DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health
Center for Family Health Research and Epidemiology

# Analysis of the 2009 Delaware Birth Defects Registry

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## EXECUTIVE SUMMARY

Birth defects are among the leading causes of infant death in Delaware and nationwide. For this reason, the state's birth defects registry was developed to collect and identify the diverse factors that may cause birth defects. This report on the birth defects registry has two objectives:

1. To provide a snapshot of the characteristics of mothers and infants listed in the birth defects registry, focusing only on those infants who were born to Delaware residents in 2009 ("registered infants").
2. To compare the demographic and health attributes of these infants to all infants born to Delaware residents in 2009.

In response to these objectives, a comprehensive set of analyses was performed on the mothers of the infants listed in the registry, on the infants listed in the registry, and on the registry itself. These analyses included but were not limited to a comparison of the demographic indicators and health status of mothers in the registry compared to all Delaware residents that gave birth in 2009, and an assessment of infants in the registry that expired within one year after birth. In addition, an investigation was conducted on whether infants listed in the registry were diagnosed with the same birth defect as a family member, recognizing the limitations that reported birth defect(s) of family member(s) were based on the mother's recollection of the birth defect(s) and that the medical records of the family member(s) were not reviewed.

Results indicated that mothers in the registry had generally the same age, education, race and ethnicity, and gravida as all Delaware residents that gave birth in 2009. Moreover, certain findings paralleled those found in other Delaware-specific maternal health assessments.

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## INTRODUCTION

A birth defect, or congenital anomaly, is an abnormality of structure, function, or metabolism that typically occurs to an infant prior to birth and can cause mental or physical disabilities or even death.[1] Approximately 120,000 infants (3% of all infants) in the United States are born with birth defects,[2] and nationwide, birth defects are the leading cause of death in the first year of life.[3] In Delaware, birth defects were the second leading cause of infant mortality in the 2005-2009 period, accounting for 12.7 percent of all infant deaths.[4] Although genetic and environmental factors – individually or in combination – can cause birth defects, the causes of 7 out of 10 birth defects are unknown.[1]

The Delaware Birth Defects Registry is a statewide program that collects and analyzes information on children with birth defects.[5] The intent of the registry is to identify the environmental, genetic, and health risk factors that may ultimately cause birth defects. To be included as a case in the Delaware Birth Defects Registry, all of the following criteria must be met:

- The mother must reside in Delaware at the time of delivery/pregnancy outcome.
- The infant or fetus must have a birth defect or developmental disability monitored by the registry.
- The birth defect must be diagnosed prenatally or within one year after delivery.

The case definition includes all pregnancy outcomes (i.e., live births, spontaneous fetal deaths, and induced pregnancy terminations for a fetus weighing at least 350 grams, or in the absence of weight, 20 weeks of gestation).

This report has two objectives:

1. To provide a snapshot of the characteristics of mothers and infants listed in the birth defects registry, focusing only on those infants who were born to Delaware residents in 2009 ("registered infants").
2. To compare the demographic and health attributes of these infants to all infants born to Delaware residents in 2009. This may assist in investigations on feto-infant health disparities and on policies relevant to maternal and child health.

These objectives were met through a meticulous analysis of the demographics, prior pregnancy history, and health conditions of the mother and an assessment of the reported birth defects and health status of the infant.

## METHODOLOGY

### Procedure for Case Finding and Ascertainment

Entries in the birth defects registry ("cases") were identified through a routine review of primary source records. Primary sources currently included, but were not limited to, the following:

- Electronic birth records.
- Hospital electronic and paper medical records.
- Maternal Fetal Medicine electronic records.
- Vital Statistics.
- Licensed birthing centers.

Cases were ascertained from multiple sources along three broad paths.

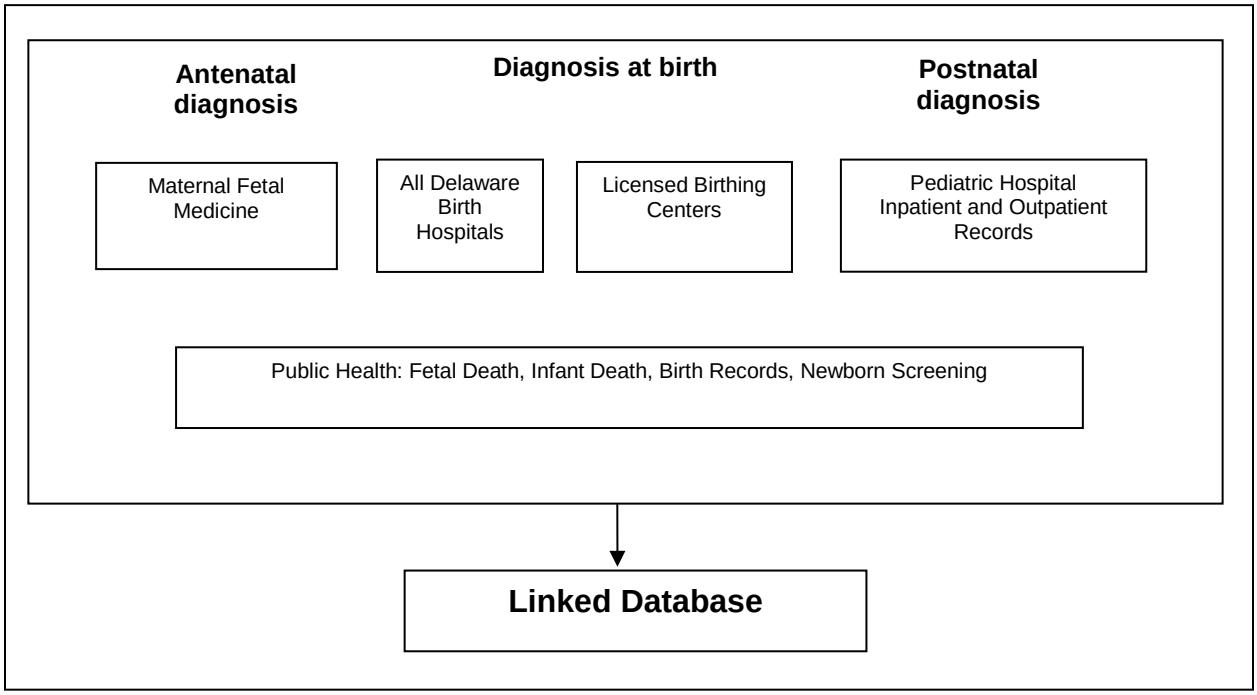
- *First Path*. The records of birth hospitals, licensed birthing centers, and midwives provided the first path for case detection. The frequency of visits to each facility was determined in part by the number of births per year in that facility. The Program Manager requested a list of all patients that were discharged during a specified birth cohort year and have one or more of the codes listed in Appendix A.
- *Second Path*. A second path for case detection involved collecting information from places where children may be prenatally diagnosed or where pregnancies may be terminated. The Program Manager requested a list of all patients that received prenatal care or testing from the Maternal Fetal Medicine groups during the specific birth cohort being abstracted and resulted in a diagnosis of one or more of the codes listed in Appendix A.
- *Third Path*. A third path of case detection involved the review of other sources by the program staff. One of these sources is the Delaware Office of Vital Statistics, which provided a list of names and date of birth or date of death. In addition to these records, staff also reviewed other data sets, such as Hospital Discharge Data and those collected by Newborn Screening – Blood Spot and Hearing. In addition to serving as a catch for any missed cases, these vital record reviews also provided a means for verifying data on completed cases and a source of data for incomplete cases.

### Creation of a Potential Case List

Potential case lists were requested by the Program Manager through each institution's medical records department. Lists were created using software to query all births and/or fetal deaths for the ICD-9 codes tracked by the registry. When an institutional list was received, it was validated for the appropriate codes and any erroneous codes that were not tracked by the registry were removed. The lists were provided in a

vertical formation in which each case has one line of data for each defect noted in the chart. The Program Manager used SPSS software to flatten the list into a horizontal formation in which each case has only one line of data with each suspected defect listed one after another. The fetal death, infant death, birth certificate and newborn screening lists were also prepared in this fashion. To obtain the suspected defects and/or cause of death from the fetal death list, a codebook of diagnoses provided by the Office of Vital Statistics was used. The infant death list was provided with ICD-10 diagnoses, which were translated into ICD-9 for consistency in the registry. The newborn screening list provided a description in words to note the screening abnormality which is transferred into ICD-9 codes by the registry team. The maternal fetal medicine groups provided potential case defect descriptions through cytogenic reports and fetal therapy lists, which were also translated into ICD-9 codes by the registry team. For any list in which defect descriptions are provided and ICD-9 codes are translated, both the code and original defect description were maintained in the registry for validation purposes.

**FIGURE 1. Flowchart for the Creation of the Linked Database.**




Once all lists are flattened and prepared for linking, the Program Manager used the Fine Grained Record Linkage (FRIL) software tool to link all lists together to create one unduplicated list of all potential cases. FRIL uses weighted matching parameters to assign a matched confidence level to the data. Since medical record numbers were different for each institution, the potential cases were matched on the baby's first and last name, the mother's first and last name, the baby's date of birth, and the mother's date of birth.

The mother's date of birth was not always available, especially from the pediatric hospital, in which case only the mother's name was used to match. When the lists were matched together, the data from institution #1 was linked to institution #2. If the same mother/child pair existed in both datasets, the pair was linked together in order for the ICD-9 codes and suspected defects from both institutions to be associated with that child. This linking process maintains a unique list of cases in which no child was duplicated, but rather, data from subsequent institutions is appended to the already existing data for that child.

Upon completion of the unduplicated list, the Program Manger automatically uploaded all potential case information into the Delaware Birth Defects Registry Access database housed within the Christiana Care Health System. The Program Assistants/Chart Abstractors used the unduplicated list in the Microsoft Access database to complete their case confirmation and abstraction. The Program Manager sorted the unduplicated case list by defect group or institution using SPSS or the Microsoft Access database.

## Case Ascertainment through Medical Records

If any of the conditions in Appendix A appeared during the case finding process, the medical record underwent a full review for any reportable defects that may be associated with these conditions. A Case Abstraction Form was then completed on all medical records where a reportable condition was confirmed. Once a Case Abstraction Form was completed on a confirmed case, additional information was entered in the Access Database. If the case was confirmed as a non-case, Program Assistants coded this as "not a case" in the database and no further information was collected for that case. A clinical geneticist made the confirmation of whether a case was a case or a non-case. All cases and non-cases were documented on the Delaware Birth Defects Progress Sheet for that cohort year.

## Analysis of the Registry

Christiana Care Health System submitted the complete 2009 Delaware Birth Defects Registry database to the Delaware Division of Public Health (DPH). DPH made the database available to APS Healthcare, the contracted evaluation specialist. APS Healthcare uploaded the database – set up as a secure Microsoft Excel spreadsheet – to Microsoft Access and analyzed the data using SQL code. Graphs, percent calculations, statistical analysis, and tables were generated in Microsoft Excel.

## CHARACTERISTICS OF THE REGISTRY

Appendix B lists the fields included in the 2009 Delaware Birth Defects Registry. The registry consists of 511 unique infants. Because certain data may not be available for each case, many of the fields listed in Appendix B do not have data for each of the 511 infants. For this reason, the counts may not add to 511 in several of the tables in this analysis.

Data for the infants in the registry was abstracted from the facilities listed in Table 1.

**TABLE 1: Facility from Where Infant Data Was Abstracted.**

| Facility | Number of Infants |
|---|---|
| A.I. DuPont Hospital | 418 |
| Christiana Care Hospital | 181 |
| CCHS NICU | 81 |
| DE Office of Vital Statistics | 41 |
| DPH Newborn Screening Program | 21 |
| Nanticoke Memorial Hospital | 20 |
| St. Francis Hospital | 11 |
| Kent General Hospital | 9 |
| Beebe Hospital | 8 |
| Bayhealth Medical Center | 4 |

*Source: State of Delaware 2009 Birth Defects Registry.*

## CHARACTERISTICS OF MOTHERS IN THE REGISTRY

### Mother's Residence

The residence of the registered infants' mothers is given in Table 2.

**TABLE 2. Location of Residence of Registered Infants' Mothers.[A]**

| County | 2009 Registry | All 2009 Events | Percentage of All 2009 Births in Registry |
|---|---|---|---|
| Kent | 108 | 2,258 | 4.78% |
| New Castle | 314 | 6,794 | 4.62% |
| Sussex | 89 | 2,317 | 3.84% |
| **Delaware** | **511** | **11,369** | **4.49%** |

*Source: State of Delaware 2009 Birth Defects Registry.*

Of the 314 infants' mothers that resided in New Castle County, 82 infants' mothers resided in Wilmington.

[A] In this analysis, the zip code of the mother's residence was used to assign whether the mother resided in Wilmington or the remainder of New Castle County. In particular, zip codes 19801, 19802, 19804, 19805, and 19806 were used to indicate residence in Wilmington.

## Mother's Age

Table 3 provides counts of the registered infants' mothers stratified by both age and county of residence.

**TABLE 3. Age of Registered Infants' Mothers.**

| County/State | 19 Years & Under | 20-24 Years | 25-29 Years | 30-34 Years | 35-39 Years | 40 Years & Over |
|---|---|---|---|---|---|---|
| Kent | 10 | 36 | 31 | 18 | 10 | 3 |
| New Castle (w/o Wilmington) | 18 | 44 | 60 | 52 | 47 | 11 |
| Sussex | 11 | 26 | 21 | 16 | 13 | 2 |
| Wilmington | 4 | 18 | 32 | 20 | 4 | 4 |
| **Delaware** | **43** | **124** | **144** | **106** | **74** | **20** |

*Source: State of Delaware 2009 Birth Defects Registry.*

## Mother's Education

Table 4 displays the counts of registered infants' mothers stratified by county of residence and educational attainment. Note that the educational attainment was unknown or not available for 128 of the 511 infants' mothers (25.05% of all infants).

**TABLE 4. Educational Attainment of Registered Infants' Mothers.**

| County/State | Less Than High School | Some High School Not Graduate | High School Graduate | 3 or Less Years College | 4 Or More Years College |
|---|---|---|---|---|---|
| Kent | 1 | 15 | 36 | 22 | 16 |
| New Castle (w/o Wilmington) | 4 | 14 | 51 | 24 | 88 |
| Sussex | 9 | 7 | 18 | 14 | 10 |
| Wilmington | 3 | 9 | 21 | 7 | 14 |
| **Delaware** | **17** | **45** | **126** | **67** | **128** |

*Source: State of Delaware 2009 Birth Defects Registry.*

## Mother's Race and Ethnicity

Table 5 provides the counts of registered infants' mothers stratified by the mother's race and ethnicity.[B]

**TABLE 5. Race and Ethnicity of Registered Infants' Mothers.**

| County/State | White Non-Hispanic | Black Non-Hispanic | Hispanic |
|---|---|---|---|
| Kent | 70 | 30 | 4 |
| New Castle (w/o Wilmington) | 143 | 40 | 25 |
| Sussex | 48 | 27 | 14 |
| Wilmington | 28 | 38 | 13 |
| **Delaware** | **289** | **135** | **56** |

*Source: State of Delaware 2009 Birth Defects Registry.*

[B] The race and ethnicity investigation was limited to "White Non-Hispanics", "Black Non-Hispanics", and "Hispanics". These three race and ethnicity designations represented 480 out of the 511 entries (93.93% of entries).

Appendix C.1 features graphs that compare the race and ethnicity of the mothers listed in the registry with the race and ethnicity of all mothers that gave birth in Delaware in 2009.[6] The graphs are stratified by race and ethnicity ("White Non-Hispanic", "Black Non-Hispanic", and "Hispanic") as well as by the location of the mother's residence. No statistically significant differences exist between the percentage of mothers in the registry and all mothers that gave birth in Delaware in 2009 in the race and ethnicity categories.[C] It is essential to note that the reported number of mothers in the registry that were Hispanic in Kent County is 4; therefore, caution should be exercised as some of the results may be affected by a small sample size.[D]

## Mother's Pregnancy History

### *Gravida*

Appendix C.2 shows graphs of the gravida (the total number of times the mother has been pregnant) of the mother at the child's birth. These graphs compare the gravida of mothers listed in the registry with the gravida of all mothers that gave birth in Delaware in 2009.[6] The graphs are stratified by the gravida value ("1", "2", "3", "4", "5", and "6 or More") as well as by the location of the mother's residence. As evidenced by these graphs, no statistically significant differences exist between the gravida of mothers in the registry and mothers that gave birth in the other counties in 2009.[C]

### *Previous Infant Death*

Eight (8) entries in the registry document that the mother had a previous birth that resulted in a neonatal death (death between 1 hour and 27 days after birth). Likewise, one entry documents that the mother had a previous birth that resulted in a postneonatal death (death between 28 days and 365 days after birth).

### *Live Children*

As displayed in Table 6, the majority of registered infants' mothers had either no live children or one live child at the time of the birth of the infant entered into the birth defects registry.

[C] Statistical significance was established using 95% confidence intervals (CI). Note that the use of overlapping/non-overlapping of 95% confidence intervals (CI) to establish statistical significance results in a more conservative estimate of the probability of a true difference in the percentages than establishing the strict statistical definition of a 95% confidence level. Strictly speaking, it is possible for two percentages to be different at the 95% confidence level even though the 95% CIs overlap.
[D] A small sample size is generally defined as a value less than 5 in the numerator and less than 20 in the denominator.

**TABLE 6. Count of Live Children for Mothers in Registry.**

| County/State | None | 1 | 2 | 3 | 4 or More |
|---|---|---|---|---|---|
| Kent | 53 (49.53%) | 28 (26.17%) | 16 (14.95%) | 6 (5.61%) | 4 (3.74%) |
| New Castle (w/o Wilmington) | 87 (37.50%) | 92 (39.66%) | 33 (14.22%) | 11 (4.74%) | 9 (3.88%) |
| Sussex | 27 (30.34%) | 34 (38.20%) | 16 (17.98%) | 7 (7.87%) | 5 (5.62%) |
| Wilmington | 29 (35.37%) | 24 (29.27%) | 17 (20.73%) | 11 (13.41%) | 1 (1.22%) |
| **Delaware** | **196 (38.43%)** | **178 (34.90%)** | **82 (16.08%)** | **35 (6.86%)** | **19 (3.73%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

## Vitamin Use

As shown in Table 7, roughly 8 out of 9 registered infants' mothers reported regular use of vitamins.

**TABLE 7. Vitamin Use by Mothers in Registry.**

| Vitamin Use | Count | Percent |
|---|---|---|
| Yes | 453 | 88.65% |
| No | 8 | 1.57% |
| Not Stated | 50 | 9.78% |

*Source: State of Delaware 2009 Birth Defects Registry.*

## Prenatal Care

As indicated by Table 8, the overwhelming majority of mothers received prenatal care during pregnancy; specifically, 501 infants (98.04% of infants) were to mothers that received some form of prenatal care.

