because personal characteristics may affect illness, organization and analysis of data by “person” may use inherent characteristics of people (for example, age, sex, race), biologic characteristics (immune status), acquired characteristics (marital status), activities (occupation, leisure activities, use of medications/tobacco/drugs), or the conditions under which they live (socioeconomic status, access to medical care).</p> <p>Reference: Chapter 8</p> <p>Please check the highest performance level that applies.</p>			
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Generate defect-specific counts, rates, and other descriptive data only on program’s surveillance area overall.</p>			
	<p>Level 2</p> <p>Generate defect-specific counts, rates, and other descriptive data stratified by infant and maternal characteristics (e.g., maternal age, race/ethnicity, infant sex). Analysis should include a measure of variability.</p>			
	<p>Level 3</p> <p>Analysis of data includes more comprehensive analytic investigations and/or statistical assessments (e.g., mortality/survival, multivariable analyses, direct or indirect adjustment of rates).</p>			
	Comments:			

Monitoring DU1.2	<p>DU1.2 Analysis of birth defects data by place</p> <p>Describing the occurrence of disease by “place” provides insight into the geographic extent of the problem and its geographic variation. Characterization by place refers not only to place of residence but to any geographic location relevant to disease occurrence. Such locations include place of diagnosis or report, residence, birthplace, or hospital unit.</p> <p>Reference: Chapter 8</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 Generate defect-specific counts, rates, and other descriptive data only on program’s surveillance area overall.</p>			
	<p>Level 2 Generate defect-specific counts, rates, and other descriptive data stratified by more granular geographic areas (e.g., county, health service regions, urban/rural or RUCA designation).</p>			
	<p>Level 3 Analysis of data includes more comprehensive analytic investigations and/or statistical assessments (e.g., statistical comparison of different levels of geographic areas [each county versus entire state]).</p>			
	<p>Comments:</p>			

Monitoring DU1.3	<p>DU1.3 Analysis of birth defects data by time</p> <p>The occurrence of disease changes over time. Some of these changes occur regularly, while others are unpredictable. Displaying the patterns of disease occurrence by time is critical for monitoring disease occurrence in the community and for assessing whether the public health interventions made a difference.</p> <p>Reference: Chapter 8</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1</p> <p>Generate defect-specific counts, rates, and other descriptive data, stratified by time periods (e.g., quarterly, annually, biannually), using at least three years of data.</p>			
	<p>Level 2</p> <p>Supplement defect-specific counts, rates, and other descriptive data with basic time/temporal analyses (e.g., annual percent change, Cochran-Armitage test for trend), for five or more years of data.</p>			
	<p>Level 3</p> <p>Analysis of data includes more comprehensive analytic investigations and/or statistical assessments by incorporating more advanced trends analyses using five or more years of data (e.g., joinpoint, ARIMA, or other regression models, observed versus expected counts/rates over time).</p>			
	<p>Comments:</p>			

Monitoring DU1.4	<p>DU1.4 Generation of program-specific birth defect reports for public use</p> <p>A birth defects surveillance program must establish goals and objectives for how data are to be collected, analyzed, disseminated, and used. It is through the latter (i.e., data use) that the efforts from the former are translated into public health action and health improvement. Thus, using data to meet a program’s objectives is the most important aspect of any public health surveillance program; merely collecting data is not enough. How data are being used is also what programs tout when they need to showcase their activities to agency officials and legislators.</p> <p>Reference: Chapter 1</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 Produce only basic reports with limited program-specific information (e.g., fact sheets, one- pagers); reports are publicly available in print and/or online.</p>			
	<p>Level 2 Produce program-specific data reports in print and/or online on a regular basis. At a minimum, reports contain counts, rates, and other descriptive data for birth defects.</p>			
	<p>Level 3 Produce program-specific “on demand” or “emerging issues” reports on special topics (e.g., folic acid and NTDs, Zika and microcephaly) in print and/or online.</p>			
	<p>Comments:</p>			

