Analysis of the 2012 Birth Defects Registry

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DELAWARE HEALTH AND SOCIAL SERVICES

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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 2012 ("registered infants").
2. To compare the demographic and health attributes of these infants to all infants born to Delaware residents in 2012.

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 2012, 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 2012. Moreover, certain findings paralleled those found in other Delaware-specific maternal health assessments.

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INTRODUCTION

Birth defects, or congenital anomalies, are health conditions that are present at birth. They change the shape or function of one or more parts of the body and can cause problems in overall health, how the body develops, or how the body works.[1] Every 4½ minutes, an infant is born in the United States with a birth defect, and in 2013, birth defects accounted for about 1 in 5 infant deaths in the United States.[2] In Delaware, birth defects were the second leading cause of infant mortality in the 2008-2012 period, accounting for 15.2 percent of all infant deaths.[3] 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.[4] 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 2012 (“registered infants”).
2. To compare the demographic and health attributes of these infants to all infants born to Delaware residents in 2012. 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.

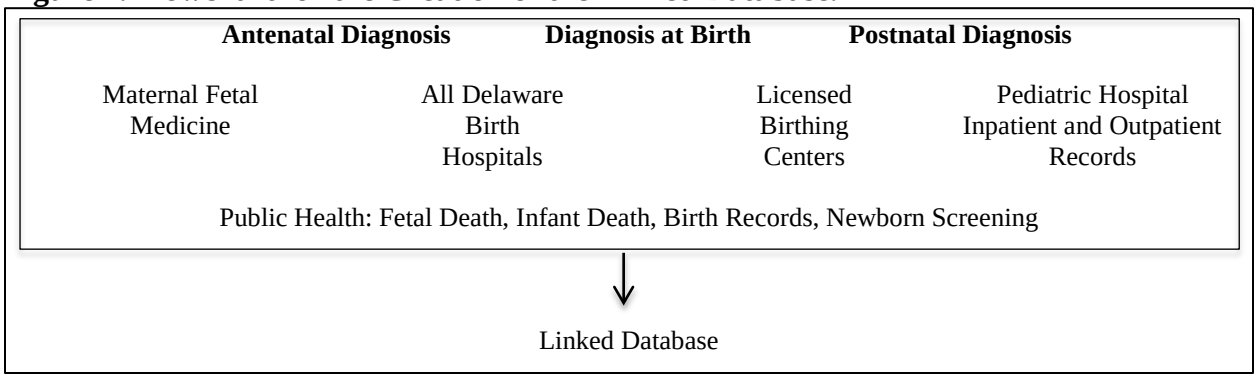
- *First Path*. The records of birth hospitals, licensed birthing centers, and midwives provided the first path for case detection. The frequency of visits to each facility was determined in part by the number of births per year in that facility. The Program Manager requested a list of all patients that 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 2012 Delaware Birth Defects Registry database to the Delaware Division of Public Health (DPH). DPH made the database available to Forward Consultants, the evaluation specialist. Forward Consultants 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 2012 Delaware Birth Defects Registry. The registry consists of 420 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 420 infants. For this reason, the counts may not add to 420 in several of the tables in this analysis.

CHARACTERISTICS OF MOTHERS IN THE REGISTRY

Mother's Residence

The residence of the registered infants' mothers is given in Table 1.

Table 1. Location of Residence of Registered Infants' Mothers.[A]

County	2012 Registry	All 2012 Events	Percentage of Events in Registry
Kent	81	2,206	3.7%
New Castle	145	5,474	2.6%
Sussex	77	2,297	3.4%
Wilmington	117	1,005	11.6%
Delaware	**420**	**10,982**	**3.8%**

Source: State of Delaware 2012 Birth Defects Registry.

Mother's Age

Table 2 provides counts of the registered infants' mothers stratified by both age and county of residence.

Table 2. Age of Registered Infants' Mothers.

County/State	19 Years And Under	20-24 Years	25-29 Years	30-34 Years	35-39 Years	40 Years And Over
Kent	5	21	22	22	8	3
New Castle (w/o Wilmington)	11	32	32	43	19	8
Sussex	6	16	21	23	9	2
Wilmington	12	26	26	35	14	4
Delaware	**34**	**95**	**101**	**123**	**50**	**17**

Source: State of Delaware 2012 Birth Defects Registry.