**TABLE 8. Prenatal Care during Pregnancy.**

| County/State | Yes | No | Not Stated |
|---|---|---|---|
| Kent | 105 | 2 | 1 |
| New Castle (w/o Wilmington) | 226 | 5 | 1 |
| Sussex | 89 | 0 | 0 |
| Wilmington | 81 | 1 | 0 |
| **Delaware** | **501** | **8** | **2** |

*Source: State of Delaware 2009 Birth Defects Registry.*

Table 9 shows that the majority of infants in the registry – 423 infants (87.04% of infants) – have mothers that initiated prenatal care in the first trimester of pregnancy. The percentage of infants with mothers who received prenatal care in the first trimester ranged from 77.65% in Sussex to 90.45% in New Castle (excluding Wilmington); Kent was 89.32% and Wilmington was 84.62%. These figures do not include infants for which prenatal care initiation was unknown ("Unknown" column in Table 9). Of those infants for which prenatal care is reported for the mother, 8 infants (1.65% of infants) were to mothers that initiated prenatal care in the third trimester. More than half of these mothers – 5 out of 8 – resided in Sussex County.

**TABLE 9. Initiation of Prenatal Care during Pregnancy.**

| County/State | 1st Trimester | 2nd Trimester | 3rd Trimester | Unknown |
|---|---|---|---|---|
| Kent | 92 | 11 | 0 | 5 |
| New Castle (w/o Wilmington) | 199 | 18 | 3 | 12 |
| Sussex | 66 | 14 | 5 | 4 |
| Wilmington | 66 | 12 | 0 | 4 |
| **Delaware** | **423** | **55** | **8** | **25** |

*Source: State of Delaware 2009 Birth Defects Registry.*

## Maternal Illnesses, Conditions, and Complications

Table 10 outlines the count of illnesses, conditions, and complications of the mothers ("condition") listed in the registry and the count and percent of infant entries with this count. This table shows that 13.11% of infants have a mother that did not have any conditions listed. These findings reveal that the clear majority of infants in the registry – 65.36% of infants – have a mother reported as having multiple conditions.

**TABLE 10. Count of Maternal Conditions by Registry Entry.**

| Count of Conditions | Count of Infant Entries | Percent of Total Infant Entries |
|---|---|---|
| 0 | 67 | 13.11% |
| 1 | 110 | 21.53% |
| 2 | 107 | 20.94% |
| 3 | 103 | 20.16% |
| 4 | 69 | 13.50% |
| 5 | 28 | 5.48% |
| 6 | 14 | 2.74% |
| 7 | 12 | 2.35% |
| 8 | 1 | 0.20% |

*Source: State of Delaware 2009 Birth Defects Registry.*

Table 11 displays the counts for each of the maternal conditions listed in the registry.

**TABLE 11. Count of Maternal Conditions.**

| Condition | Count | Condition | Count |
|---|---|---|---|
| Surgery-Non Gynecologic Non Transplant | 216 | Rubella Immune Status-Non-Immune | 8 |
| Tobacco | 145 | Substance Abuse | 6 |
| Surgery-Gynecologic | 141 | Diabetes Mellitus Type I | 5 |
| Obesity | 136 | Other Psychiatric Disorders | 5 |
| Alcohol | 129 | Coagulopathy | 4 |
| Depression | 81 | Heart Disease | 4 |
| Illicit Drugs | 65 | Lupus | 4 |
| Hypertension (PIH) | 54 | Hepatitis C | 3 |
| Diabetes Gestation | 53 | HIV/AIDS | 3 |
| Chronic Hypertension | 27 | Eclampsia | 2 |
| Toxemia/Preeclampsia | 26 | Influenza | 2 |
| Placenta Previa | 19 | Inflammatory Bowel Disease | 2 |
| Thyroid Disease | 19 | Schizophrenia | 2 |
| Genital Herpes | 14 | Cytomegalovirus (CMV) | 1 |
| Bipolar Disorder | 13 | Hepatitis B | 1 |
| Seizure Disorder | 13 | Phenylketonuria | 1 |
| Weight Loss | 11 | Varicella-Chicken Pox | 1 |
| Diabetes Mellitus Type II | 9 | | |

*Source: State of Delaware 2009 Birth Defects Registry*.

Tables 12-13 and Tables 15-19 provide the count of infant entries that correspond to a set of the most common conditions listed in Table 11. In each table, the counts are stratified by the mother's race and ethnicity[B] and the location of the mother's residence at the time of the infant's birth. The percentage to the right of each count corresponds to the accompanying count divided by the total count of mothers that meet the criteria based on the two stratifying criteria; Table 5 displays these denominator values. For example, in Table 12, twenty-six (26) infant entries were to mothers residing in Kent County that were White non-Hispanic, and according to the registry, were documented as having used some form of tobacco. These 26 infant entries represent 37.14% of all infant entries for mothers residing in Kent County that were White non-Hispanic. Caution should be exercised when examining these tables as several counts have small values (i.e., count of less than 5). In addition, information on alcohol use and tobacco use is based on what is recorded in the mother's medical record, which in turn, is based on what is reported by the mother to her health care provider.

Table 12 provides the count of infants in the registry who have a mother that reported having used some form of tobacco. Generally speaking, a higher percentage of White non-Hispanic mothers – as compared to the other two race and ethnicity groups – used some form of tobacco.

**TABLE 12. Tobacco Use among Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 26 (37.14%) | 8 (26.67%) | 1 (25.00%) |
| New Castle (w/o Wilmington) | 48 (33.57%) | 12 (30.00%) | 4 (16.00%) |
| Sussex | 12 (25.00%) | 6 (22.22%) | 0 (0.00%) |
| Wilmington | 10 (35.71%) | 14 (36.84%) | 2 (15.38%) |
| **Delaware** | **96 (33.22%)** | **40 (29.63%)** | **7 (12.50%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

Table 13 outlines the count of infants in the registry who have a mother that used some form of alcohol.

**TABLE 13. Alcohol Use among Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 20 (28.57%) | 3 (10.00%) | 0 (0.00%) |
| New Castle (w/o Wilmington) | 54 (37.76%) | 8 (20.00%) | 6 (24.00%) |
| Sussex | 4 (8.33%) | 1 (3.70%) | 1 (7.14%) |
| Wilmington | 14 (50.00%) | 15 (39.47%) | 1 (7.69%) |
| **Delaware** | **92 (31.83%)** | **27 (20.00%)** | **8 (14.29%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

Note that 58 infants (11.35% of infants) in the registry have a mother that was documented as having used *both* alcohol and tobacco. Also, 216 infants (42.27% of infants) have a mother documented as having used *either* alcohol or tobacco.

Table 14 delineates both alcohol and tobacco use by whether the registered infant's mother used the substance *only before* pregnancy ("Only Before") or *before and during* pregnancy ("Before/During"). Only two mothers stated that they used a substance *only during* pregnancy: one Black non-Hispanic mother in Wilmington used tobacco only during pregnancy and one Black non-Hispanic mother in Wilmington used alcohol only during pregnancy. The percentages in Table 14 were calculated by taking the neighboring count and dividing it by the total number of women in the respective county; Table 2 provides the total number of women in each county. For example, eighteen (18) registered infants' mothers that resided in Kent County used alcohol only before pregnancy. This represents 16.67% of all registered infants' mothers that resided in Kent County. Finally, the counts in Table 14 include all race and ethnicity groups.

[E] Kent, Sussex, and Wilmington counts and percentages may be low due to differences in how these conditions were reported.
[F] Hispanic counts and percentages may be low due to language and/or cultural barriers in reporting of these conditions.

**TABLE 14. Alcohol and Tobacco Use during Pregnancy among Mothers in the Registry.**

| County/State[E] | Alcohol Use | | Tobacco Use | |
|---|---|---|---|---|
| | Only Before | Before/During | Only Before | Before/During |
| Kent | 18 (16.67%) | 5 (4.63%) | 7 (6.48%) | 28 (25.93%) |
| New Castle (w/o Wilmington) | 61 (26.29%) | 8 (3.45%) | 22 (9.48%) | 44 (18.97%) |
| Sussex | 5 (5.62%) | 1 (1.12%) | 2 (2.25%) | 16 (17.98%) |
| Wilmington | 24 (29.27%) | 6 (7.32%) | 9 (10.98%) | 16 (19.51%) |
| **Delaware** | **108 (21.14%)** | **20 (3.91%)** | **40 (7.83%)** | **104 (20.35%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

These findings suggest that while fewer registered infants' mothers used alcohol before and during pregnancy as compared to before pregnancy alone, *more* infants' mothers continued use of tobacco during pregnancy as compared to registered infants' mothers that only used tobacco prior to pregnancy.

Table 15 reports the number of registered infants' mothers documented as having obesity. Aside from cells with low counts (less than 5), the percentages listed in the table generally approximate one another.

**TABLE 15. Obesity among Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 16 (22.86%) | 11 (36.67%) | 3 (75.00%) |
| New Castle (w/o Wilmington) | 33 (23.08%) | 14 (35.00%) | 9 (36.00%) |
| Sussex | 12 (25.00%) | 8 (29.63%) | 3 (21.43%) |
| Wilmington | 3 (10.71%) | 19 (50.00%) | 3 (23.08%) |
| **Delaware** | **64 (22.15%)** | **52 (38.52%)** | **18 (32.14%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

Although the counts are relatively low, the percentage of Black non-Hispanic mothers reported as obese is higher than the other two race and ethnicity groups, a finding consistent with other Delaware-specific maternal health assessments.[7,8]

Table 16 lists the counts and percentages of registered infants' mothers with pregnancy-induced hypertension (PIH). Table 17 lists the counts and percentages of registered infants' mothers documented as having depression. Finally, Table 18 supplies the counts and percentages of registered infants' mothers reported as having gestational diabetes.

**TABLE 16. Hypertension (PIH) among Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 10 (14.29%) | 2 (6.67%) | 0 (0.00%) |
| New Castle (w/o Wilmington) | 13 (9.09%) | 6 (15.00%) | 5 (20.00%) |
| Sussex | 4 (8.33%) | 3 (11.11%) | 0 (0.00%) |
| Wilmington | 2 (7.14%) | 6 (15.79%) | 1 (7.69%) |
| **Delaware** | **29 (10.03%)** | **17 (12.59%)** | **6 (10.71%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

**TABLE 17. Depression among Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 9 (12.86%) | 1 (3.33%) | 1 (25.00%) |
| New Castle (w/o Wilmington) | 34 (23.78%) | 7 (17.50%) | 5 (20.00%) |
| Sussex | 7 (14.58%) | 1 (3.70%) | 0 (0.00%) |
| Wilmington | 3 (10.71%) | 9 (23.68%) | 2 (15.38%) |
| **Delaware** | **53 (18.34%)** | **18 (13.33%)** | **8 (14.29%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

**TABLE 18. Gestational Diabetes among Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 7 (10.00% | 3 (10.00%) | 0 (0.00%) |
| New Castle (w/o Wilmington) | 17 (11.89%) | 4 (10.00%) | 1 (4.00%) |
| Sussex | 7 (14.58%) | 1 (3.70%) | 0 (0.00%) |
| Wilmington | 2 (7.14%) | 2 (5.26%) | 2 (15.38%) |
| **Delaware** | **33 (11.42%)** | **10 (7.41%)** | **3 (5.36%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

Table 19 presents the counts of registered infants' mothers who have multiple (at least two) of the most commonly reported conditions from Table 11.

**TABLE 19. Multiple Conditions of Mothers in the Registry.**

| County/State[E] | White Non-Hispanic | Black Non-Hispanic | Hispanic[F] |
|---|---|---|---|
| Kent | 52 (74.29%) | 15 (50.00%) | 2 (50.00%) |
| New Castle (w/o Wilmington) | 113 (79.02%) | 28 (70.00%) | 12 (48.00%) |
| Sussex | 30 (62.50%) | 14 (51.85%) | 2 (14.29%) |
| Wilmington | 21 (75.00%) | 29 (76.32%) | 5 (38.46%) |
| **Delaware** | **216 (74.74%)** | **86 (63.70%)** | **21 (37.50%)** |

*Source: State of Delaware 2009 Birth Defects Registry.*

The results from Table 19 are not surprising given that these registered infants' mothers may have interrelated co-morbidities such as obesity, pregnancy-induced hypertension, and gestational diabetes. In addition, some of the counts and percentages may be due to the high count of registered infants' mothers who were reported as having used tobacco or alcohol. This may help to explain the relatively higher

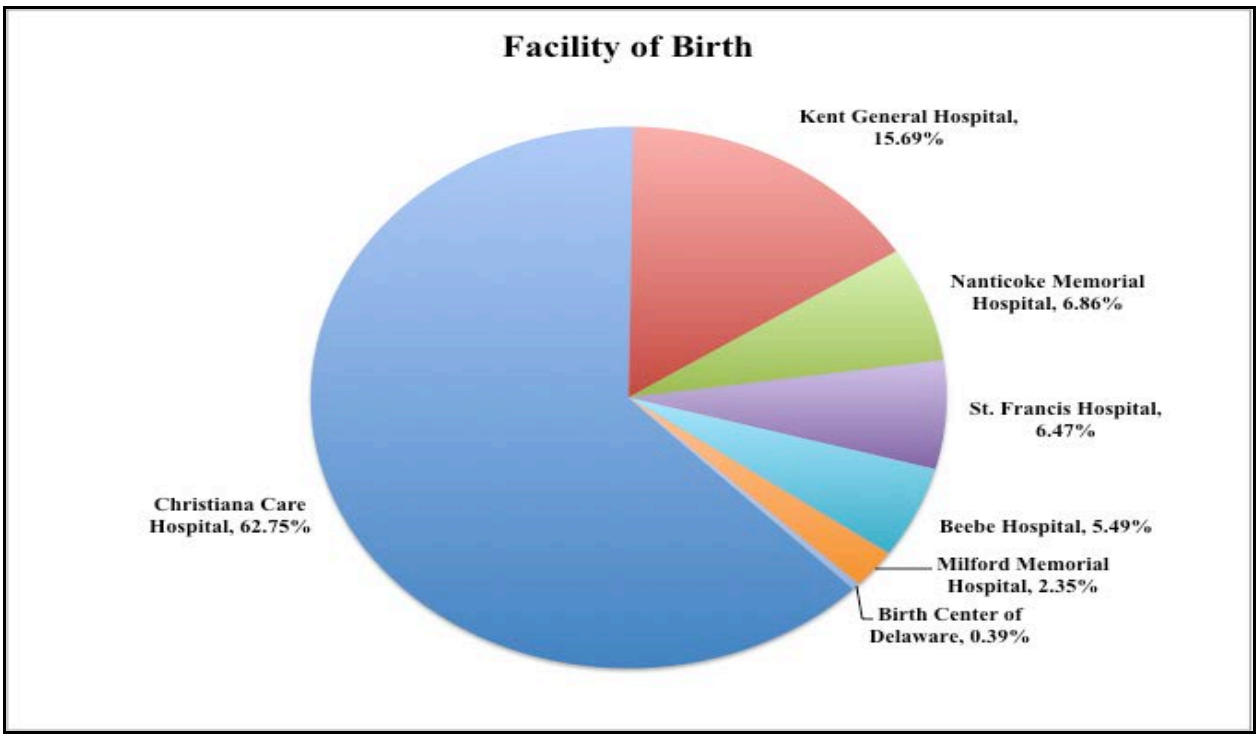
percentages reported for White non-Hispanic women in Table 19 given that a higher percentage of White non-Hispanic mothers - compared to the other two race and ethnicity groups - were reported as using some form of tobacco and/or alcohol.

## CHARACTERISTICS OF INFANTS IN THE REGISTRY

### Facility of Birth

As displayed in Figure 2, the majority of births in the registry occurred at Christiana Care Hospital.

**FIGURE 2. Facility of Birth.**




*Source: State of Delaware 2009 Birth Defects Registry*.

### Gestational Weeks

Appendix C.3 displays graphs of the number of gestational weeks of the infant at birth. These graphs compare the number of gestational weeks of the infants listed in the registry with those of all infants born in Delaware in 2009.[6] The graphs are stratified by different ranges of gestation ("Births Less than 32 Weeks of Gestation", "Births Between 32 and 36 Weeks of Gestation", and "Births 37 or More Weeks of Gestation") as well as by the location of the mother's residence. For Kent County, New Castle County, and the State of Delaware, the "Births Less Than 32 Weeks of Gestation" graph shows that the percentage of infants in the registry was more than double that of the percentage of all infants born in 2009.

Moreover, for all counties, the percentage of infants born at or above 37 weeks was significantly lower among infants in the registry as compared to infants born in 2009. These findings align with research that suggests an association exists between preterm birth and birth defects.[9,10]

## Pregnancy Outcome

Table 20 lists the numbers and percentages of live births and fetal deaths from the registry. In this assessment, fetal death includes stillbirth and termination of pregnancy.

**TABLE 20. Pregnancy Outcome for Registry Entries.**

| County | Live Birth | | Fetal Death | |
|---|---|---|---|---|
| | Count | Percentage | Count | Percentage |
| Kent | 103 | 95.37% | 5 | 4.63% |
| New Castle (w/o Wilmington) | 228 | 98.28% | 4 | 1.72% |
| Sussex | 86 | 96.63% | 3 | 3.37% |
| Wilmington | 79 | 96.34% | 3 | 3.66% |
| **Delaware** | **496** | **97.06%** | **15** | **2.94%** |

*Source: State of Delaware 2009 Birth Defects Registry.*

## Plurality

Table 21 shows the number and percentage of infants that are singleton (a single birth), twins, or triplets.

**TABLE 21. Plurality for Infants in the Registry.**

| Plurality | Count | Percentage |
|---|---|---|
| Singleton | 488 | 95.50% |
| Twin | 22 | 4.31% |
| Triplet | 1 | 0.20% |

*Source: State of Delaware 2009 Birth Defects Registry.*

Of the 22 infants that are part of a set of twins, 12 were the first-born twin and 10 were the second-born twin. For the triplets, the second-born was the infant diagnosed with a birth defect.

