

Birth Defects In Rhode Island

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Birth defects are structural abnormalities that affect the development of organs and tissues of an infant or child. These abnormalities may be identified during pregnancy, at birth or following birth. Possible causes or contributing factors to birth defects include genetic factors, environmental pollutants, occupational hazards, dietary factors, infections, medications, and personal behaviors.¹ In both the United States and Rhode Island, birth defects are a leading cause of infant mortality and contribute to childhood illness and disability. However, early recognition and response to birth defects may often prevent more serious effects.

Rhode Island began developing a birth defects surveillance system in 2000, with funding from the **Centers for Disease Control and Prevention (CDC)**. During 2003, the Rhode Island General Assembly enacted legislation (Rhode Island General Law 23-13.3) requiring the development and implementation of a birth defects reporting, surveillance and information system by the Rhode Island Department of Health. The Rhode Island Birth Defects Program, created in response to this mandate, is designed to track the prevalence of birth defects among children ages 0 – 5 in Rhode Island and collect information on the characteristics of those children and their parents, assure that those children and their families receive appropriate services and referrals, and identify and close gaps in services for families of children with birth defects. This report presents selected summary data from the Birth Defects Program for the years 2001-2005.

METHODS

Data on birth defects in the Rhode Island population are collected in two ongoing data sources maintained by the Department of Health: birth certificate data collected by the Office of Vital Records and hospital discharge data collected by the Center for Health Data and Analysis. Birth certificate data include a wide variety of information on the characteristics of the child, parent, and birth experience, but may not capture all birth defects and does not identify birth defects at the level of detail in the **International Classification of Diseases coding system (ICD-9-CM)**.² Hospital discharge data include a record for nearly every birth occurring in the state and code all recorded birth defects in ICD-9-CM, but collect few data items on the characteristics of the child and parents. Therefore, the Birth Defects Program uses hospital discharge data to identify newborns with birth defects and links their hospital records with their birth certificate records. In addition to case identification through the hospital discharge database, the Birth Defects Program is working with Women & Infants Hospital, Rhode Island Hospital, and Hasbro Children's Hospital to obtain additional cases of birth defects and information on services provided to families of children with birth defects. To determine whether children with birth defects receive appropriate preventive services, the Birth Defects Program links children identified with birth defects to

Rhode Island's integrated child health information system, KIDSNET. Since KIDSNET maintains information from ten program databases, children who are not receiving services can be identified and provided outreach and referrals.

RESULTS

Among the 61,870 Rhode Island babies born in the state's maternity hospitals during 2001-2005, hospital discharge data indicate that 3,510 (5.7%) had at least one birth defect. By year, the number of newborns with birth defects ranged from a low of 691 in 2001 to a high of 720 in 2005. Overall, the statewide prevalence rate per 10,000 births for birth defects has remained stable over the past five years, varying within a range of only 7% around the five-year average rate of 567 babies per 10,000. (Figure 1)

Birth defects have been reported in all organ systems among Rhode Island newborns during 2001-2005. (Table 1) The most frequent birth defects are those related to the cardiovascular system, where one in 40 babies are born with a cardiovascular de-

Table 1.
Prevalence of Birth Defects by Body System
Rhode Island, 2001-2005

Organ System	Number	Prevalence Rate per 10,000 Live Births*
Cardiovascular	1487	240.3
Musculoskeletal/Integumentary	1368	213.3
Genitourinary	834	134.8
Gastrointestinal	306	49.5
Eye, Ear, Face and Neck	217	35.1
Central Nervous System	149	24.1
Chromosomal	107	17.3
Respiratory	88	14.2

*Because newborns may have birth defects in more than one organ system, the prevalence rates for organ systems add to a total that is greater than the overall prevalence rate of 567 per 10,000 live births.

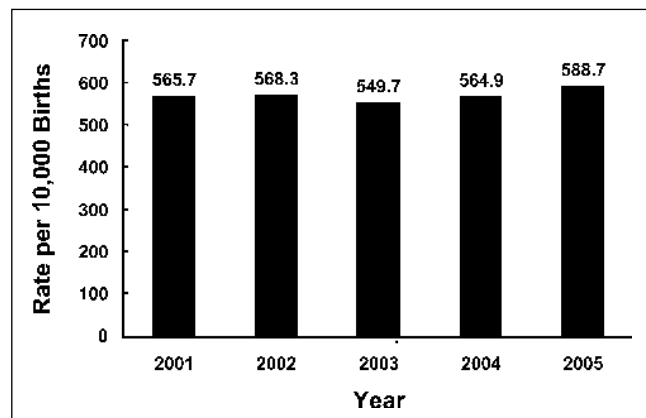


Figure 1. Newborns with birth defects per 10,000 live births, Rhode Island, 2001-2005.