Monitoring DU1.5	<p>DU1.5 Submission of data to external partners/users outside of the program</p> <p>Dissemination plays an active role in turning data from throughout the US into useful information and encourages the use of birth defect data for decisions regarding health services planning, such as secondary disabilities prevention and referral to services. Ideally, the development of goals, objectives, and outcome measurements will be done in collaboration with stakeholders and with internal and external advisory groups.</p> <p>Reference: Chapters 6 and 10</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 Submit standard birth defects data to external partners for routine data calls (e.g., NBDPN annual report).</p>			
	<p>Level 2 Submit birth defects data in various formats for “special calls” for data (e.g., MMWR, multi-state NBDPN data projects).</p>			
	<p>Level 3 Level 2 plus case-level data are available to external users and provision of data occurs regularly.</p>			
	<p>Comments:</p>			

Monitoring DU1.6	<p>DU1.6 Geocoding of birth defects data (address at delivery)</p> <p>The application of Geographic Information Systems (GIS) methods has become an integral component of aggregating, analyzing, and evaluating 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. This requires the transformation, as accurately as possible, of records containing addresses or location information into geographic objects. This process is called geocoding, also known as address matching.</p> <p>Reference: Appendix 11.2</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Geocoding performed only for individual studies or special projects.</p>			
	<p>Level 2</p> <p>Geocoding performed at least annually for all cases or a subset of cases; however, routine geocoding is not available for non-cases.</p>			
	<p>Level 3</p> <p>Geocoding performed at least annually for all live born cases and non-cases (e.g., vital records [birth certificates] geocoded each year).</p>			
	Comments:			

Monitoring DU1.7	<p>DU1.7 Linkage of registry data to health/service-related databases</p> <p>The potential to link records and consolidate information from different databases contributes to the public health applications of surveillance data. For example, data from birth defects surveillance programs can be used to determine whether reported cases of birth defects represent existing cases in other databases. The ability to link records on individuals in more than one database can streamline treatment and referral processes and help maintain a certain level of fidelity and trust in prevalence data. Another utility of record linkage is the ability to supply crucial data required for various research efforts.</p> <p>Reference: Chapter 1</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Registry data are linked to vital records only.</p>			
	<p>Level 2</p> <p>Registry data are linked to vital records plus at least one additional encounter-level data source (e.g., hospital discharge, Medicaid, National Death Index, disease registries, census data, environmental data, etc.).</p>			
	<p>Level 3</p> <p>Registry data are linked to vital records and at least one additional data source longitudinally (e.g., hospital discharge, National Death Index, etc. at multiple points in time).</p>			
	Comments:			

DU2: Public Health Practice

The ongoing, systematic collection, analysis, and interpretation of health data essential to the planning, implementation and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know.

Public Health Practice DU2.1	DU2.1 Referral plan for referral to services Information collected as part of birth defects surveillance can be used to refer specific children and their families to appropriate services. Referral plans may be “direct” (i.e., the birth defects program itself directly refers children to services), or “indirect” (the program works with other partners to facilitate, support, or evaluate referral networks). Established referral networks serve as a resource for children and their families to learn about available medical services, community programs, and social support. Reference: Chapter 1	Level 1	Level 2	Level 3
	Please check the highest performance level that applies.			
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 State is planning for a referral program using information collected from birth defects surveillance.			
	Level 2 Data driven referral protocol is in place, whether cases are directly referred from the birth defects surveillance program or indirectly referred (e.g., through social workers or case management programs). Partner input has been included.			
	Level 3 Referral protocol is in place and regularly evaluated for effectiveness, either qualitatively (e.g., parent or service provider surveys, questionnaires on effectiveness of the referral process) and/or quantitatively (e.g., examining whether referrals from the birth defects program result in service enrollment/use).			
	Comments:			