## Gender

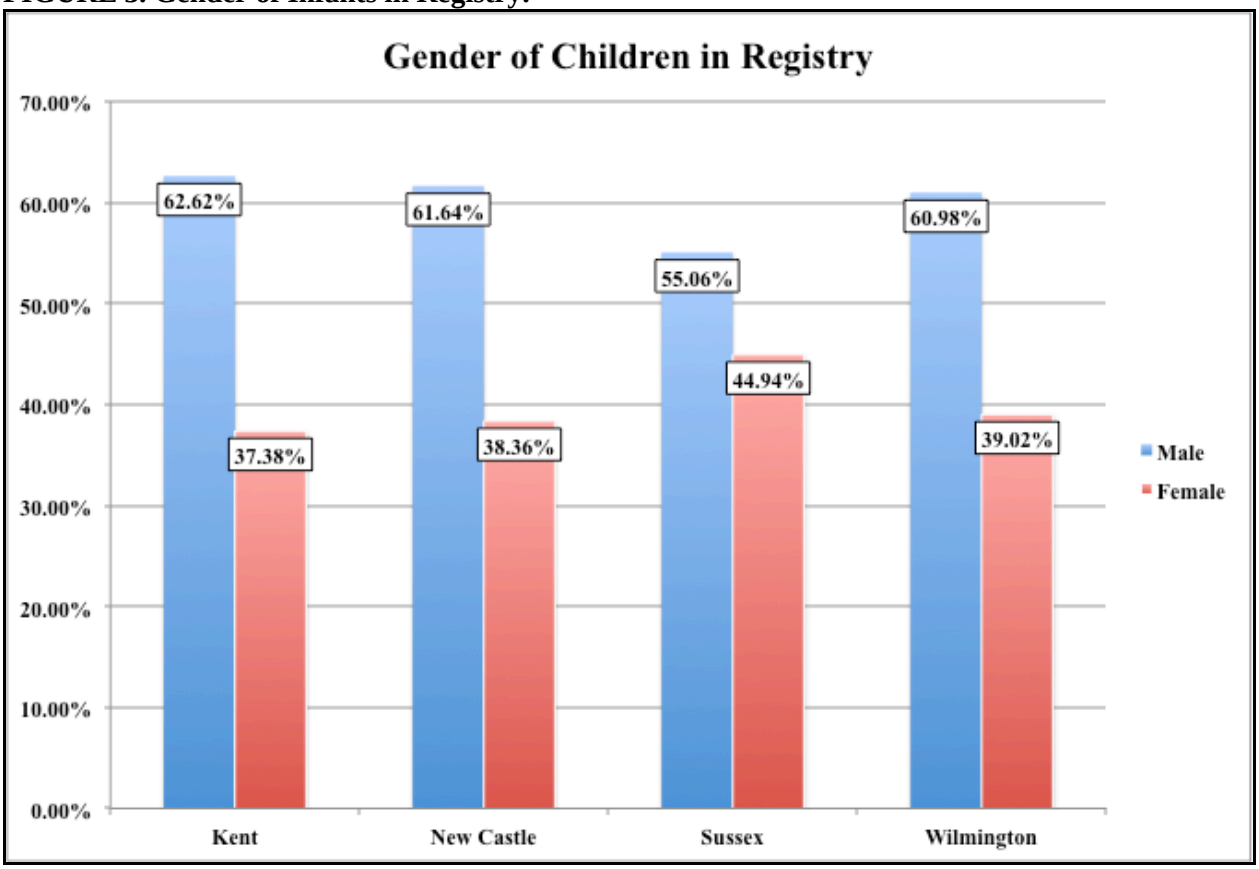
As indicated in Table 22 and Figure 3, the majority of infants in the registry were male.

**TABLE 22. Gender of Infants in the Registry.**

| County | Total | Female | Male |
|---|---|---|---|
| **Kent** | 107 | 40 | 67 |
| **New Castle** | 232 | 89 | 143 |
| **Sussex** | 89 | 40 | 49 |
| **Wilmington** | 82 | 32 | 50 |

*Source: State of Delaware 2009 Birth Defects Registry.*

**FIGURE 3. Gender of Infants in Registry.**




*Source: State of Delaware 2009 Birth Defects Registry.*

## Growth Percentiles

The WHO Child Growth Standards[11] were applied to calculate the percentages of infants in the registry that were below the 25th, between the 25th and 75th, and above the 75th percentiles in weight, length (stature), and head circumference. The age at birth (0 months) was used when aligning these percentiles and percentiles were adjusted based on the infant's gender. The results of these growth percentile measures are intended to see if any correlations exist; a causal link between birth defects and these results cannot be established.

### *Weight Percentiles*

Table 23 illustrates that a sizeable percentage of the infants in the birth defects registry are at or below the 25th percentile for weight at the time of birth.

**TABLE 23. Weight Percentile at Time of Birth.**

| County/State | 25th and Below | Between 25th – 75th | 75th and Over |
|---|---|---|---|
| Kent | 41.51% | 42.45% | 16.04% |
| New Castle w/o Wilmington | 34.05% | 33.62% | 32.33% |
| Sussex | 29.21% | 41.57% | 29.21% |
| Wilmington | 41.46% | 42.68% | 15.85% |
| **Delaware** | **35.95%** | **38.31%** | **25.74%** |

*Source: State of Delaware 2009 Birth Defects Registry*

*Length (Stature) Percentiles*

As shown in Table 24, the counties had a similar percentage of infants at or below the 25th percentile, between the 25th and 75th percentile, and at or above the 75th percentile for length at the time of birth.

**TABLE 24. Length (Stature) at Time of Birth.**

| County/State | 25th and Below | Between 25th – 75th | 75th and Over |
|---|---|---|---|
| Kent | 30.10% | 33.01% | 36.89% |
| New Castle w/o Wilmington | 28.02% | 25.86% | 46.12% |
| Sussex | 26.74% | 25.58% | 47.67% |
| Wilmington | 40.24% | 29.27% | 30.49% |
| **Delaware** | **30.22%** | **27.83%** | **41.95%** |

*Source: State of Delaware 2009 Birth Defects Registry*

*Head Circumference Percentiles*

Note that of the 511 infants in the registry, 400 (78.28%) had a head circumference reported. This helps to explain the considerable variation in head circumference percentages by county in Table 25.

**TABLE 25. Head Circumference at Time of Birth.**

| County/State | 25th and Below | Between 25th – 75th | 75th and Over |
|---|---|---|---|
| Kent | 36.46% | 47.92% | 15.63% |
| New Castle w/o Wilmington | 33.12% | 46.50% | 20.38% |
| Sussex | 31.40% | 47.67% | 20.93% |
| Wilmington | 11.48% | 44.26% | 44.26% |
| **Delaware** | **30.25%** | **46.75%** | **23.00%** |

*Source: State of Delaware 2009 Birth Defects Registry*

## Diagnoses of Birth Defects

Each ICD-9 code was categorized as a "confirmed" or "possible/probable" diagnosis of a birth defect. In the registry, 503 infants (98.43% of infants) had only a "confirmed" diagnosis of a birth defect while 5 infants (0.98% of infants) had only a "possible/probable" diagnosis of a birth defect. Finally, 3 infants (0.59% of infants) had at least one "possible/probable" and at least one "confirmed" diagnosis of a birth

defect. Given that almost all of the infants had a "confirmed" diagnosis of a birth defect, all infants were included in the analysis even if the infant had only a "possible/probable" diagnosis of a birth defect. Table 26 matches the number of reported ICD-9 codes for each infant listed in the registry. This table shows that more than one-fifth (22.50%) of the infants had more than one diagnosed birth defect.

**TABLE 26. Count of ICD-9 Codes for Infants in the Registry.**

| Count of Reported ICD-9 Codes | Count of Infants Meeting Criteria | Percent of Infants Meeting Criteria |
|---|---|---|
| 1 | 396 | 77.50% |
| 2 | 55 | 10.76% |
| 3 | 26 | 5.09% |
| 4 | 11 | 2.15% |
| 5 | 13 | 2.54% |
| 6 | 6 | 1.17% |
| 7 | 3 | 0.59% |
| 8 | 1 | 0.20% |
| **Total** | **511** | **100.00%** |

*Source: State of Delaware 2009 Birth Defects Registry*

Table 27 provides a count of the ICD-9 codes documented in the registry.

**TABLE 27. ICD-9 Codes for Infants in the Registry.**

| ICD-9 Code | ICD-9 Code Description | Count |
|---|---|---|
| 745 | Bulbus cordis anomalies and anomalies of cardiac septal closure | 154 |
| 753 | Congenital anomalies of urinary system | 138 |
| 752 | Congenital anomalies of genital organs | 59 |
| 758 | Chromosomal anomalies | 50 |
| 746 | Other congenital abnormalities of the heart | 46 |
| 747 | Other congenital anomalies of circulatory system | 36 |
| 754 | Certain congenital musculoskeletal deformities | 35 |
| 756 | Other congenital musculoskeletal anomalies | 35 |
| 742 | Other congenital anomalies of nervous system | 33 |
| 744 | Congenital anomalies of ear, face, and neck | 22 |
| 750 | Other congenital anomalies of upper alimentary tract | 20 |
| 749 | Cleft palate | 18 |
| 751 | Other congenital anomalies of digestive system | 17 |
| 759 | Other and unspecified congenital anomalies | 17 |
| 282 | Hereditary hemolytic anemias | 14 |
| 318 | Other specified mental retardation | 12 |
| 743 | Congenital anomalies of eye | 11 |
| Other | - | 41 |
| **Total** | | **758** |

*Source: State of Delaware 2009 Birth Defects Registry*

A substantial number of codes are associated with congenital anomalies of the circulatory system (ICD-9 745, 746, and 747; 236 diagnoses or 31.13% of all diagnoses) or congenital urinary tract abnormalities (ICD-9 753; 138 or 18.21% of all diagnoses).

Table 28 outlines the methods by which the birth defect was diagnosed. Roughly 3 out of 4 (76.63%) of the reported birth defects were definitively diagnosed by one of three methods: ultrasound, echocardiogram, and clinical (physical exam).

**TABLE 28. Method of Diagnosis for Birth Defect.**

| Method of Diagnosis | Count of Diagnoses by Method | Percent of All Diagnoses |
|---|---|---|
| Ultrasound | 245 | 32.32% |
| Echocardiogram | 219 | 28.89% |
| Clinical | 130 | 17.15% |
| Genetics | 58 | 7.65% |
| Laboratory | 28 | 3.69% |
| X-ray | 28 | 3.69% |
| Audiogram | 14 | 1.85% |
| Ophthalmologic Exam | 10 | 1.32% |
| MRI | 9 | 1.19% |
| Autopsy | 6 | 0.79% |
| CT Scan | 6 | 0.79% |
| Surgical Observation | 5 | 0.66% |
| **Total** | **758** | **100.00%** |

*Source: State of Delaware 2009 Birth Defects Registry*

Of the 758 birth defect diagnoses, 260 (34.30%) were confirmed at a prenatal visit while the remaining 498 (65.70%) were confirmed at a postnatal visit. Table 29 displays the count of infants in the registry for which all birth defects diagnoses were confirmed only during prenatal visits, only during postnatal visits, or at both prenatal and postnatal visits. For example, if an infant was diagnosed with multiple birth defects and all of these diagnoses were confirmed only at one or more prenatal visits, then the infant was counted in the "Prenatal" category. Likewise, if an infant was diagnosed with multiple birth defects and all of these diagnoses were confirmed only at one or more postnatal visits, then the infant was counted in the "Postnatal" category. Finally, if an infant had multiple birth defect diagnoses and some of these diagnoses were confirmed at a prenatal visit while other diagnoses were confirmed at a postnatal visit, then the infant was counted in the "Both" category.

**TABLE 29. Infants with Diagnosis of All Birth Defects Confirmed at Prenatal, Postnatal, or Both.**

| Prenatal | Postnatal | Both |
|---|---|---|
| 144 (28.18%) | 331 (64.77%) | 36 (7.05%) |

*Source: State of Delaware 2009 Birth Defects Registry*

This table indicates that 28.18% of infants in the registry were diagnosed with one or more birth defects that were confirmed only at one or more prenatal visits. Moreover, the overwhelming majority of infants (64.77%) had a confirmed diagnosis of one or more birth defects only at one or more postnatal visits.

## Family Member with Birth Defect

The reported birth defect(s) of family member(s) were based on the mother's recollection of the birth defect(s) ,the medical records of the family member(s) were not reviewed. Accordingly, some bias in the reporting of birth defects by family member may have occurred. As shown in Table 30, 134 infants in the registry had at least one family member with a birth defect.

**TABLE 30. Number of Family Members with Birth Defect.**

| Family Members with Birth Defect | Count |
|---|---|
| No Family Members | 377 |
| 1 Family Member | 95 |
| 2 Family Members | 26 |
| 3 Family Members | 10 |
| 4 Family Members | 3 |
| **Total** | **511** |

*Source: State of Delaware 2009 Birth Defects Registry*

Table 31 provides the specific relation between the infant in the registry and the family member documented as having the birth efect. Although the "Cousin" and "Sibling" categories feature the highest counts, these categories may match to more than one specific individual as an individual may have multiple cousins or siblings. This contrasts with the "Birth Mother" and "Father" categories, which represent only one family member per infant in the registry.

**TABLE 31. Family Members in the Registry.**

| Family Member | Count |
|---|---|
| Cousin (Maternal/Paternal Not Stated) | 49 |
| Sibling (Gender Not Stated) | 42 |
| Birth Mother | 26 |
| Uncle | 19 |
| Aunt | 14 |
| Father | 12 |
| Grandmother (Maternal/Paternal Not Stated) | 5 |
| Grandfather (Maternal/Paternal Not Stated) | 4 |
| Other | 18 |
| **Total Family Members Reported with Birth Defect** | **189** |

*Source: State of Delaware 2009 Birth Defects Registry*

Table 32 lists the corresponding birth defect of the family member reported in the registry.

**TABLE 32. Birth Defects of Family Members in the Registry.**

| Birth Defect of Family Member | Count |
|---|---|
| Congenital Heart Defect | 45 |
| Cleft Lip or Palate | 10 |
| Club Foot | 10 |
| Down Syndrome (Trisomy 21) | 7 |
| Autism | 7 |
| Mental Retardation | 7 |
| Sickle Cell Disease | 6 |
| Hip Dysplasia | 5 |
| Deaf or Hearing Loss | 5 |
| Cystic Fibrosis | 4 |
| Spina Bifida | 4 |
| Other | 79 |
| **Total Family Members Reported with Birth Defect** | **189** |

*Source: State of Delaware 2009 Birth Defects Registry*

Based on Table 31 and Table 32, 189 birth defects, at the most, could be analogous between infants in the registry and reported family members.

Table 33 indicates that 50 birth defects (26.45% of the 189 birth defects) were the same or similar between the infants and their respective family members.

**TABLE 33. Commonly-Shared Birth Defects between Infants and Family Members in Registry.**

| Commonly-Shared Birth Defects | Count |
|---|---|
| Bulbus cordis anomalies and anomalies of cardiac septal closure | 11 |
| Chromosomal anomalies | 5 |
| Cleft palate | 5 |
| Certain congenital musculoskeletal deformities | 4 |
| Hereditary hemolytic anemias | 4 |
| Other congenital musculoskeletal anomalies | 4 |
| Other congenital anomalies of circulatory system | 3 |
| Other congenital anomalies of heart | 3 |
| Other congenital anomalies of limbs | 3 |
| Sensorineural hearing loss | 3 |
| Congenital anomalies of urinary system | 2 |
| Congenital anomalies of eye | 1 |
| Congenital anomalies of genital organs | 1 |
| Other and unspecified congenital anomalies | 1 |
| **Total** | **50** |

*Source: State of Delaware 2009 Birth Defects Registry*

Of these 50 birth defects, fourteen (14) were diagnosed in a prenatal care setting and 36 were reported during a postnatal visit. The 14 birth defects that were reported during a prenatal visit are quite diverse: four diagnoses of congenital heart defects, two diagnoses of congenital anomalies of the urinary system, three diagnoses of a congenital anomalies of limbs, and five diagnoses of chromosomal anomalies.

## Infant Deaths in the Registry

In the registry, 38 entries (7.44% of entries) show documentation that a fetal or infant death occurred. Of these 38 entries, 16 were fetal deaths (stillbirth and termination of pregnancy) and 22 were documented as an infant death (infant with a live birth that expired within the first year after birth). According to the registry, an autopsy was performed on 11 of these 38 deaths while no autopsy was conducted on 25 of the deaths; it is unknown whether an autopsy was performed on the remaining two deaths. The results of the autopsy are not provided in the registry, and therefore, it cannot be determined whether the reported birth defect(s) was a causal factor for the death. With this in mind, this analysis of deaths is intended only to better understand the characteristics of this specific set of entries in the birth defect registry.

### *Characteristics of the Expired Infants*

Table 34 describes where each of the mothers of the 38 expired infants and fetal deaths resided.

**TABLE 34. Mother's Residence for Expired Infants and Fetal Deaths in the Registry.**

| County/State of Residence | Count |
|---|---|
| Kent | 9 |
| New Castle (w/o Wilmington) | 18 |
| Sussex | 4 |
| Wilmington | 7 |
| **Delaware** | **38** |

*Source: State of Delaware 2009 Birth Defects Registry*

Among the 22 infant deaths, 11 were female and 11 were male. Moreover, 12 were within one month of birth (neonatal death) with four neonatal deaths occurring on the day of birth. The remaining 10 deaths took place between one month after birth and one year after birth (postneonatal death). Nine (9) out of the 22 infants were born at term (greater than or equal to 37 gestational weeks) while 5 were born early preterm (at less than 32 gestational weeks).

Table 35 provides the growth percentile measures for the 22 infant deaths in the registry. The "Total Infant Deaths" column provides the number out of the 22 infant deaths for which there exists data on the growth percentile measure. As evidenced by this table, the overwhelming majority of expired infants were at or below the 25th percentile for weight (81.82%), length (77.27%), and head circumference (84.62%) at the time of birth. Moreover, each of the 11 infants below the 25th percentile on the head circumference measure was at or below the 25th percentile on the other two measures as well.

**TABLE 35. Growth Percentile Measures for the Infant Deaths in the Registry.**

| Growth Percentile Measure | Number Below 25th | Total Infant Deaths | Percentage |
|---|---|---|---|
| Weight | 18 | 22 | 81.82% |
| Length (Stature) | 17 | 22 | 77.27% |
| Head Circumference | 11 | 13 | 84.62% |

*Source: State of Delaware 2009 Birth Defects Registry*

*Reported Birth Defects of the Infant Deaths in the Registry*

Unlike Table 26 where 77.50% of infants in the registry had documentation of one birth defect, Table 36 indicates that only 27.27% of expired infants had only one reported birth defect. This may indicate that since a higher proportion of expired infants had more than one birth defect, these infants were more likely to have had multiple anomalies that may have resulted or contributed to the infant's mortality. At the same time, these conclusions cannot be justified given the relatively low count of expired infants and the overall lack of autopsy data.

**TABLE 36. Count of ICD-9 Codes for the Infant Deaths in the Registry.**

| Count of Reported ICD-9 Codes | Count of Infants Meeting Criteria | Percent of Infants Meeting Criteria |
|---|---|---|
| 1 | 6 | 27.27% |
| 2 | 6 | 27.27% |
| 3 | 3 | 13.64% |
| 4 | 1 | 4.55% |
| 5 | 2 | 9.09% |
| 6 | 3 | 13.64% |
| 7 | 1 | 4.55% |
| **Total** | **22** | **100.00%** |

*Source: State of Delaware 2009 Birth Defects Registry*

Table 37 lists all of the ICD-9 codes provided in the registry for the 22 infant deaths. Note that the ICD-9 codes are listed in relatively the same order as those listed in Table 27.

**TABLE 37. ICD-9 Codes for the Infant Deaths in the Registry.**

| ICD-9 Code | ICD-9 Code Description | Count |
|---|---|---|
| 745 | Bulbus cordis anomalies and anomalies of cardiac septal closure | 12 |
| 758 | Chromosomal anomalies | 11 |
| 746 | Other congenital abnormalities of the heart | 10 |
| 749 | Cleft palate | 4 |
| 753 | Congenital anomalies of urinary system | 4 |
| 756 | Other congenital musculoskeletal anomalies | 4 |
| 742 | Other congenital anomalies of nervous system | 3 |
| 747 | Other congenital anomalies of circulatory system | 3 |
| 752 | Congenital anomalies of genital organs | 3 |
| 754 | Certain congenital musculoskeletal deformities | 3 |
| 759 | Other and unspecified congenital anomalies | 3 |
| 743 | Congenital anomalies of eye | 2 |
| 277 | Other and unspecified disorders of metabolism | 1 |
| 658 | Other problems associated with amniotic cavity and membranes | 1 |
| 750 | Other congenital anomalies of upper alimentary tract | 1 |
| 755 | Other congenital anomalies of limbs | 1 |
| **Total** | | **66** |

*Source: State of Delaware 2009 Birth Defects Registry*

*Family Member with Birth Defect among Infant Deaths in the Registry*

The registry documents three of the 22 infants as having a family member with a birth defect. Of the three infants, two infants had one family member with a birth defect and one infant had two family members with a birth defect. This results in four [(2•1) + (1•2)] possible linkages in similar birth defects between the expired infants and respective family members. Of these four familial relations, one was

with the infant's aunt, one was with the infant's brother (or half brother), one was with the infant's cousin, and one was with the infant's uncle. Two of these four relations shared a similar birth defect: an expired infant and her aunt each had a birth defect involving their eyes and an expired infant and her brother (or half brother) each had a birth defect related to a metabolic disorder.

