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# Rhode Island Birth Defects Program Database

Kristen St. John, MPH and Samara Viner-Brown, MS Center for Health Data and Analysis, Rhode Island Department of Health

# **Background/Description**

#### What are Birth Defects?

- Birth defects are structural abnormalities that affect the development of organs and tissues of an infant or child. They may be identified during pregnancy, at birth or following birth.
- Possible causes or contributing factors to birth defects include genetic, environmental pollutants, occupational hazards, dietary factors, medications and personal behaviors.
- Each year in Rhode Island, approximately 400 babies are born with a birth defect. Early recognition and response to birth defects often prevents more serious effects.

## **Case Ascertainment and Reporting**

- Rhode Island's birth defects information system began in 2000 with Centers for Disease Control and Prevention (CDC) funding. RIBDP is currently one of fourteen CDC-funded birth defects programs.
- The Rhode Island Birth Defects Program (RIBDP) is located at the Rhode Island Department of Health (RIDOH) and housed in the Center for Health Data and Analysis.
- During 2003, the Rhode Island General Assembly enacted legislation requiring the state to develop and implement a birth defects reporting, surveillance and information system that would:
- describe the occurrence of birth defects in newborns and children up to age 5;
- detect trends of morbidity and mortality and stimulate epidemiological research; and
- identify children with birth defects to intervene on a timely basis for treatment.
- The legislation also enabled the establishment of reporting regulations which went into effect in November 2005.
- Cases are identified using newborn hospital discharge data and reports from centers and clinics at Rhode Island/Hasbro Children's Hospital and Women and Infants Hospital.
- The Birth Defects Database links Rhode Island hospital discharge data to vital records data and an integrated child health information system, KIDSNET, which was developed and is maintained by RIDOH. KIDSNET receives prompt information on all births, including newborn hearing assessment, newborn developmental risk screening, newborn bloodspot screening, and vital records.

#### **Service Assessment and Assurance**

- A RIBDP priority is to assure that children with birth defects receive necessary services on a timely basis. Children with selected birth defects identified through surveillance are referred for a service assessment to determine if they received necessary medical, educational, and developmental support services.
- Families of children with selected birth defects are asked to complete a service assessment (via mail or in-person) to determine which services and referrals they have received. The RIBDP works with centers and clinics at Rhode Island/Hasbro Children's hospital to interview families.

## Sample Data

#### Prevalence of Birth Defects in Rhode Island

- Hospital discharge data indicate that from 2014-2018, among 53,577 babies born among Rhode Island residents in Rhode Island maternity hospitals, 1,810 (3.3%) had at least one birth defect.
- During this period, the rate of birth defects in Rhode Island increased by 24%, from 317 per 10,000 live births in 2014 to 394 per 10,000 in 2018. (**Figure 1**)
- The most frequently reported birth defects are those related to the cardiovascular system followed by the genitourinary and musculoskeletal systems.

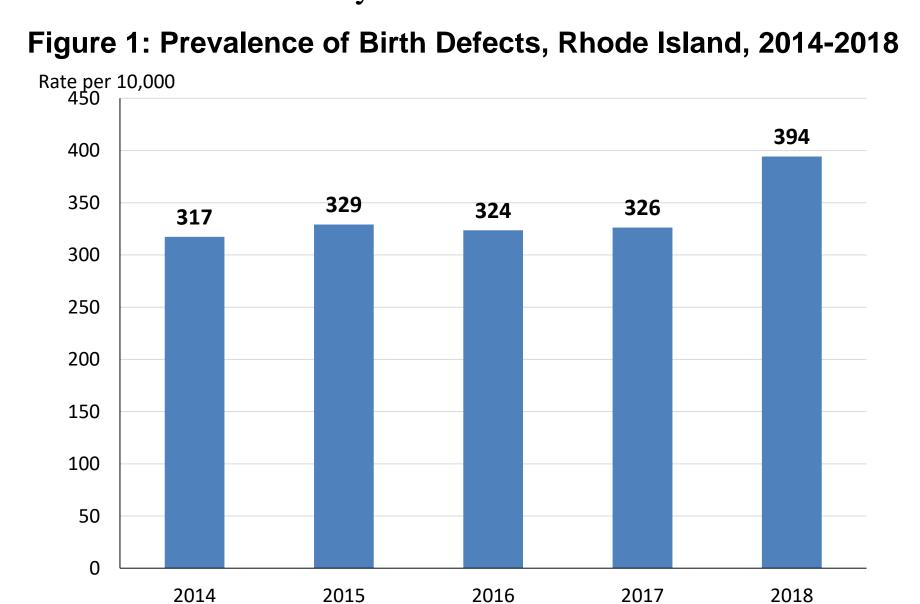
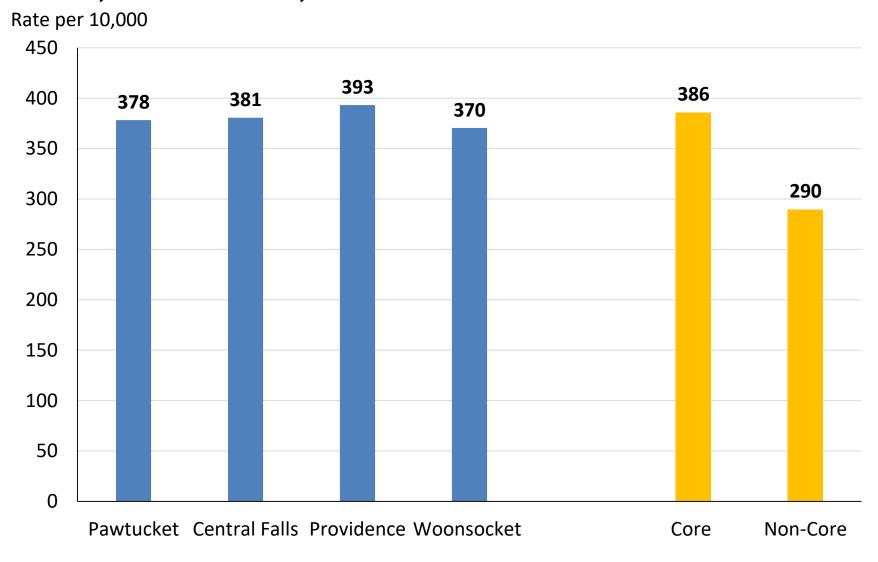


Figure 2: Prevalence of Birth Defects by Selected Geographic Areas, Rhode Island, 2014-2018



## Geographic Disparities

- Babies born to residents of Rhode Island's core cities (Central Falls, Pawtucket, Providence, and Woonsocket) were 1.3 times more likely to have a birth defect than those born to residents living in the rest of the state.
- Compared to the other core cities, the birth defects rate in Woonsocket (370) was the lowest; Providence (393) and Central Falls (381) had the highest rates in the state (**Figure 2**).

## **Maternal Characteristics**

• Babies born to young women (aged less than 25), older women (aged 35 or older), women with less than a college education, single women, and women with publicly funded health insurance were at a higher risk for birth defects. (**Figure 3**)

Figure 3: Prevalence of Birth Defects by Selected Maternal Characteristics, Rhode Island, 2014-2018