Public Health Practice DU2.2	DU2.2 Type of programs/services referred to	Level 1	Level 2	Level 3	
	There are a number of services to which children and their families may be referred, including: early intervention, family support, bereavement case management, nutrition, financial/insurance, or specialty services (e.g., genetics, cardiology). Having agencies use birth defects data to link patients with appropriate services is a critical data use that has immediate and direct impact on the lives of those affected.				
	Reference: Chapter 1				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Educational information about services is made available to families (brochure, letter, or information available online).				
	Level 2 Families of potentially eligible children are identified and referred to at least one service or program.				
Level 3 Families of potentially eligible children are identified and the birth defects program can refer to multiple services directly or indirectly (Early Intervention, clinical or family support services, etc.).					
Comments:					

Public Health Practice DU2.3	DU2.3 Data verification prior to referral	Level 1	Level 2	Level 3
	Some suggested “filters”: determine vital status, (i.e. living or deceased), removing minor conditions, selecting children with at least one confirmed eligible condition, confirm contact information, adoptions, gestational carriers, etc.			
	Reference: Appendix 4.1			
	Please check the highest performance level that applies.			
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 Records are filtered on vital status only prior to referral.			
	Level 2 Records are filtered on vital status, and eligible diagnoses are confirmed prior to referral.			
Level 3 Vital status and eligible diagnoses are confirmed prior to referral, along with at least one additional validation criterion (confirming contact information, adoptions, etc.).				
Comments:				

Public Health Practice DU2.4	<p>DU2.4 Timeliness of referrals</p> <p>Eligible children and their families should be connected with appropriate services in a timely fashion. Eligible conditions should include, at a minimum, conditions defined by state policy. If information is used to refer children directly to services or to other agencies that refer children to services, then the case-finding process should be designed to collect identifying and contact information early enough in the process to make the referral in a timely manner.</p> <p>Reference: Chapter 1</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>50% of eligible cases (as defined by the birth defect surveillance program) are referred within 12 months of identification by the birth defects program.</p>			
	<p>Level 2</p> <p>50% of eligible cases (as defined by the birth defect surveillance program) are referred within 6 months of identification by the birth defects program.</p>			
	<p>Level 3</p> <p>50% of eligible cases (as defined by the birth defect surveillance program) are referred within 3 months of identification by the birth defects program.</p>			
	Comments:			

Public Health Practice DU2.5	<p>DU2.5 Key linkages/data integration for analyzing referral to services outcomes</p> <p>Birth defects data can be linked to service program data to examine referral rates to services. Service programs may include: early intervention, family support, bereavement case management, nutrition, financial/insurance, specialty services (e.g., genetics, cardiology), WIC or home visiting, etc. Evaluating a program for service referral can give investigators information on the efficacy of their referral agencies or the appropriateness of services offered.</p> <p>Reference: Chapter 1</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 The birth defects program has established a relationship with a service program or referral partner agency.</p>			
	<p>Level 2 Birth defects data are periodically linked to service program data for special projects that examine rates of referral and service use.</p>			
	<p>Level 3 Birth defects data are routinely linked to service program data, and referral and service use rates are analyzed regularly.</p>			
	<p>Comments:</p>			

Public Health Practice DU2.6	DU2.6 Education and outreach materials	Level 1	Level 2	Level 3	
	Beginning with the audience (e.g., Primary Care Providers, Specialists, Researchers, Families) will help determine the objectives of the presentation, formulate the message, and select the best medium to use in conveying that message. Materials should be culturally relevant. Reference: Chapter 11				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Program only uses educational materials developed by other entities (e.g. NBDPN, CDC, March of Dimes).				
	Level 2 Program uses educational materials developed by other entities (e.g. NBDPN, CDC, March of Dimes) with some modification (may include local or state-specific data).				
	Level 3 Program uses materials (including those developed with state or national partner agencies) with frequently updated state-specific data (prevalence rates and risk factors), available in multiple formats (e.g. print, web site, social media) and multiple languages.				
Comments:					