Again, it is important to note that the reported birth defect(s) of family member(s) were based on the mother's recollection of the birth defect(s) and that the medical records of the family member(s) were not reviewed. Moreover, as aforementioned, the results of the autopsy are not provided in the registry, and therefore, it cannot be determined whether the reported birth defect(s) was a causal factor for the death.

*Illnesses, Conditions, and Complications of Mothers of the Infant Deaths in the Registry*

Table 38 presents the number of illnesses, conditions, and complications ("conditions") of the mothers of the 22 registry entries documented as infant deaths. As shown in this table, only 9.09% of the mothers with an infant death had no reported conditions and 77.27% had multiple conditions.

**TABLE 38. Number of Reported Conditions for Mothers of Infant Deaths in the Registry.**

| Number of Reported Conditions | Number of Infant Entries Meeting Criteria | Percent of Infant Entries Meeting Criteria |
|---|---|---|
| 0 | 2 | 9.09% |
| 1 | 3 | 13.64% |
| 2 | 5 | 22.73% |
| 3 | 6 | 27.27% |
| 4 | 3 | 13.64% |
| 5 | 3 | 13.64% |
| **Total** | **22** | **100.00%** |

*Source: State of Delaware 2009 Birth Defects Registry*

Table 39 provides counts for all of the maternal conditions listed for the 22 infant deaths in the registry.

**TABLE 39. Count of Maternal Conditions for Expired Infants in the Registry.**

| Condition | Count | Condition | Count |
|---|---|---|---|
| Surgery-Non Gynecologic Non Transplant | 10 | Toxemia/Preeclampsia | 3 |
| Obesity | 9 | Diabetes Gestational | 2 |
| Hypertension (PIH) | 6 | Thyroid Disease | 2 |
| Surgery-Gynecologic | 6 | Chronic Hypertension | 2 |
| Alcohol | 5 | Tobacco | 2 |
| Placenta Previa | 3 | Coagulopathy | 1 |
| Weight Loss | 3 | Depression | 1 |
| Illicit Drugs | 3 | | |

*Source: State of Delaware 2009 Birth Defects Registry*

## DISCUSSION

The results show that mothers to infants in the registry had generally the same age, education, race and ethnicity, and gravida as all mothers that gave birth in Delaware in 2009. Moreover, the majority of mothers in the registry regularly used vitamins and had their first prenatal visit in the first trimester of pregnancy. Finally, as shown in Table 14, a smaller percentage of mothers consumed alcohol during pregnancy as opposed to before pregnancy.

However, this same table reveals that a higher percentage of registered infants' mothers were likely to use tobacco before and during pregnancy rather than only prior to pregnancy. This finding is consistent with results from other Delaware-specific maternal health assessments.[7,8] Table 40 provides a cursory comparison of the birth defects registry results and the most applicable Delaware's 2009 Pregnancy Risk Assessment Monitoring System (PRAMS) results for the remaining selected maternal conditions.

**TABLE 40. Comparison of 2009 Birth Defects Registry with 2009 PRAMS by Maternal Condition.**

| Maternal Condition | 2009 Birth Defects Registry | 2009 PRAMS |
|---|---|---|
| Obesity | 26.61% | 21.98%[G] |
| Pregnancy-Induced Hypertension | 10.57% | 14.05%[H] |
| Depression | 15.85% | 12.42%[I] |
| Gestational Diabetes | 10.37% | 7.92%[J] |

*Source: State of Delaware 2009 Birth Defects Registry*

Unlike mothers in the registry, infants in the registry have generally different demographic and health attributes as compared to all infants born in Delaware. At the state level, a higher percentage of registered infants are born preterm and male. Moreover, although comparisons for growth percentile measures cannot be made, a higher proportion of infants in the registry are typically at or below the 25th percentile for birth weight, body length, or head circumference.

Furthermore, as indicated in Table 26, roughly three out of four registered infants had documentation of one birth defect with the remaining one out of four had multiple birth defects reported. The registry lists 134 infants as having at least one or more family members with a birth defect, bringing the total count of

[G] In PRAMS, this was calculated by taking the sum of the CDC's assigned weighted averages of the respondents who had a BMI of 30 or greater and dividing this value by the CDC's weighted averages of all respondents.
[H] In PRAMS, this is item 27E: "During your most recent pregnancy, did you have a problem with high blood pressure, hypertension (including pregnancy-induced hypertension [PIH]), preeclampsia, or toxemia?"
[I] In PRAMS, this is item 61A: "Since your new baby was born, have you often or always felt down, depressed, or sad?"
[J] In PRAMS, this is item 26: "During your most recent pregnancy, were you told by a doctor, nurse, or other health care worker that you had gestational diabetes?"

familial connections to 189. Finally, the registry documented 16 fetal deaths and 22 infant deaths, and in comparison to all infants in the registry, a lower proportion of these 22 infant deaths (six out of 22) had only one birth defect.

The results of this report should add more to the body of knowledge of maternal and child wellbeing in Delaware. Although the etiology of a birth defect generally cannot be uncovered and one calendar year of data may limit the strength of the results, this report may afford some cursory insights about what factors could be modified to reduce the incidence of birth defects in Delaware.

**APPENDIX A. Birth Defects Registry Reportable Diagnoses.**

| Diagnosis |
|---|
| Congenital syphilis |
| Neurofibromatosis |
| Congenital hypothyroidism |
| Congenital adrenal hyperplasia (adrenogenital disorders) |
| Multiple carboxylase deficiency |
| Phenylketonuria |
| Other disturbances of aromatic amino-acid metabolism |
| Disturbances of branched-chain amino-acid metabolism |
| Disturbances of sulphur-bearing amino-acid metabolism |
| Disorder of urea cycle metabolism |
| Glutaric aciduria |
| 3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency |
| Galactosemia |
| Cystic fibrosis |
| Biotinidase deficiency |
| Carnitine uptake deficiency |
| Disorders of fatty acid oxidation |
| Sickle cell disease |
| Other hemoglobinopathies |
| Hemoglobinopathies - SS Disease, SC Disease, Variant Hgb |
| Developmental language disorder |
| Coordination Disorder |
| Mental Retardation/Cognitive delay |
| Hearing loss (sensorineural) |
| Known or suspected fetal abnormality affecting management of the mother |
| Other fetal and placental problems affecting management of the mother: intrauterine death |
| Anencephalus |
| Spina bifida without anencephalus |
| Encephalocele |
| Microcephalus |
| Holoprosencephaly/porencephaly |
| Hydrocephalus without spina bifida |
| Other congenital anomalies of nervous system |
| Anophthalmia/microphthalmia |
| Glaucoma |
| Congenital cataract |
| Aniridia |
| Coloboma |
| Anotia / microtia |
| Common truncus |
| Transposition of great arteries, double outlet right ventricle |
| Tetralogy of Fallot |
| Single Ventricle |

**APPENDIX A. Birth Defects Registry Reportable Diagnoses.** *Continued*

| Diagnosis | ICD-9 Code |
|---|---|
| Ventricular septal defect | 745.4 |
| Atrial Septal Defect | 745.5 |
| Enocardial cushion defect | 745.60, 745.61, 745.69 |
| Pulmonary valve atresia and stenosis | 746.01, 746.02 |
| Tricuspid valve atresia and stenosis | 746.1 |
| Ebstein's anomaly | 746.2 |
| Aortic valve stenosis | 746.3 |
| Hypoplastic left heart syndrome | 746.7 |
| Patent ductus arteriosus >2500 grams | 747.0 |
| Coarctation of aorta | 747.10 |
| Pulmonary artery anomalies | 747.3 |
| Choanal atresia | 748.0 |
| Anomalies of larynx /trachea /bronchus | 748.30 |
| Congenital cystic lung | 748.4 |
| Lung agenesis/hypoplasia | 748.5 |
| Cleft palate without cleft lip | 749.00-749.04 |
| Cleft lip with or without cleft palate | 749.1, 749.2 |
| Esophageal atresia/tracheoesophageal fistula | 750.3 |
| Atresia/stenosis of intestine | 751.10, 751.2 |
| Hirschsprung's disease (congenital megacolon) | 751.3 |
| Anomalies of internal fixation of bowel | 751.40 |
| Biliary atresia | 751.61 |
| Pyloric stenosis | 750.5 |
| Anorectal malformation | 751.4 |
| Cloacal exstrophy | 751.5 |
| Renal Agenesis / hypoplasia | 753.0 |
| Cystic/dysplastic kidneys | 753.10, 753.15 |
| Obstructive genitourinary defect | 753.2, 753.6 |
| Hypospadias and epispadias | 752.6 |
| Ambiguous genitalia | 752.9 |
| Polycystic kidneys | 753.12-753.14 |
| Bladder exstrophy | 753.5 |
| Scoliosis / Lordosis / Kyphosis | 754.0, 756.19 |
| Congenital developmental hip dysplasia | 754.30, 754.31, 754.35 |
| Club Foot | 754.50, 51, 754.53, 754.60, 754.70, 754.79 |
| Arthrogrvposis multiplex congenital | 754.89 |
| Polydactyly/syndactyly/adactyly | 755.00-755.02, 755.10-755.14, 755.4 |
| Reduction defect, upper limbs | 755.20-755.29 |
| Reduction defect, lower limbs | 755.30-755.39 |
| Craniosynostosis | 756.0 |
| Achondroplasia | 756.4 |
| Osteogenesis imperfecta | 756.51 |
| Diaphragmatic hernia (moved up) | 756.6 |
| Gastroschisis | 756.7 |

**APPENDIX A. Birth Defects Registry Reportable Diagnoses.** *Continued*

| Diagnosis | ICD-9 Code |
|---|---|
| Trisomy 21 (Down syndrome) | 758.0 |
| Trisomy 13 | 758.1 |
| Trisomy 18 | 758.2 |
| Autosomal deletion syndromes | 758.30 |
| Other conditions due to autosomal anomalies | 758.50 |
| Gonadal dysgenesis (Turner syndrome) | 758.60 |
| Klinefelter syndrome | 758.70 |
| Other conditions due to sex chromosome anomalies | 758.80 |
| Conditions due to anomaly of unspecified chromosome | 758.90 |
| Prader-Wili | 759.81 |
| Fragile X Syndrome | 759.83 |
| Other specified anomalies (e.g. Noonan, De Lange, Williams and Beckwith) | 759.89 |
| Congenital anomaly, unspecified | 759.9 |
| Fetal Alcohol syndrome | 760.71 |
| Phenytoin | 760.77 |
| Isotretinoin | 760.79 |
| Congenital rubella | 771.0 |
| Congenital cytomegalovirus | 771.1 |
| Congenital toxoplasmosis (not specific code) | 771.2 |
| Other infections specific to perinatal period | 771.80 |
| Other congenital infections | 771.x |
| Unspecified condition originating in the perinatal period | 779.9 |
| Personal history of other diseases: Congenital malformations | V13.6 |
| Outcome of delivery: single stillborn | V27.1 |
| Outcome of deliver: Twins, one liveborn and one stillborn | V27.3 |
| Outcome of delivery: Twins, both stillborn | V27.4 |
| Twin, mate stillborn: Born in hospital | V32.0 |

**APPENDIX B. Birth Defects Registry Fields.**

| Field | Description |
|---|---|
| Study_ID | Unique Identifier for Child |
| C_FNAME | Child First Name |
| C_MNAME | Child Middle Name |
| C_LNAME | Child Last Name |
| C_DOO | Child Date of Birth |
| C_SSN | Child Social Security Number |
| M_FNAME | Mother First Name |
| M_MNAME | Mother Middle Name |
| M_LNAME | Mother Last Name |
| M_DOB | Maternal Date of Birth |
| M_SSN | Maternal Social Security Number |
| FACILITYNAME.1, FACILITYNAME.2, FACILITYNAME.3, FACILITYNAME.4, FACILITYNAME.5, FACILITYNAME.6, FACILITYNAME.7, FACILITYNAME.8, FACILITYNAME.9, FACILITYNAME.10, FACILITYNAME.11, FACILITYNAME.12 | Facility Where Entry was Abstracted |
| M_MRN_CCHS, M_MRN_AIDUPONT, M_MRN_BAYHEALTH, M_MRN_NBS, M_MRN_VITALS, M_MRN_KENTGENERAL, M_MRN_STFRANCIS, M_MRN_NANTICOKE, M_MRN_BEEBE, M_MRN_BIRTHCENTER, M_MRN_NICU, M_MRN_MILFORD | Maternal ID at Facility Where Entry was Abstracted |
| C_MRN_CCHS, C_MRN_AIDUPONT, C_MRN_BAYHEALTH, C_MRN_NBS, C_MRN_VITALS, C_MRN_KENTGENERAL, C_MRN_STFRANCIS, C_MRN_NANTICOKE, C_MRN_BEEBE, C_MRN_BIRTHCENTER, C_MRN_NICU, C_MRN_MILFORD | Child ID at Facility Where Entry was Abstracted |
| M_ADD | Mother's Address |
| M_CITY | Mother's City |
| M_ZIP | Mother's Zip Code |
| M_HPHNE | Mother's Home Phone |
| M_OB | Mother's Obstetrician |
| LMP | Last Menstrual Period Date |
| EDC | Estimated Date of Delivery |
| GRAVID | Mother's Gravida |
| PARA | Mother's Para |
| LIV_CHDN | Number of Live Children to Mother |
| STB_CHDN | Number of Stillborn Children |
| SP_AB | Number of Prior Spontaneous Abortions |
| EL_AB | Number of Prior Elective Abortions |
| NN_DEATH | Number of Prior Neonatal Deaths |
| PN_DEATH | Number of Prior Postneonatal Deaths |
| MB_PRIOR | Number of Prior Birth Defects |
| WTGAIN | Maternal Weight Gain During Pregnancy |
| PREG_OUT | Pregnancy Outcome |

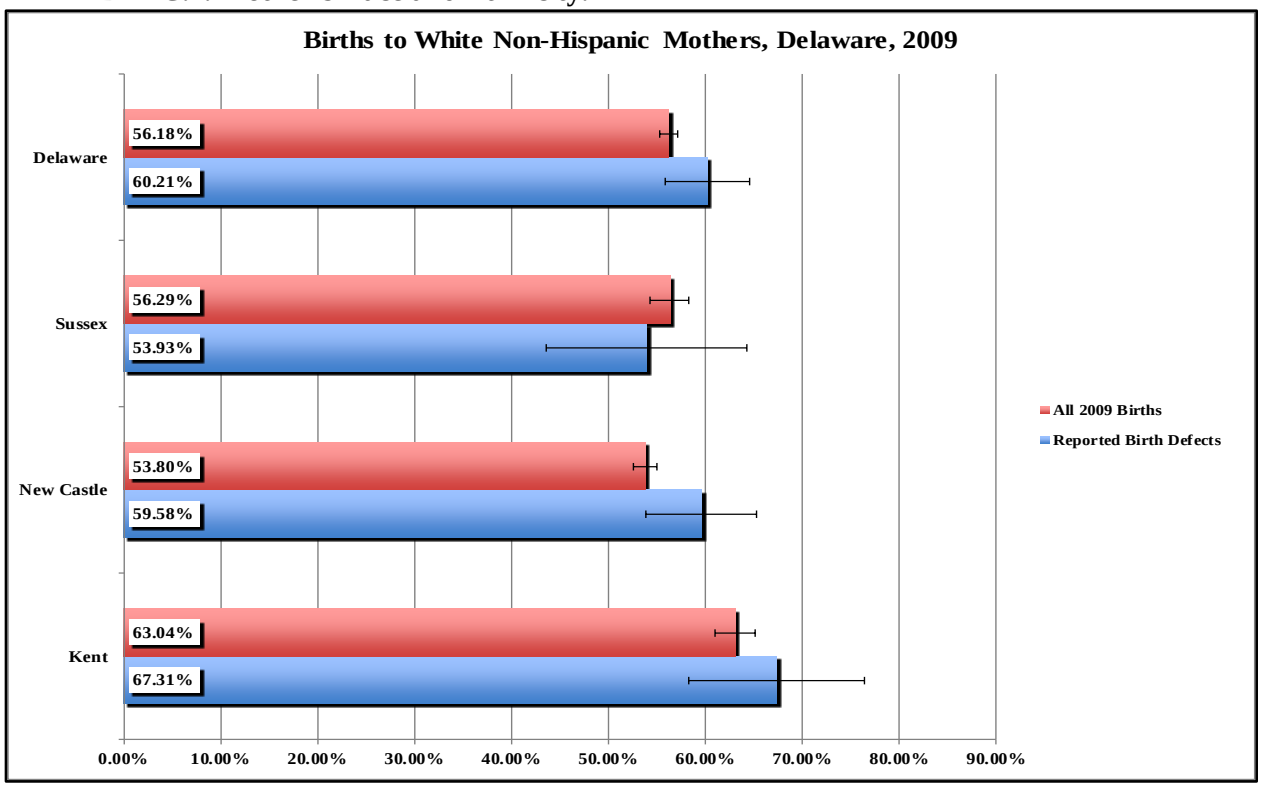
**APPENDIX B. Birth Defects Registry Fields.** *Continued*

| Field | Description |
|---|---|
| F_FNAME | Father's First Name |
| F_MNAME | Father's Middle Name |
| F_LNAME | Father's Last Name |
| F_DOB | Father's Date of Birth |
| F_SSN | Father's Social Security Number |
| MCURR_ADD | Mother's Current Address |
| MCURR_CITY | Mother's Current City |
| MCURR_ZIP | Mother's Current Zip Code |
| M_RACE | Mother's Race |
| M_ETHNICITY | Mother's Ethnicity |
| M_EDUC_LVL | Mother's Educational Level |
| M_OCC | Mother's Occupation |
| F_RACE | Father's Race |
| F_ETHNICITY | Father's Ethnicity |
| F_EDUC_LVL | Father's Educational Level |
| F_OCC | Father's Occupation |
| PRENATAL_CARE | Prenatal Care (Y/N) |
| PRENATAL_CARE_DATE | Prenatal Care Start Date |
| PRENATAL_CARE_TRIMESTER | Trimester When Prenatal Care Started |
| VITAMIN_USE | Vitamin Use (Y/N) |
| MAT_COND.1, MAT_COND.2, MAT_COND.3, MAT_COND.4, MAT_COND.5, MAT_COND.6, MAT_COND.7, MAT_COND.8 | Maternal Illness, Condition, or Complication |
| COND_COM.1, COND_COM.2, COND_COM.3, COND_COM.4, COND_COM.5, COND_COM.6, COND_COM.7, COND_COM.8 | Time at which Maternal Illness, Condition, or Complication Occurred |
| C_ADDRES | Child's Street Address |
| C_CITY | Child's City of Residence |
| C_ZIP | Child's Zip Code |
| PED_NME | Name of Pediatrician |
| C_GEND | Child's Gender |
| BW_G | Child's Weight at Birth (g) |
| BL_CM | Child's Length at Birth (cm) |
| BL_IN | Child's Length at Birth (in) |
| BHC_CM | Child's Head Circumference at Birth (cm) |
| BHC_IN | Child's Head Circumference at Birth (in) |
| B_GA | Child's Gestational Weeks at Birth |
| PLURAL | Plurality |
| DESIGNATION | Plurality Birth Order |
| APGAR_1 | Apgar at 1 Minute |
| APGAR_5 | Apgar at 5 Minutes |
| APGAR_10 | Apgar at 10 Minutes |
| EXPIRE | Expire (Y/N) |
| EXPIRE_D | Expiration Death |
| AUTOPSY | Autopsy (Y/N) |
| AUTOPSY_D | Autopsy Death |
| ADOPT_FOSTER | Adoption or Foster |

