Preface

The National Birth Defects Prevention Network (NBDPN) originally produced the first ***Guidelines for Conducting Birth Defects Surveillance*** (or ***Guidelines***) as a manual to help states and regions establish surveillance programs, collect accurate data, and contribute to the regional and national understanding of the prevalence rates of birth defects. As the medical, legal, technological, and social landscape has changed over the last 20+ years, the practices for birth defects surveillance programs have also evolved. This updated edition seeks to address those changes.

We have distilled practical guidance into Standards and Recommendations which can be found embedded throughout the chapters, and also summarized in the **At a Glance** section.

- ***Standards*** are the activities (i.e., outputs and performance indicators) expected of a birth defects surveillance program. They are presented in tables which serve as a tiered rubric for birth defects surveillance program activities, as in the example shown here:

Example Standards Table and Description of Tiers	
Core	The minimum criteria needed for surveillance activities to ensure a birth defects surveillance program meets an acceptable level of performance.
Enhanced	The minimum criteria (Core tier), *plus* some additional activities a birth defects surveillance program might engage in based on available resources and local policies.
Extended	The archetype of what an ideal birth defects surveillance program's activities would encompass.

- ***Recommendations*** denote specific guidance that NBDPN strongly suggests incorporating into every birth defects surveillance program to ensure timely, accurate, and complete data. Each is presented in a shaded box for ease of identification, as shown here:

Recommendation 1.0.0: NBDPN strongly recommends that birth defects surveillance programs strive to conduct all Core activities defined by the Surveillance Guideline Standards and achieve minimum data quality standards prior to expanding into Enhanced and/or Extended practices.

Throughout the manual, key terms are noted in ***bold italics***, and can also be found in the glossary.

We will use the phrase ***birth defects surveillance program***, although some programs may refer to their work as a surveillance registry or system. We will use the term ***birth defect*** to refer to major congenital anomalies, chromosomal abnormalities, and genetic syndromes. We recognize that the term birth defect can have different meanings depending on the context, and that the terms congenital abnormality, congenital anomaly, and congenital malformation are often used as synonyms for birth defect.

This is a living document, intended to be updated over time as new best practices are identified

in response to advancing knowledge. Programs are encouraged to evaluate and modify their current surveillance practices to align with the updated recommendations and standards to the extent feasible within their mission, objectives, and resources, and in accordance with their agency's policies, priorities, and information technology (IT) capabilities.

We express our gratitude for all of the individuals, programs, and agencies who participated in the multi-year process of bringing this updated manual to fruition.