Public Health Practice DU2.7	DU2.7 Outreach/education/prevention plan	Level 1	Level 2	Level 3	
	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. Relevant partners (e.g. community-based organizations, service providers, prevention programs) should be engaged in the planning and implementation process, as appropriate. Reference: Chapter 11				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Outreach/prevention plan is at least in development or draft form but does not contain partner input or is not evidence-based.				
	Level 2 Outreach/prevention plan is in place and partner input has been included.				
	Level 3 Evidence-based outreach/prevention plan is implemented and there is ongoing partner input and evaluation.				
Comments:					

Public Health Practice DU2.8	DU2.8 Prevention efforts targeted at high-risk populations (e.g., NTD recurrence, diabetes, smoking, FAS)	Level 1	Level 2	Level 3	
	Data produced at each phase of a program’s development can be mobilized to inform action. Actions should be appropriate, informed by evidence, and maximally effective and cost-effective.				
	Reference: Chapter 11				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Only broad (non-targeted) prevention efforts are in place.				
	Level 2 At least one targeted prevention effort per year. State program actively uses state-specific data, including data linkages and descriptive epi, to conduct needs assessments and develop efforts.				
Level 3 In addition to the criteria in level 2, data are put into action (i.e., making a change in practice or policy).					
Comments:					

Public Health Practice DU2.9	DU2.9 Efforts to raise awareness through communication and interaction, regardless of audience	Level 1	Level 2	Level 3	
	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. Common communication channels include reports and publications, professional presentations (in-person or web-based), mass media, websites, and community outreach.				
	Reference: Chapter 11				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Distribution or publication of written materials/reports only.				
	Level 2 Capacity to present information to and interact with multiple audiences and some interactions occur.				
Level 3 Strategies or policies were implemented based on awareness activities.					
Comments:					

Public Health Practice DU2.10	<p>DU2.10 Outreach to other birth defect surveillance programs and NBDPN</p> <p>Public input through partnerships with multi-state agencies and organizations and the effective utilization of advisory committees are essential to establishing and revising program objectives and ensuring that the resources exist to meet them.</p> <p>Reference: Chapter 1</p> <p>Please check the highest performance level that applies for any program personnel.</p>	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Passive participation (list serve member, some meeting participation) in committees within a birth defects-related organization (NBDPN or others).</p>			
	<p>Level 2</p> <p>Active participation (regular contribution and meeting attendance, work group participation) in at least one committee.</p>			
	<p>Level 3</p> <p>Leadership role (chair, board member, committee lead or other officer-level position) at a national level.</p>			
	<p>Comments:</p>			

Public Health Practice DU2.11	DU2.11 Outreach/education/prevention evaluation	Level 1	Level 2	Level 3	
	Program evaluation is a valuable and desired area of activity with important scientific, academic, social, and policy applications. Program evaluation can focus on different aspects of surveillance program activities.				
	Reference: Chapter 1				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Outreach or prevention efforts are in place, but no evaluation of efforts is performed.				
	Level 2 Effectiveness of efforts to reach targeted audiences is evaluated and reported for special projects only.				
Level 3 Effectiveness of efforts to reach targeted audiences is routinely evaluated and reported.					
Comments:					

Public Health Practice DU2.12	<p>DU2.12 Community investigations (e.g., ability to assess cluster concerns or respond to new emerging threats)</p> <p>It is recommended that the state establish protocols for dealing with community concerns and include descriptions of how information regarding the investigation is communicated to concerned stakeholders.</p> <p>Reference: Chapter 11</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 Ability to respond to community concerns, even if only basic (sharing info/rates or providing education).</p>			
	<p>Level 2 Program or agency has capacity to perform initial investigation into community concern in a timely manner. Program does not necessarily perform the full investigation.</p>			
	<p>Level 3 Program has capacity and protocol in place to perform cluster investigation. Program has generated report(s) on cluster investigation or investigation processes.</p>			
	<p>Comments:</p>			

DU3: Research

Systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.