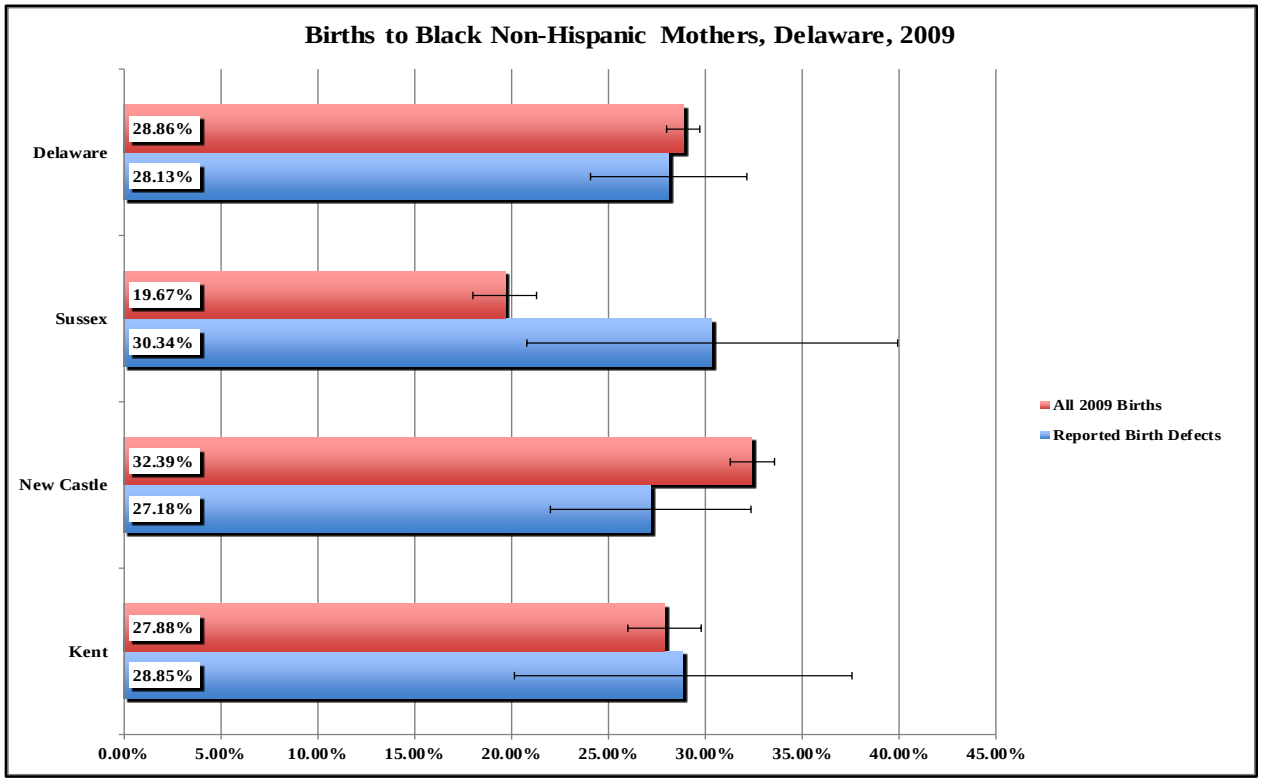
**APPENDIX B. Birth Defects Registry Fields.** *Continued*

| Field | Description |
|---|---|
| FAM_MEM.1, FAM_MEM.2, FAM_MEM.3, FAM_MEM.4 | Family Member with Birth Defect |
| FAM_MEM_BD.1, FAM_MEM_BD.2, FAM_MEM_BD.3, FAM_MEM_BD.4 | Family Member's Birth Defect |
| MALF.1, MALF.2, MALF.3, MALF.4, MALF.5, MALF.6, MALF.7, MALF.8 | ICD-9 Code and Description for Birth Defect |
| MALF_C.1, MALF_C.2, MALF_C.3, MALF_C.4, MALF_C.5, MALF_C.6, MALF_C.7, MALF_C.8 | Note on Birth Defect |
| MALF_DXM.1, MALF_DXM.2, MALF_DXM.3, MALF_DXM.4, MALF_DXM.5, MALF_DXM.6, MALF_DXM.7, MALF_DXM.8 | How Birth Defect was Diagnosed |
| MALF_DATE.1, MALF_DATE.2, MALF_DATE.3, MALF_DATE.4, MALF_DATE.5, MALF_DATE.6, MALF_DATE.7, MALF_DATE.8 | Date Birth Defect was Diagnosed |
| MALF_WHEN.1, MALF_WHEN.2, MALF_WHEN.3, MALF_WHEN.4, MALF_WHEN.5, MALF_WHEN.6, MALF_WHEN.7, MALF_WHEN.8 | When Birth Defect was Diagnosed (Prenatal/Postneonatal) |
| MALF_CON.1, MALF_CON.2, MALF_CON.3, MALF_CON.4, MALF_CON.5, MALF_CON.6, MALF_CON.7, MALF_CON.8 | Confirmation of Birth Defect (Confirmed/Probable) |
| MALF_CD.1, MALF_CD.2, MALF_CD.3, MALF_CD.4, MALF_CD.5, MALF_CD.6, MALF_CD.7, MALF_CD.8 | ICD-9 Code for Birth Defect |

## APPENDIX C.1. Mother's Race and Ethnicity.

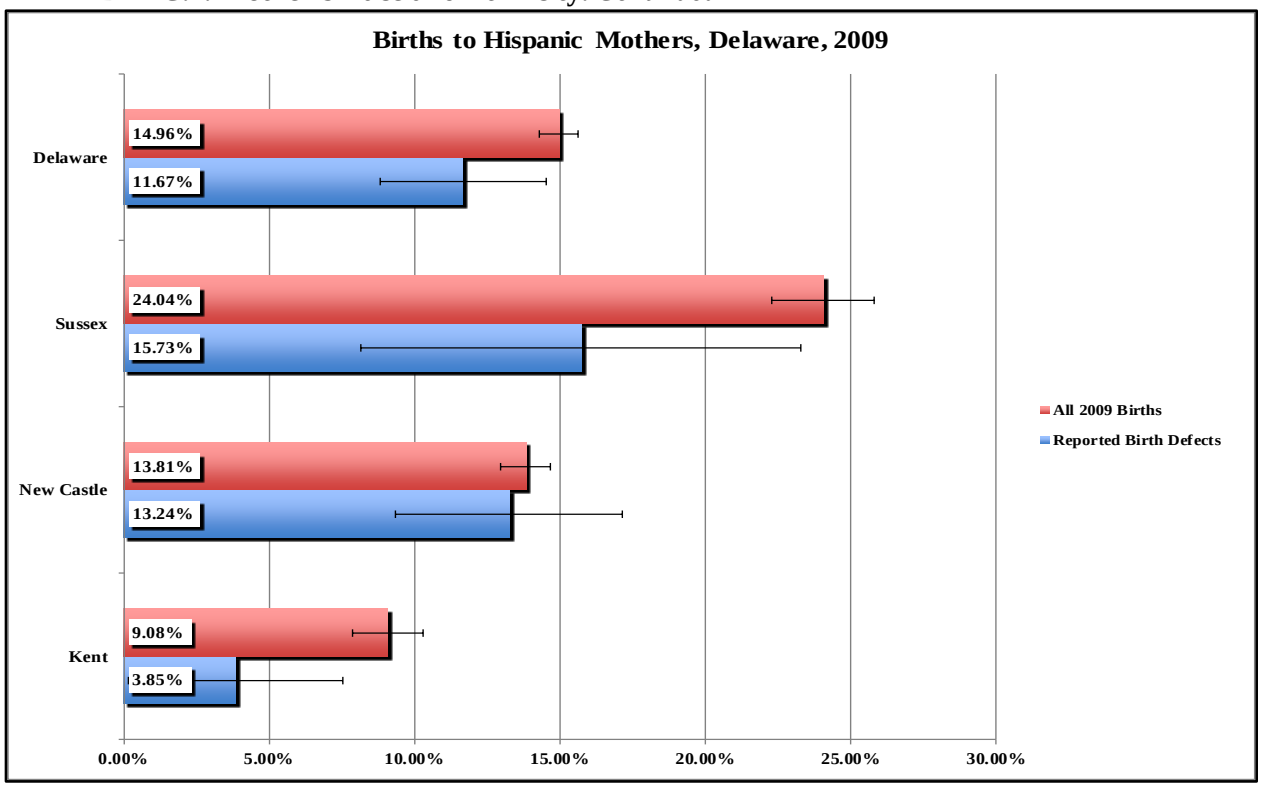



*Source: State of Delaware 2009 Birth Defects Registry*

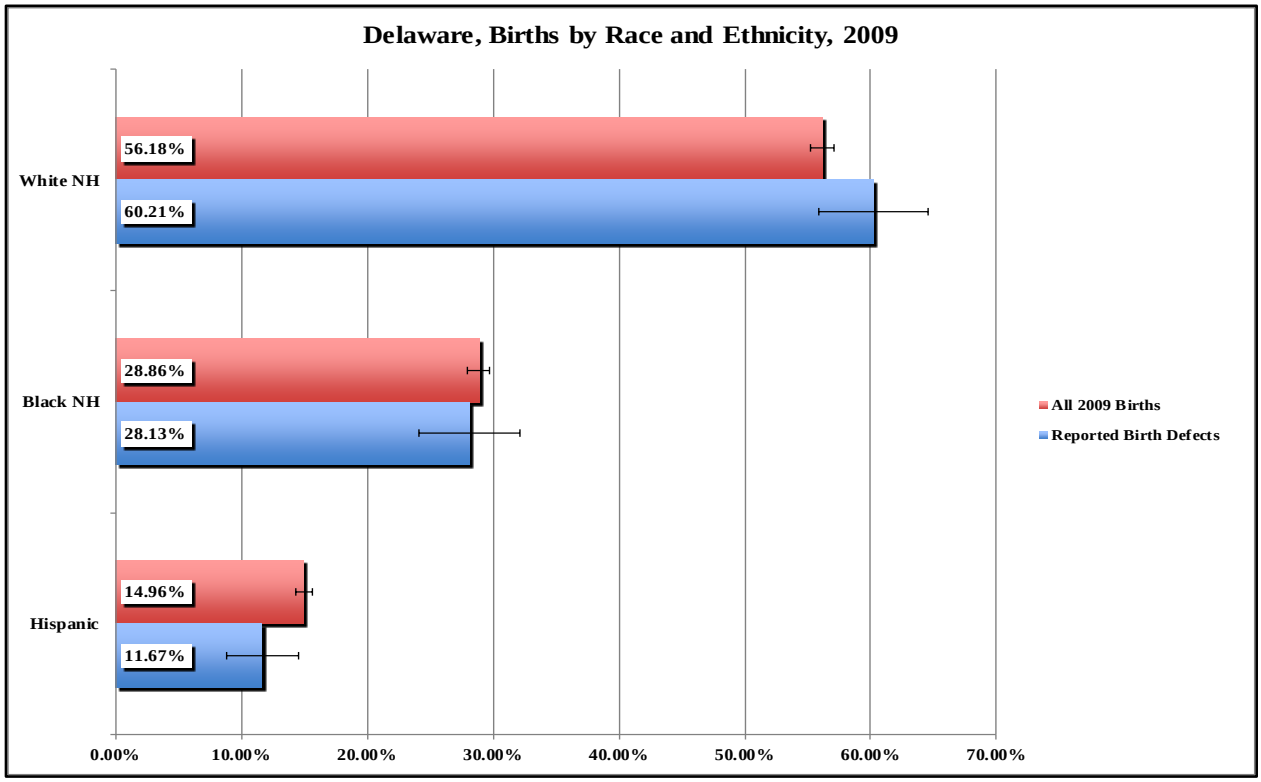



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.1. Mother's Race and Ethnicity.** *Continued*

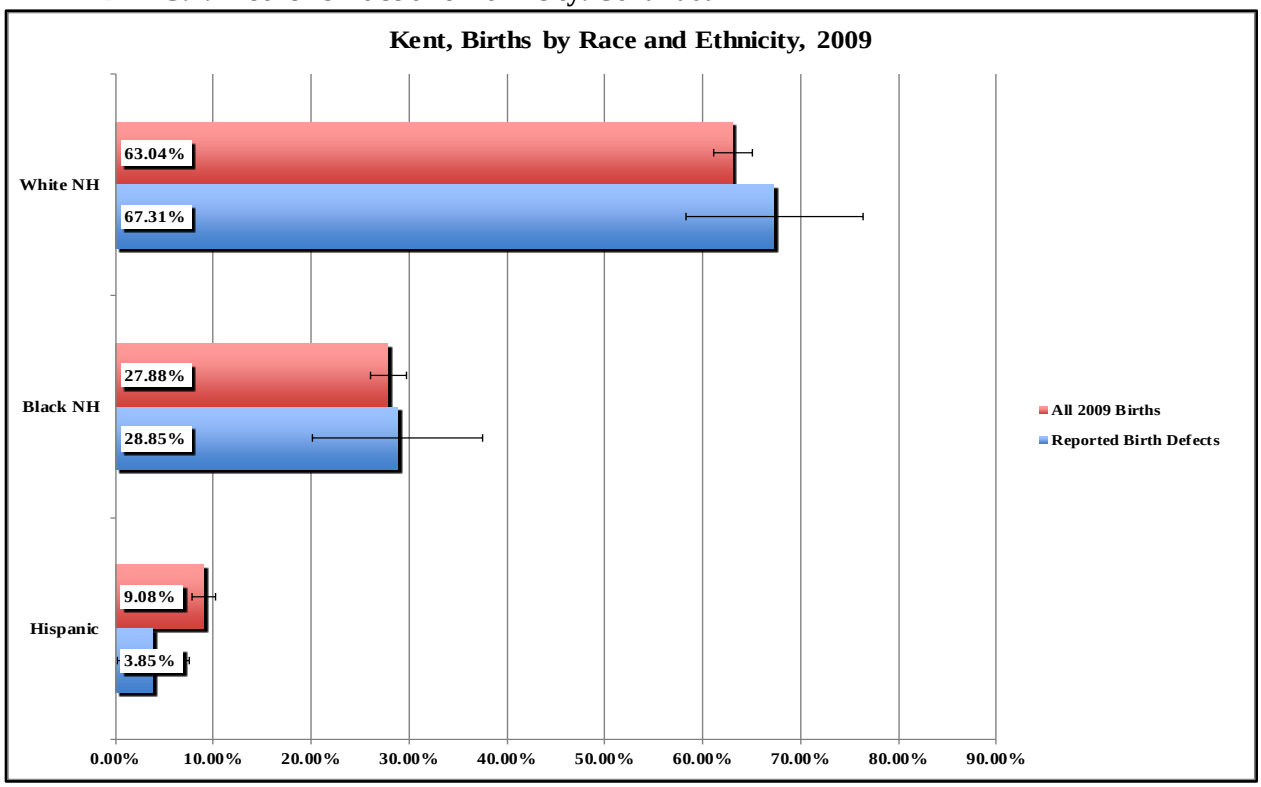



*Source: State of Delaware 2009 Birth Defects Registry*

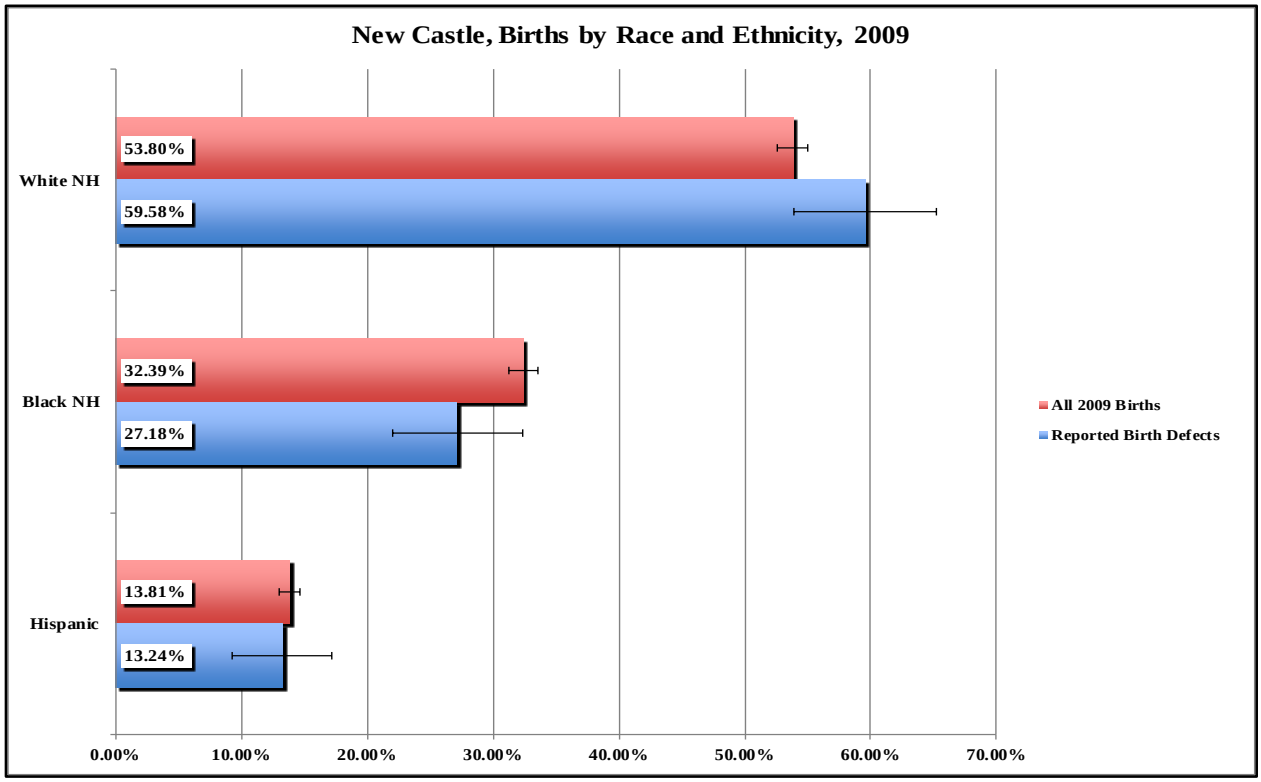



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.1. Mother's Race and Ethnicity.** *Continued*