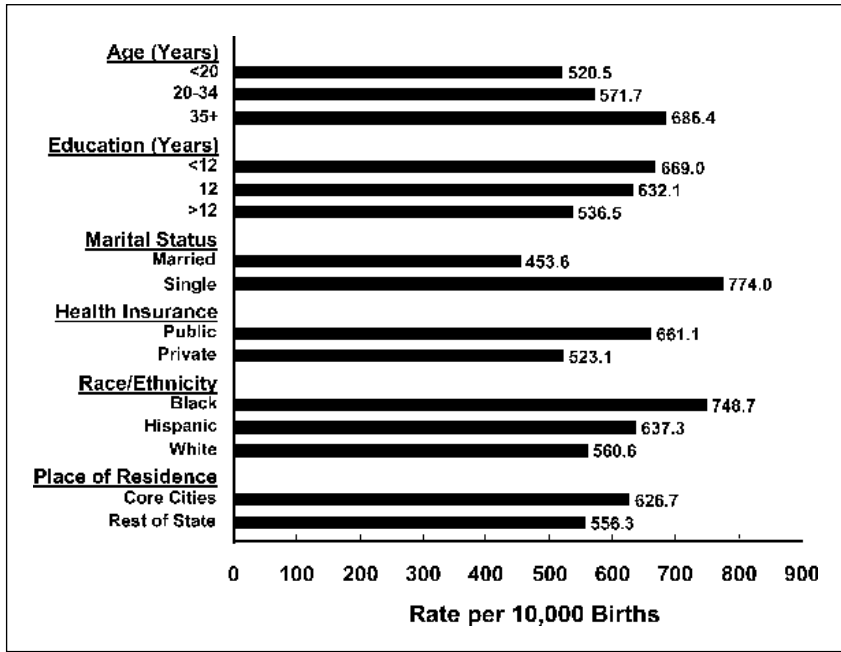


Figure 2. Newborns with birth defects per 10,000 live births, by selected maternal characteristics, Rhode Island, 2005.

fect. Also common are birth defects affecting the musculoskeletal and integumentary systems and the genitourinary system.

The prevalence rate for birth defects varies with maternal characteristics. Babies born to older women (ages 35 or greater), women with less than a high school education, single women, women with publicly funded health insurance, or women of color, are at a higher risk for birth defects. (Figure 2) During 2005, the birth defects rate among women aged 35 or greater was 686.4 compared to 520.5 among women aged less than 20. Similarly, the birth defects rate among women with less than a high school education (669.0) was 1.25 times the rate among women with more than a high school education (536.5). Single women (774.0) were nearly twice as likely to have a baby with a birth defect than married women (453.6). Women who were insured through public programs such as RIte Care and Medicaid were also more likely to have a baby with a birth defect (661.1) than women insured by commercial or private providers, such as Blue Cross and United Healthcare (523.1). Black/African American women were more

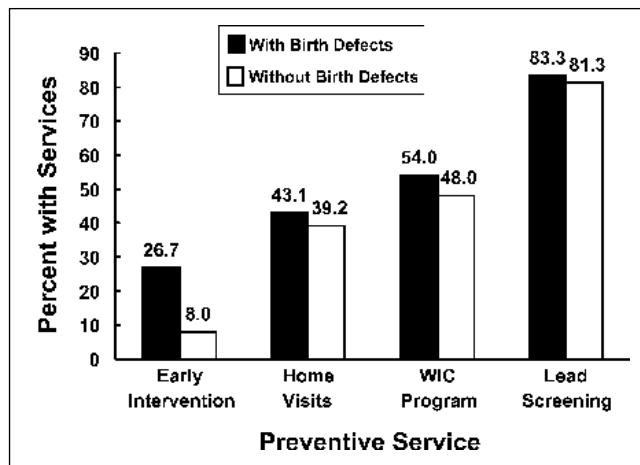


Figure 3. Newborns receiving selected preventive services, by diagnosis of birth defects, Rhode Island, 2004.

likely to have a baby with a birth defect (748.7) than White women (560.6). Birth defect rates were also higher among those who resided in the core cities, including Central Falls, Newport, Pawtucket, Providence, West Warwick and Woonsocket (626.7 per 10,000 newborns) than those who lived in the rest of the state (556.3).

Data indicate that among Rhode Island children born in state during 2004, a higher proportion of children with birth defects were screened for lead poisoning, were enrolled in the state's WIC and Early Intervention programs, and received home visits compared to children without birth defects. (Figure 4)

DISCUSSION

Over the last five years, 5.7% of newborns in Rhode Island, or approximately 700 per year, have been diagnosed with birth defects. Nationally, the reported prevalence rate is much lower, at 3.0%.³ However, because there are no national uniform standards for case ascertainment, it is difficult to compare rates across states. For example, some state registries use active surveillance (i.e., a case finding process where cases are identified at multiple data sources and includes identifying potential birth defect cases, medical record abstraction and follow-up), while others use passive surveillance (i.e., wait for data to be submitted to the program by limited data reporting sources), and still others use a combination of passive and active systems.⁴ Also, some states limit their registries to live birth outcomes while others may also include fetal deaths. Although Rhode Island is working to make its case ascertainment system an active one, the system currently is passive and does not include data on fetal deaths.

Once birth defects cases are identified, the Rhode Island Birth Defects Program works to assure that these children and their families receive appropriate services and referrals. The Program also has been conducting focus groups, interviews and surveys with families to learn about their experiences with the health care system and to determine any gaps in or barriers to the system. This information will be used to develop strategies that will help link families to follow-up and treatment services, which hopefully, will lead to a reduction in disparities.

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REFERENCES

1. Rhode Island Birth Defects Program, Rhode Island Department of Health. Birth Defects Data Book. 2005. <http://www.health.ri.gov/family/birthdefects/birth-defects-databook.pdf>
2. Public Health Service and Health Care Financing Administration. *International Classification of Diseases, 9th Revision, Clinical Modification, 6th ed.* Washington: Public Health Service, 1996.
3. <http://www.cdc.gov/ncbddd/bd/facts.htm>
4. National Birth Defects Prevention Network. Guidelines for Conducting Birth Defects Surveillance. June 2004.