		Level 1	Level 2	Level 3
Research DU3.1	<p>DU3.1 Descriptive studies</p> <p>Birth defects surveillance systems should be developed to facilitate the essential activities of data collection, data analysis, data evaluation, and information dissemination consistent with a program’s established goals and objectives. A common use of data produced by surveillance programs is to describe the occurrence (prevalence at birth) of the monitored conditions.</p> <p>Reference: Chapters 1 and 6</p> <p>Please check the highest performance level that applies.</p>			
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 Ability to generate data on birth defect diagnoses only.			
	Level 2 Ability to provide and prepare data on birth defect diagnoses and important covariates, including socio-demographic factors			
	Level 3 Program takes the lead on studies or regularly supports external research partners.			
	Comments:			

Research DU3.2	DU3.2 Linkages for follow-up/longitudinal studies (e.g., survival, long-term effects, economic analysis) The potential to link records and consolidate information from different databases contributes to the public health applications of surveillance data. One utility of record linkage is the ability to supply crucial data required for various research efforts. Linkages may be in either direction (to or from the Birth Defects Program). Relevant databases may include: Newborn Screening, Vital records, Hospital discharge, Medicaid, Early intervention, Early hearing screening, pulse oximetry screening, environmental exposure, disease reporting, etc. Reference: Chapter 1 Please check the highest performance level that applies.	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 Linkage to vital records only.			
	Level 2 Linkages to 2 or more relevant databases that include socio-demographic or health outcome data.			
	Level 3 Linkages to 2 or more relevant databases, plus contribution to follow-up or longitudinal studies (taking the lead on studies or working with external groups).			
	Comments:			

Research DU3.3	<p>DU3.3 Etiologic studies (to get beyond basic descriptive studies)</p> <p>While epidemiologic research methods have evolved significantly, the ultimate goal of these studies has remained constant: namely, to identify, define, and associate birth defects with possible etiologic factors.</p> <p>Reference: Chapter 1</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Ability to provide case data only (available surveillance data).</p>			
	<p>Level 2</p> <p>Program participates in study design and provides case-level data for studies investigating possible causes of birth defects (e.g., case-control studies). Program provides data on birth defect diagnoses and important covariates, including socio-demographic factors.</p>			
	<p>Level 3</p> <p>Program takes the lead on etiologic studies or actively collaborates with external research partners, with the capacity to contact subjects, perform intensive record review, or contribute biologic materials on cases.</p>			
	Comments:			

Summary

[Note that you do not need to complete the following table. These scores will be generated automatically.]

Performance Measure	None	Level 1	Level 2	Level 3
DU1: Monitoring				
DU1.1 Analysis of birth defects data by person				
DU1.2 Analysis of birth defects data by place				
DU1.3 Analysis of birth defects data by time				
DU1.4 Generation of program-specific birth defect reports for public use				
DU1.5 Submission of data to external partners/users outside of the program				
DU1.6 Geocoding of birth defects data (address at delivery)				
DU1.7 Linkage of registry data to health/service-related databases				
DU2: Public Health Practice				
DU2.1 Referral plan for referral to services				
DU2.2 Type of programs/services referred to				
DU2.3 Quality assurance criteria prior to referral				
DU2.4 Timeliness of referrals				
DU2.5 Key linkages/data integration for analyzing referral to services outcomes				
DU2.6 Education and outreach materials				
DU2.7 Outreach/education/prevention plan				
DU2.8 Prevention efforts targeted at high-risk populations (e.g., NTD recurrence, diabetes, smoking, FAS)				
DU2.9 Efforts to raise awareness through communication and interaction, regardless of audience				
DU2.10 Outreach to other birth defect surveillance programs and NBDPN				
DU2.11 Outreach/ education/prevention evaluation				
DU2.12 Community investigations (e.g., ability to assess cluster concerns or respond to new emerging threats)				
DU3: Research				
DU3.1 Descriptive studies				
DU3.2 Linkages for follow-up/longitudinal studies (e.g., survival, long-term effects, economic analysis)				
DU 3.3 Etiologic studies (to get beyond basic descriptive studies)				