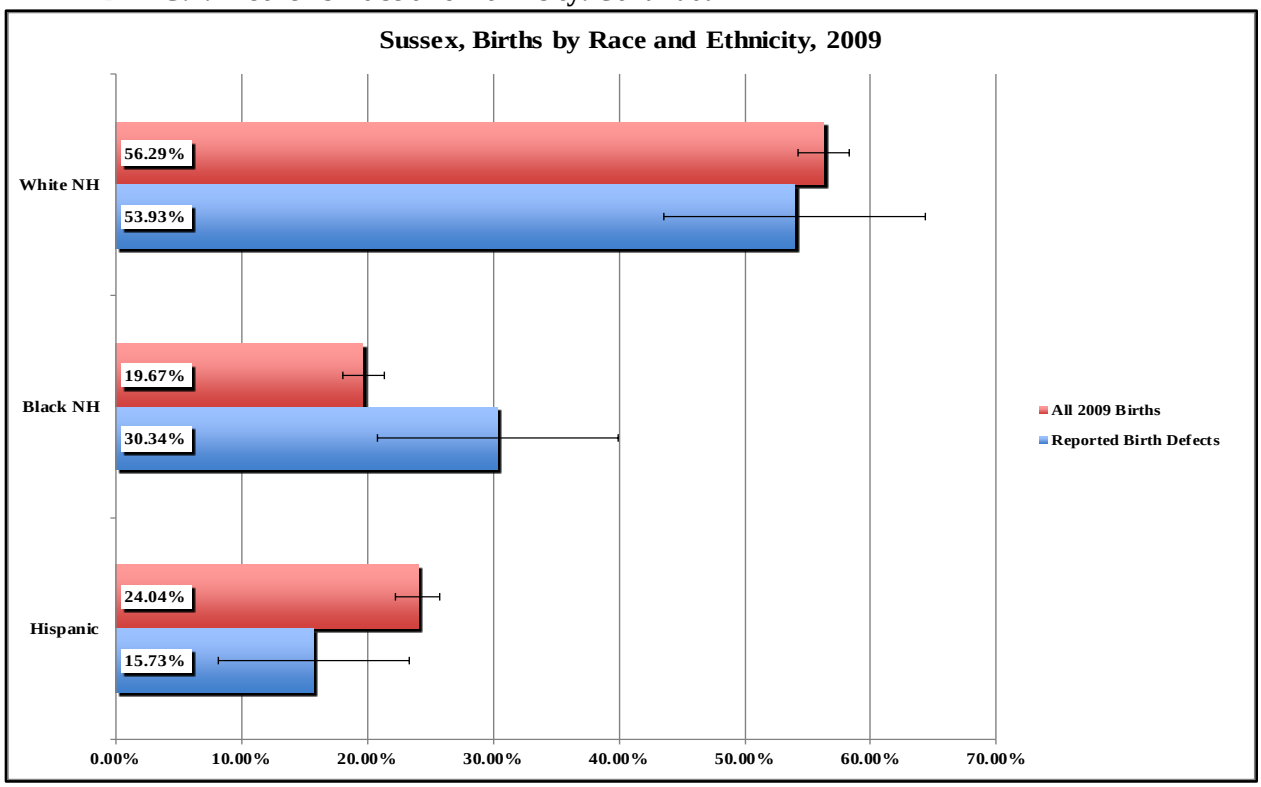



*Source: State of Delaware 2009 Birth Defects Registry*



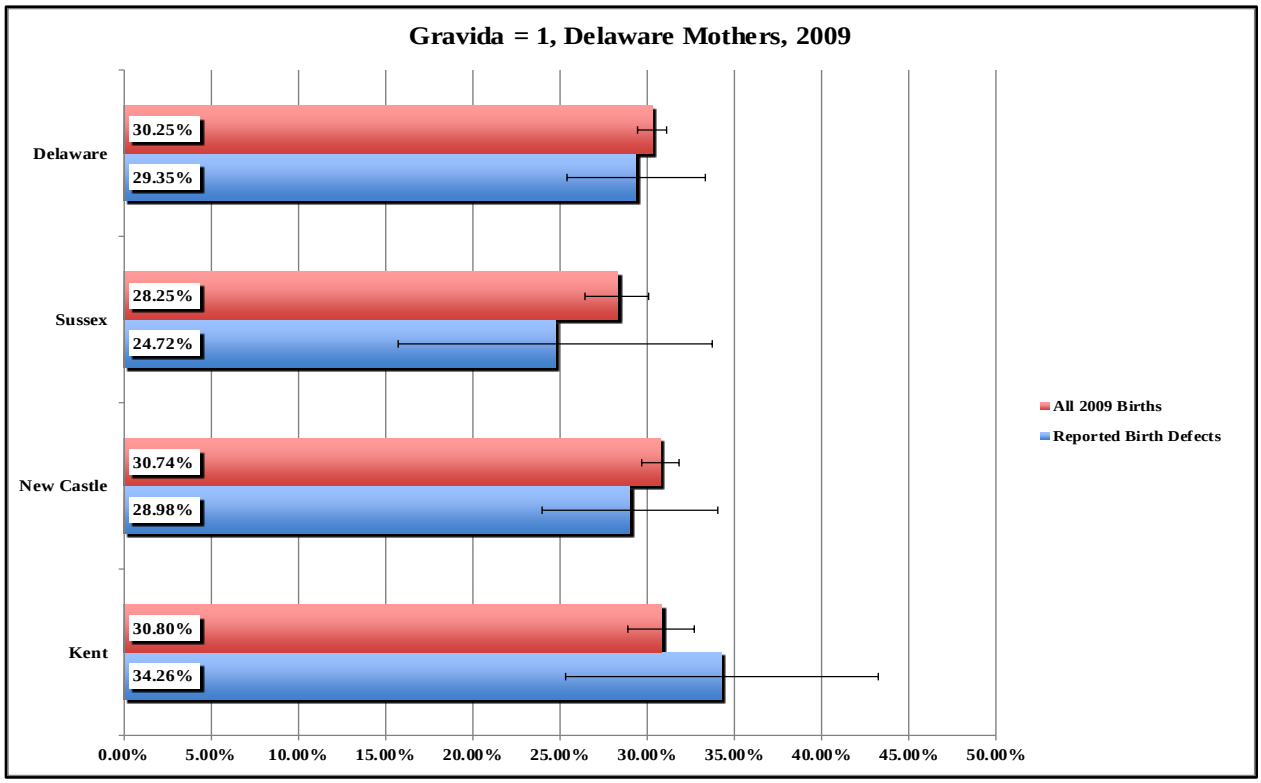

*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.1. Mother's Race and Ethnicity.** *Continued*

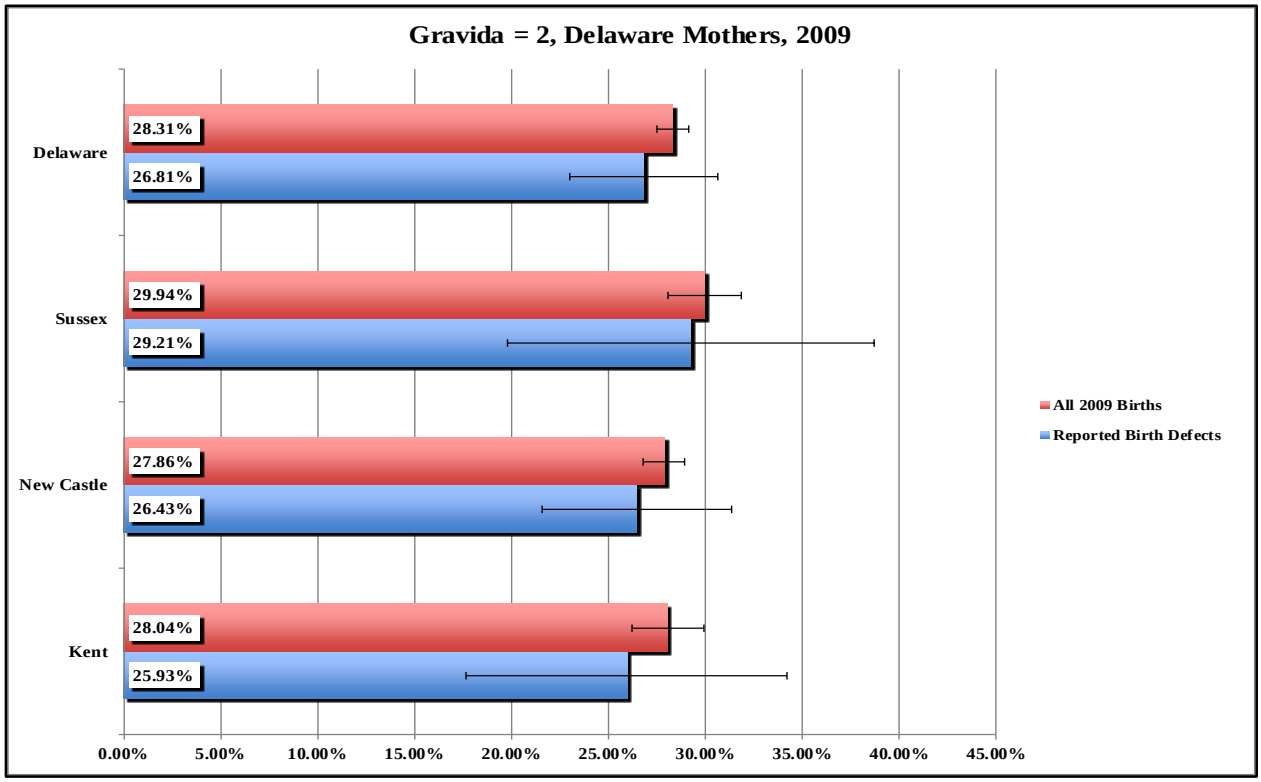



*Source: State of Delaware 2009 Birth Defects Registry*

## APPENDIX C.2. Gravida.

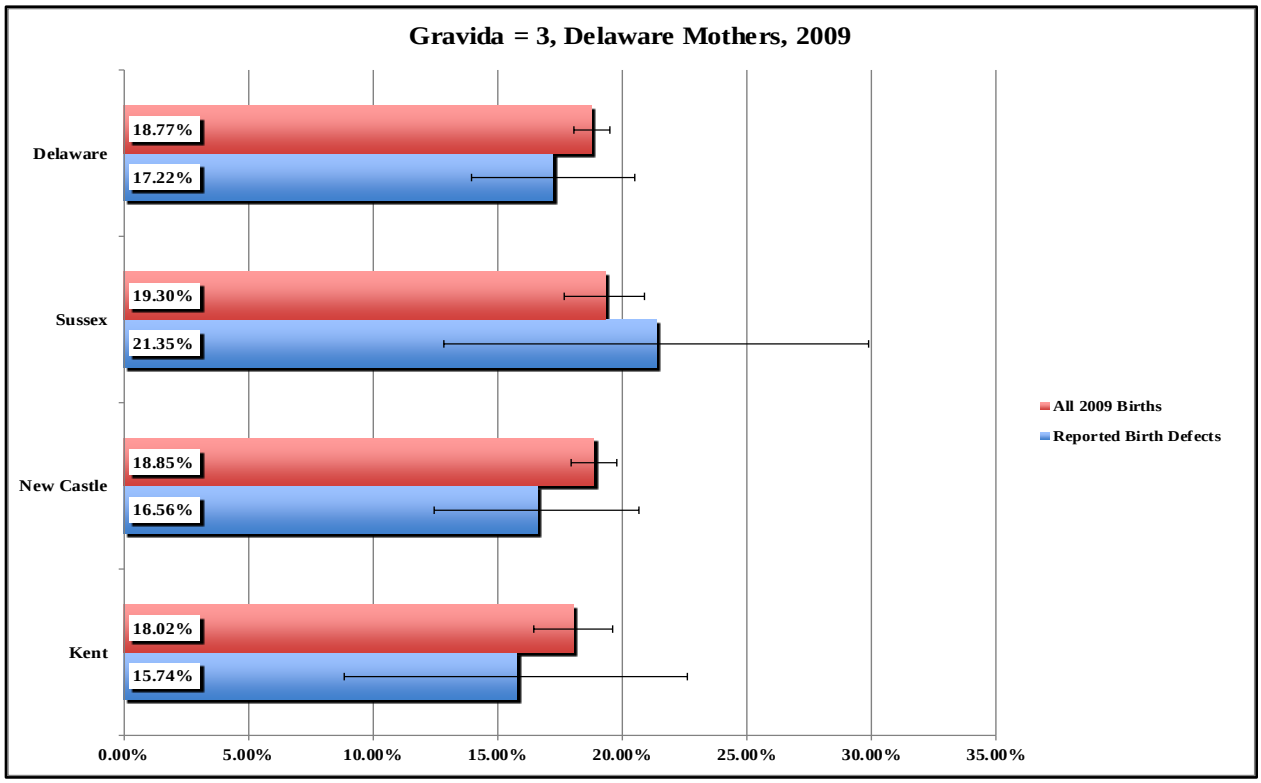



*Source: State of Delaware 2009 Birth Defects Registry*

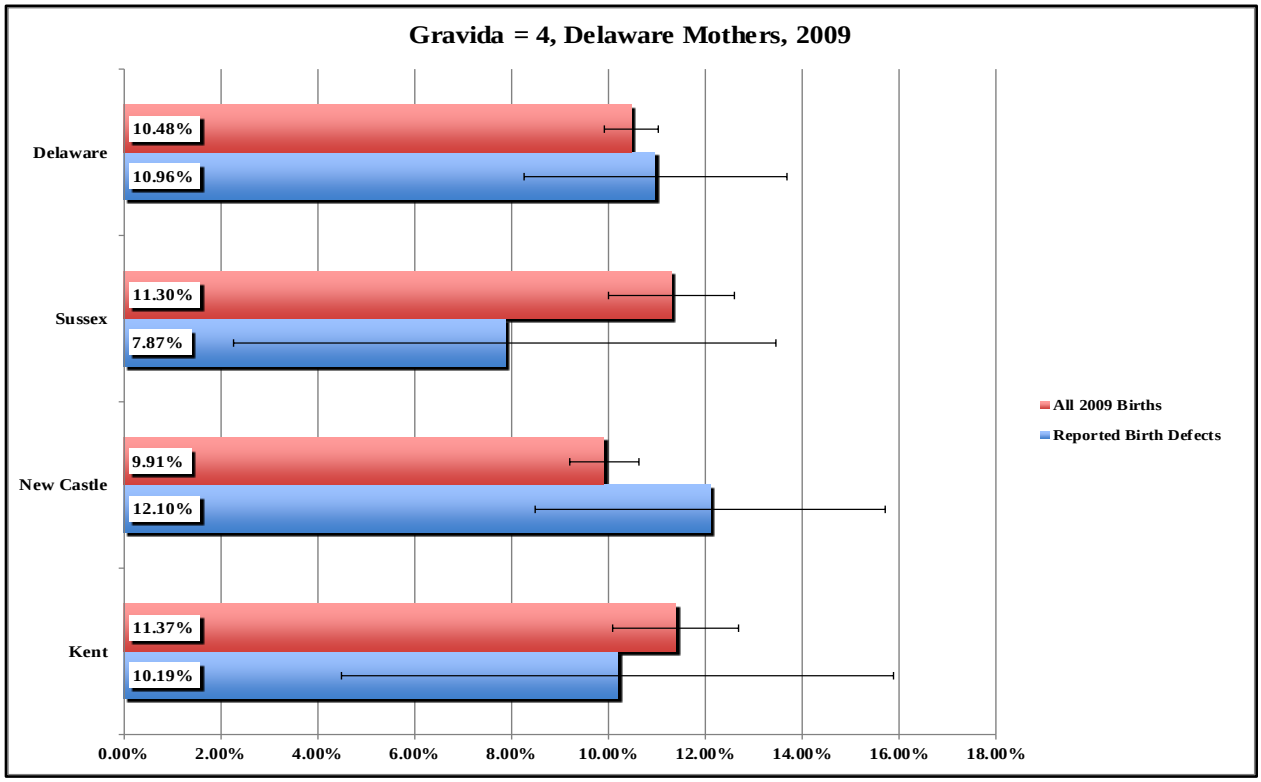



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.2. Gravida.** *Continued*

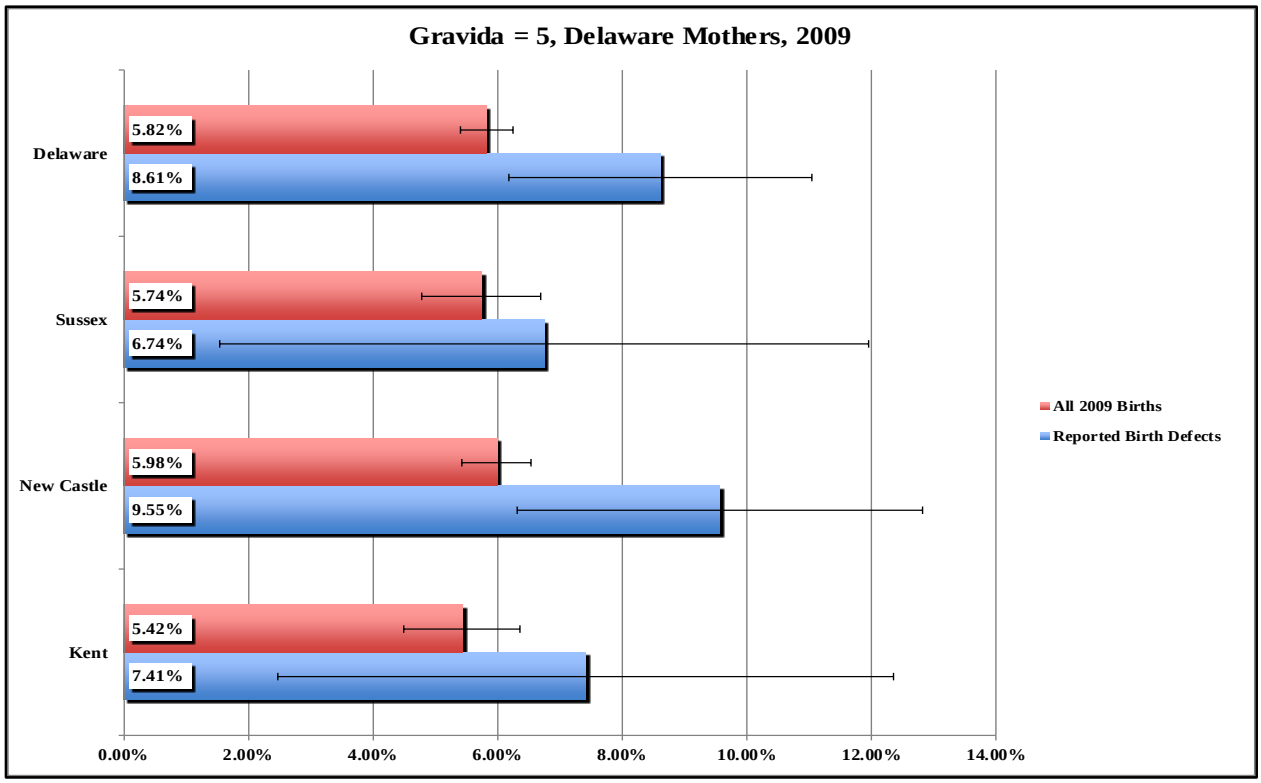



*Source: State of Delaware 2009 Birth Defects Registry*

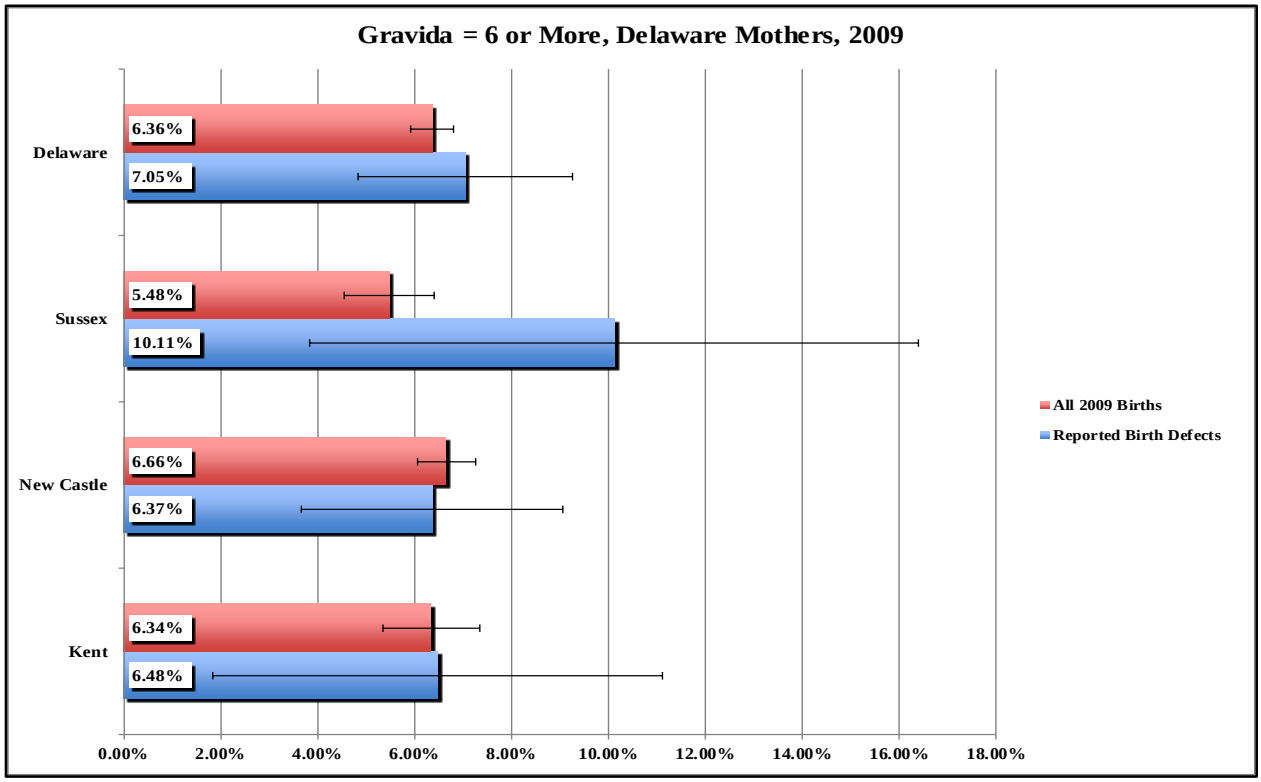



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.2. Gravida.** *Continued*

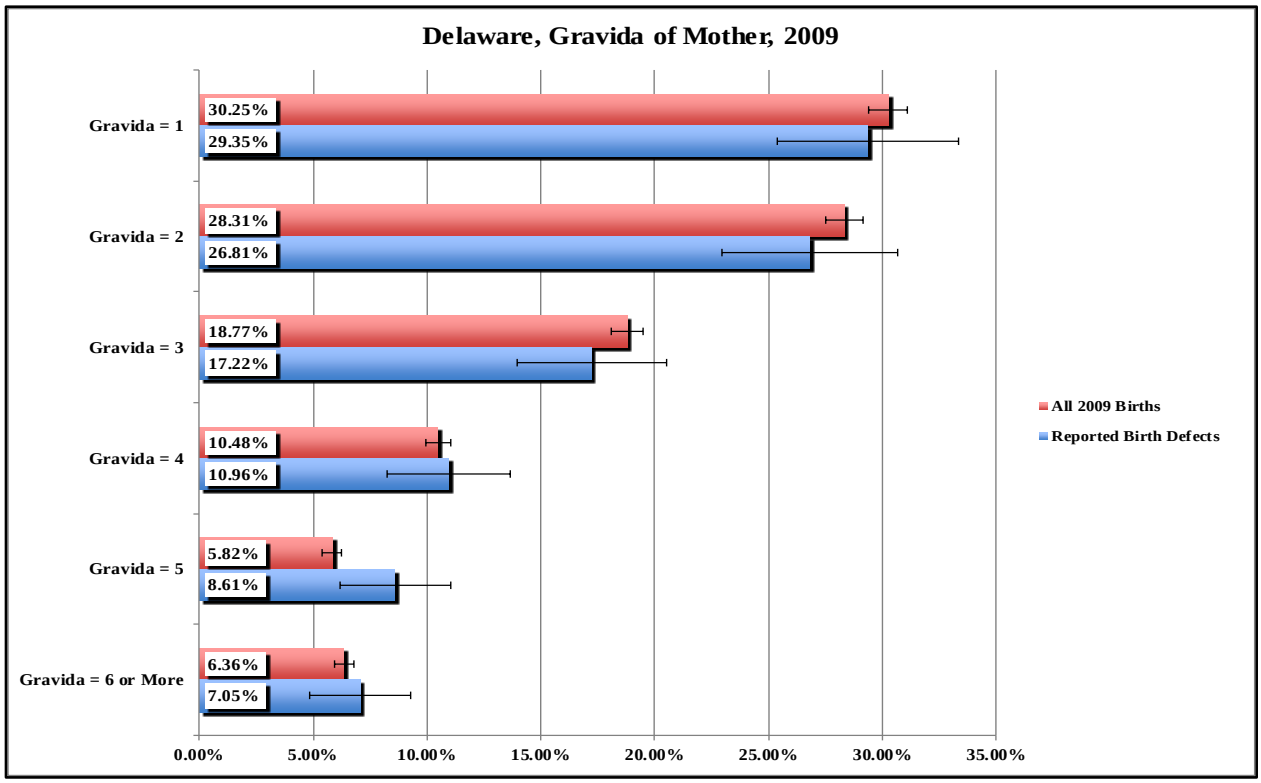



*Source: State of Delaware 2009 Birth Defects Registry*

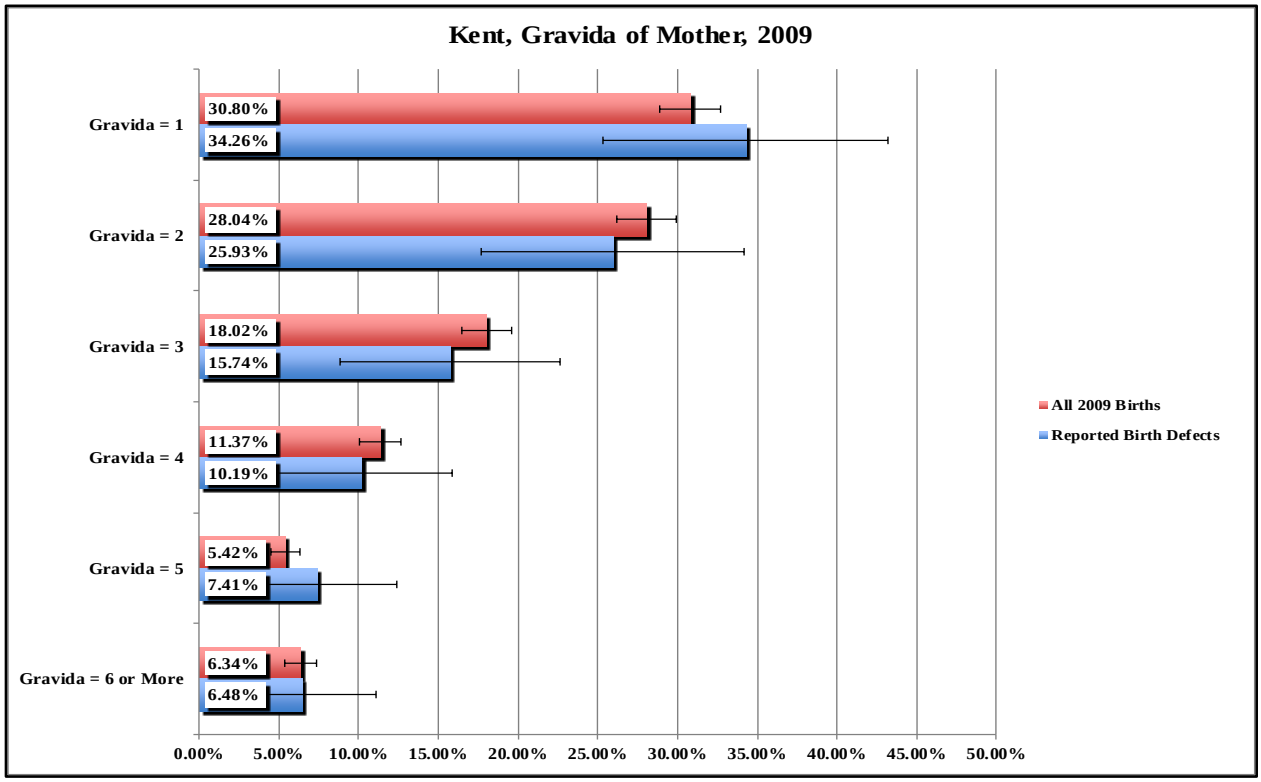



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.2. Gravida.** *Continued*

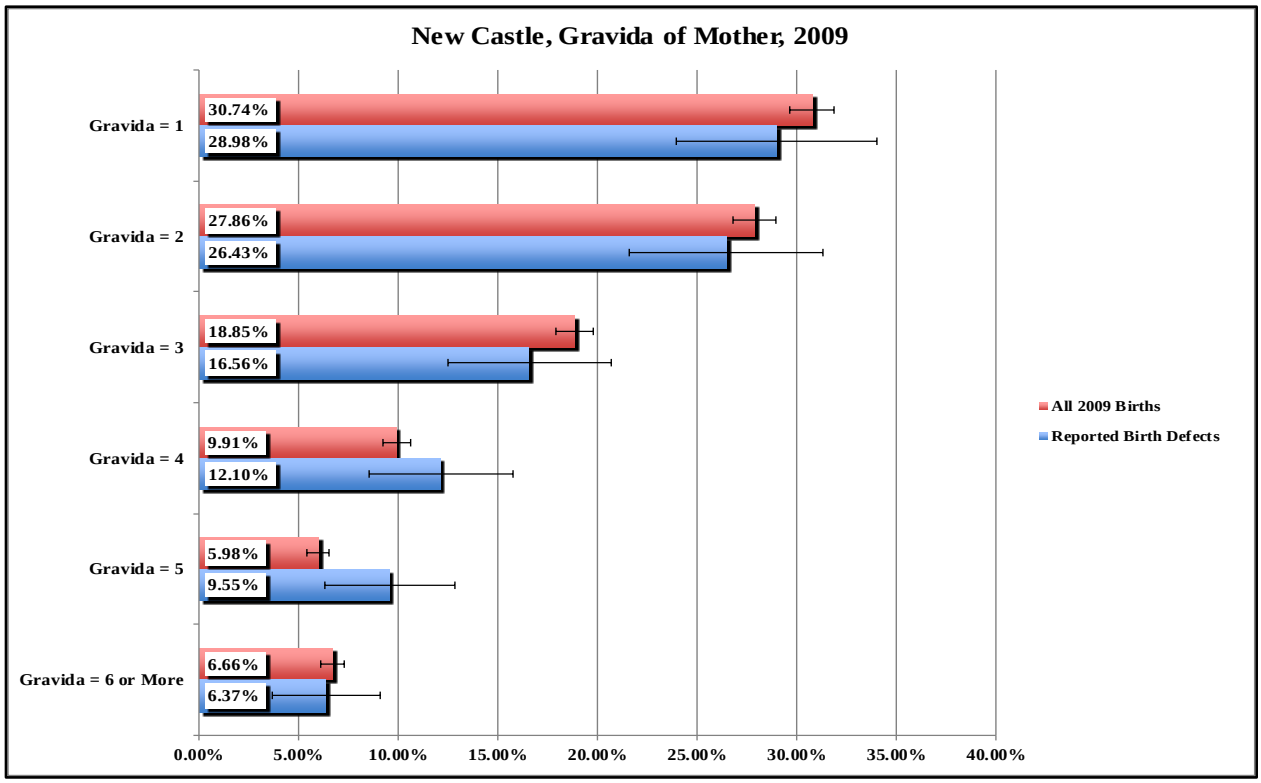



*Source: State of Delaware 2009 Birth Defects Registry*

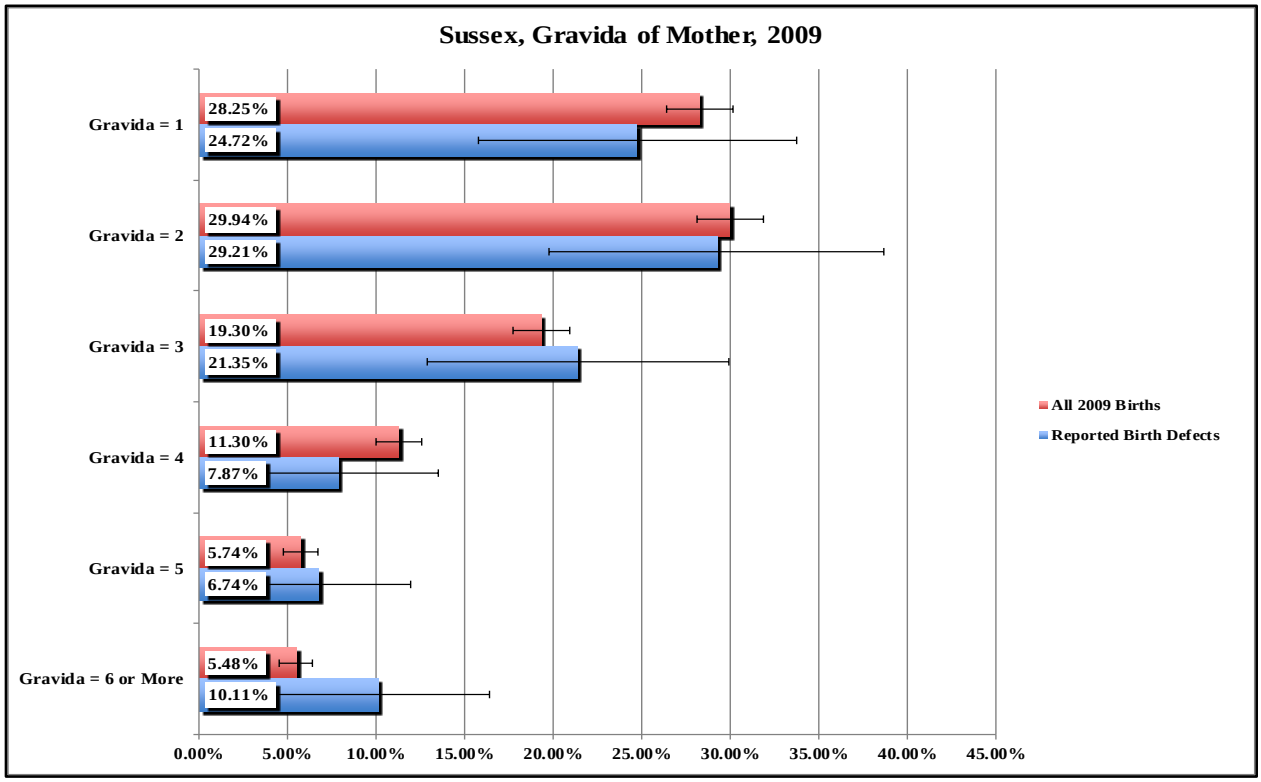



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.2. Gravida.** *Continued*

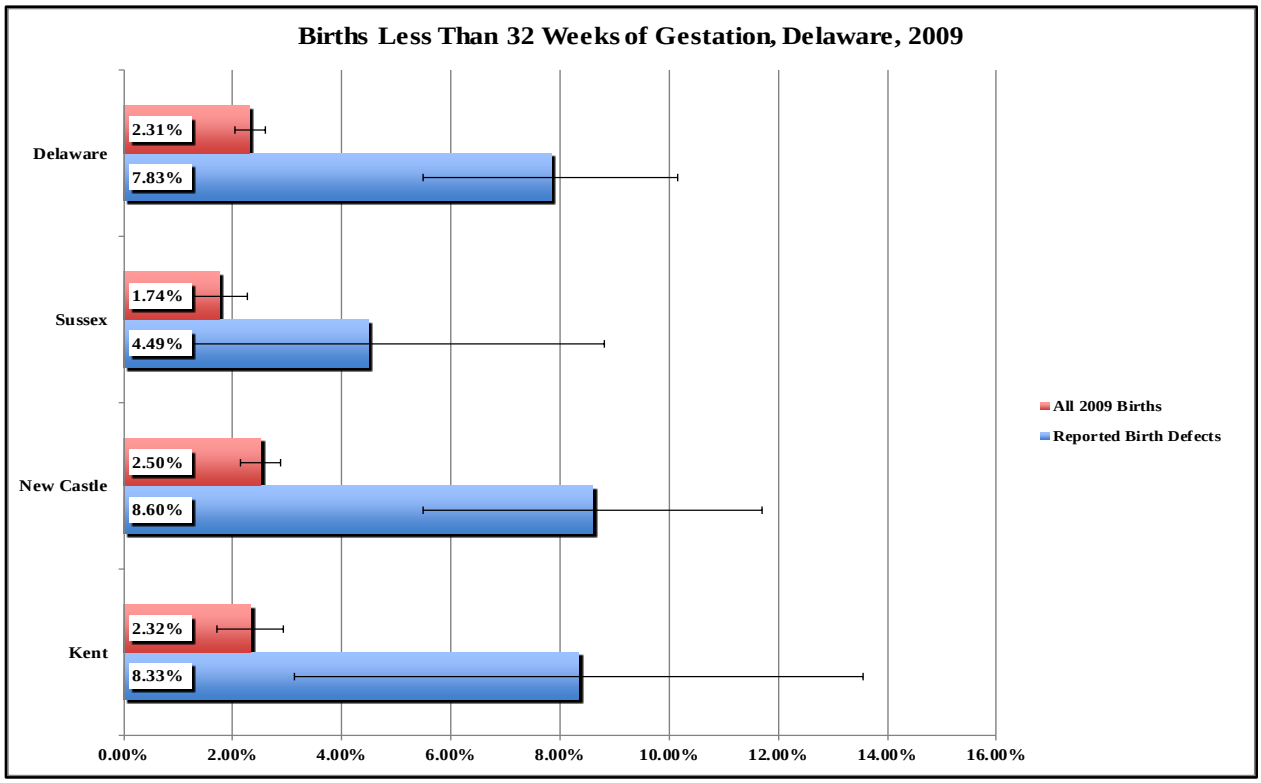



*Source: State of Delaware 2009 Birth Defects Registry*

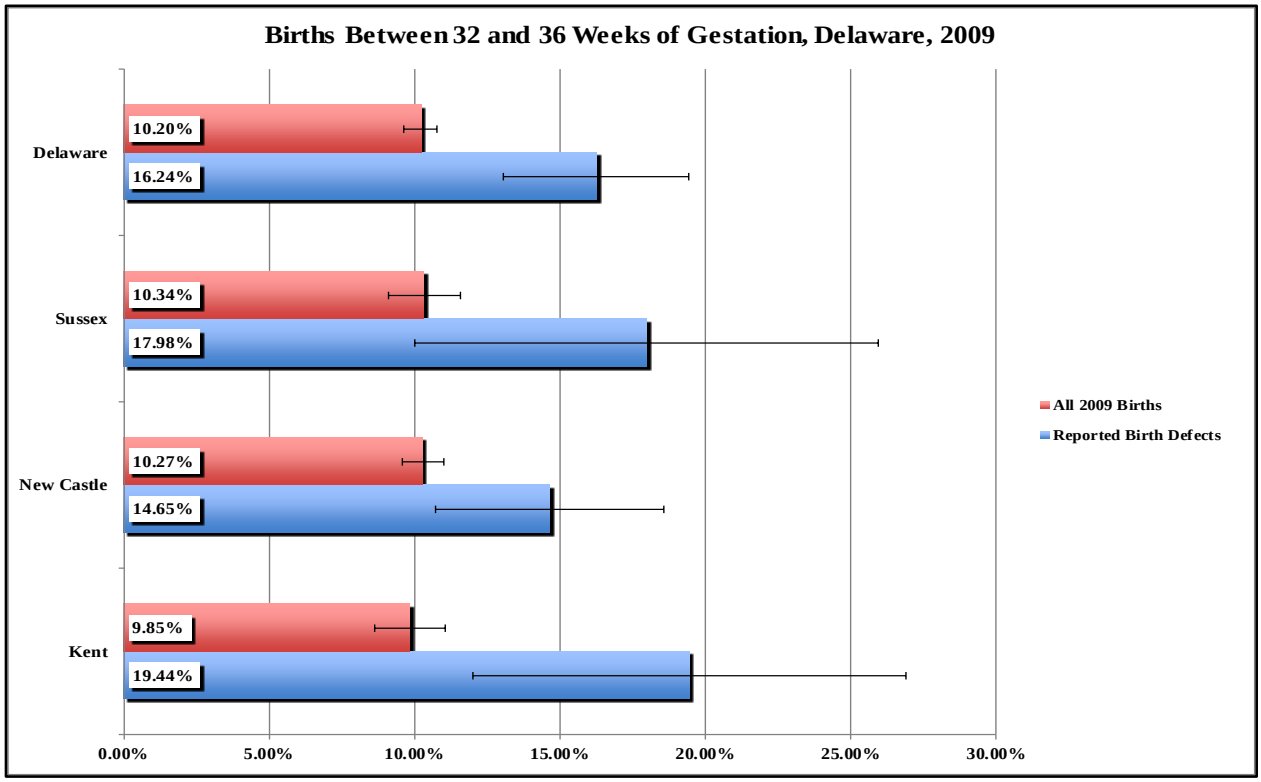



*Source: State of Delaware 2009 Birth Defects Registry*

## APPENDIX C.3. Gestational Weeks.

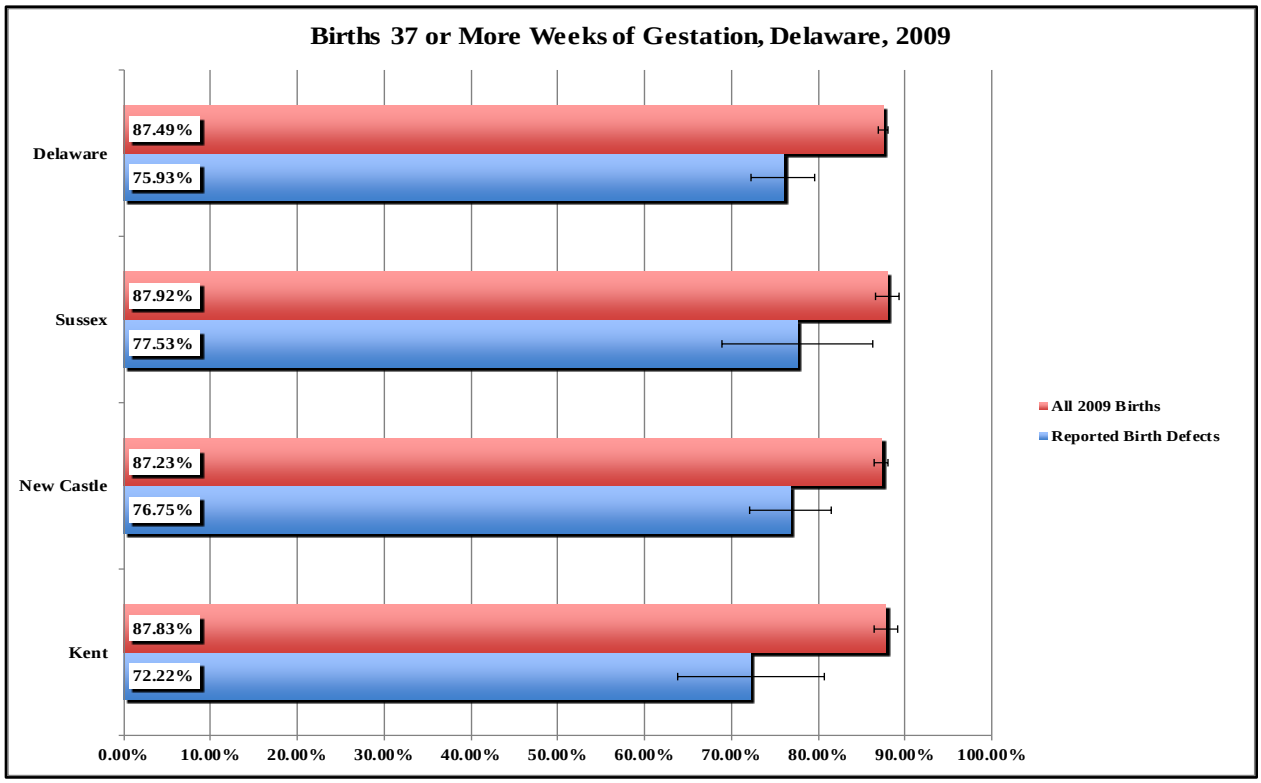



*Source: State of Delaware 2009 Birth Defects Registry*

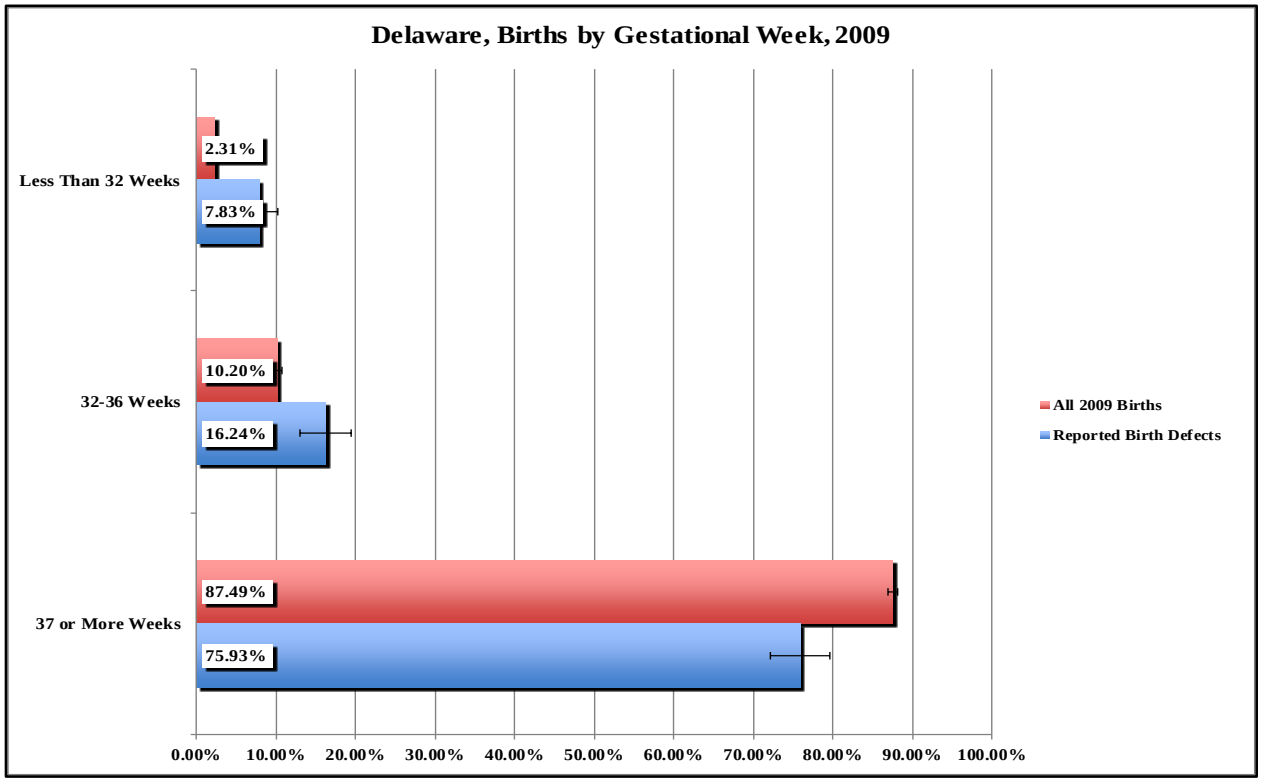



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.3. Gestational Weeks.** *Continued*

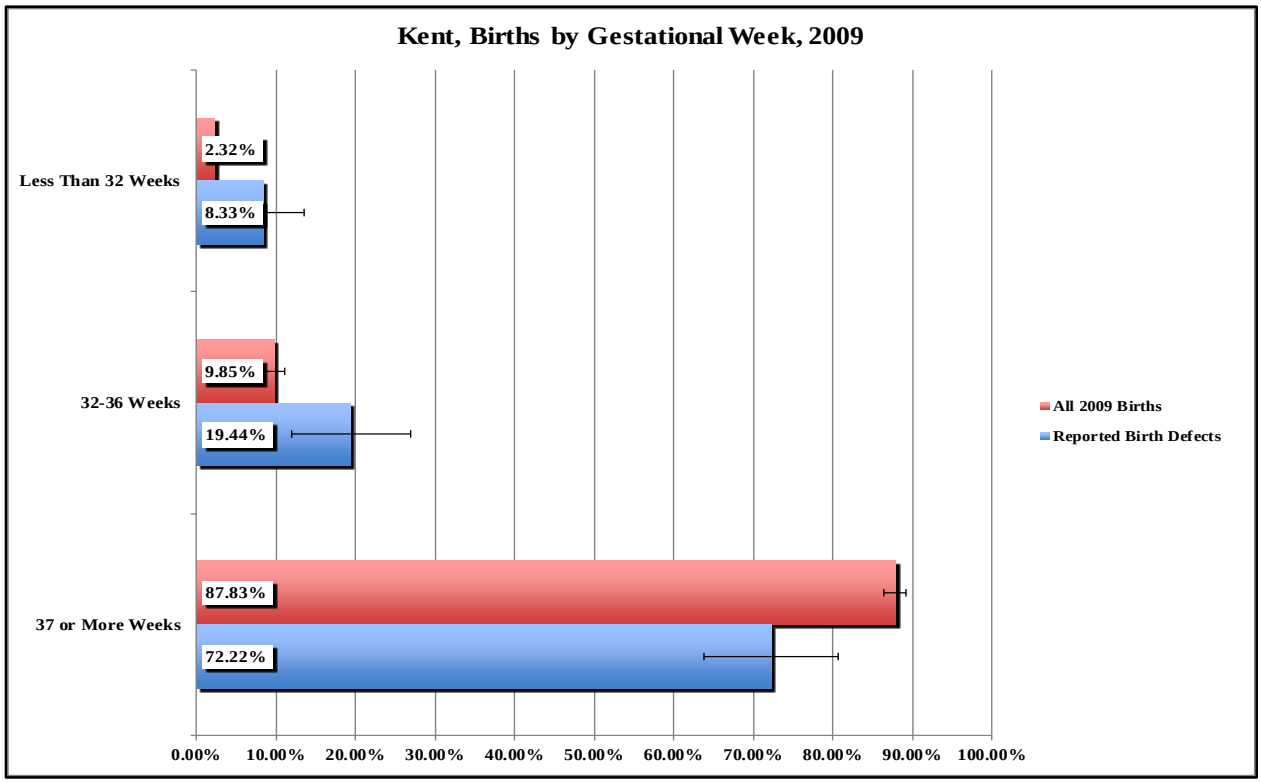



*Source: State of Delaware 2009 Birth Defects Registry*

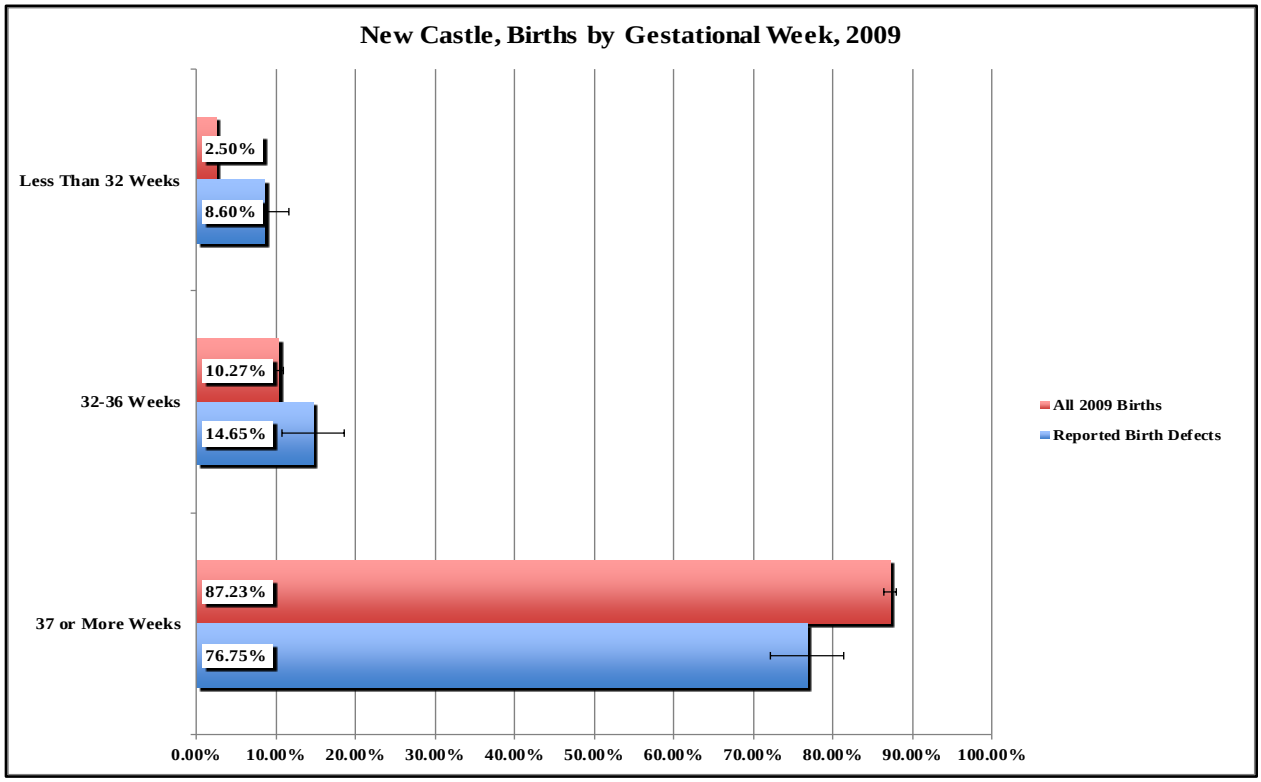



*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.3. Gestational Weeks.** *Continued*

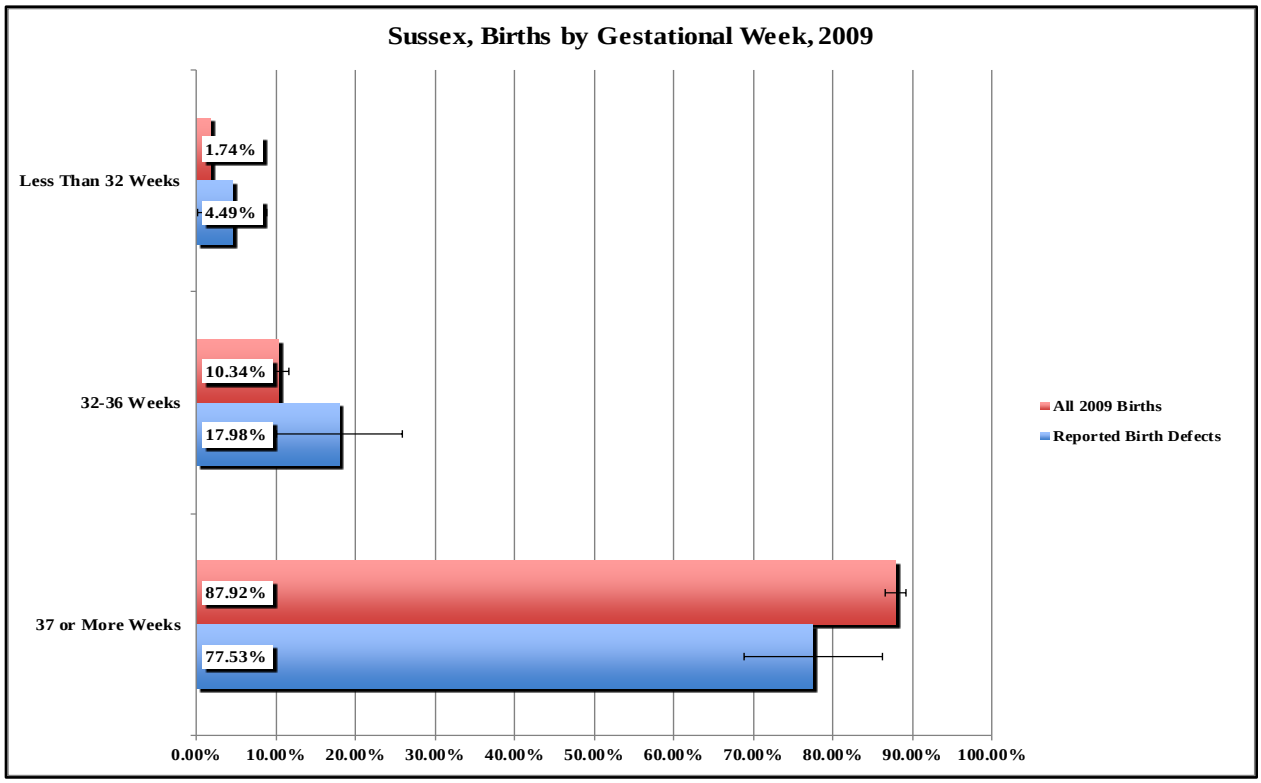



*Source: State of Delaware 2009 Birth Defects Registry*




*Source: State of Delaware 2009 Birth Defects Registry*

**APPENDIX C.3. Gestational Weeks.** *Continued*




*Source: State of Delaware 2009 Birth Defects Registry*

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