Mother's Education

Table 3 on the following page 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 64 of the 420 infants' mothers (15.2% of all infants).

Mother's Race and Ethnicity

Table 4 provides the counts of registered infants' mothers stratified by the mother's race and ethnicity.[B]

[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.

[B] The race and ethnicity investigation was limited to "White Non-Hispanics", "Black Non-Hispanics", and "Hispanics". These three race and ethnicity designations represented 392 out of the 420 entries (93.3% of entries).

Table 3. 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	3	3	25	12	20
New Castle (w/o Wilmington)	1	5	27	37	57
Sussex	7	8	31	8	14
Wilmington	5	15	24	21	33
Delaware	**16**	**31**	**107**	**78**	**124**

Source: State of Delaware 2012 Birth Defects Registry.

Table 4. Race and Ethnicity of Registered Infants' Mothers.

County/State	White Non-Hispanic	Black Non-Hispanic	Hispanic
Kent	57	15	4
New Castle (w/o Wilmington)	77	36	17
Sussex	52	8	15
Wilmington	57	41	13
Delaware	**243**	**100**	**49**

Source: State of Delaware 2012 Birth Defects Registry.

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 2012.[5] 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 noteworthy statistically significant differences exist between the percentage of mothers in the registry and all mothers that gave birth in Delaware in 2012 in the race and ethnicity categories.[C]

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 2012.[5] The graphs are stratified by the gravida value ("1", "2", "3", "4", "5", and "6 or More") as well as by the

[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.

location of the mother's residence. As evidenced by these graphs, no meaningful, statistically significant differences exist between the gravida of mothers in the registry and mothers that gave birth in the other counties in 2012.[C]

Previous Infant Death

Three (3) 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). Two (2) entries document 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 5, 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.

Table 5. Count of Live Children for Mothers in Registry.

County/State	None	1	2	3	4 or More
Kent	30 (37.0%)	22 (27.2%)	15 (18.5%)	9 (11.1%)	5 (6.2%)
New Castle (w/o Wilmington)	85 (58.6%)	38 (26.2%)	16 (11.0%)	4 (2.8%)	2 (1.4%)
Sussex	34 (44.2%)	21 (27.3%)	12 (15.6%)	5 (6.5%)	5 (6.5%)
Wilmington	44 (37.6%)	34 (29.1%)	25 (21.4%)	7 (6.0%)	7 (6.0%)
Delaware	**193 (46.0%)**	**115 (27.4%)**	**68 (16.2%)**	**25 (6.0%)**	**19 (4.5%)**

Source: State of Delaware 2012 Birth Defects Registry.

Vitamin Use

As shown in Table 6, the overwhelming majority of registered infants' mothers reported regular use of vitamins.

Table 6. Vitamin Use by Mothers in Registry.

Vitamin Use	Count	Percent
Yes	389	92.6%
No	6	1.4%
Not Stated	25	6.0%

Source: State of Delaware 2012 Birth Defects Registry.

Prenatal Care

As indicated by Table 7, the almost every mother received prenatal care during pregnancy; specifically, 414 infants (98.6% of infants) were to mothers that received some form of prenatal care.

Table 7. Prenatal Care during Pregnancy.

County/State	Yes	No	Not Stated
Kent	81 (100.0%)	0 (0.0%)	0 (0.0%)
New Castle (w/o Wilmington)	142 (97.9%)	3 (2.1%)	0 (0.0%)
Sussex	76 (98.7%)	1 (1.3%)	0 (0.0%)
Wilmington	115 (98.3%)	1 (0.9%)	1 (0.9%)
Delaware	**414 (98.6%)**	**5 (1.2%)**	**1 (0.2%)**

Source: State of Delaware 2012 Birth Defects Registry.

Table 8 shows that the majority of infants in the registry – 215 infants (78.2% 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 75.0% in Kent County to 90.9% in Sussex County. It is important to note, however, that these percentages do not include infants for which prenatal care initiation was unknown ("Unknown" column in Table 8). Of those infants for which prenatal care is reported for the mother, 10 infants (3.6% of infants) were to mothers that initiated prenatal care in the third trimester.

Table 8. Initiation of Prenatal Care during Pregnancy.

County/State	1st Trimester	2nd Trimester	3rd Trimester	Unknown
Kent	18 (75.0%)	3 (12.5%)	3 (12.5%)	57
New Castle (w/o Wilmington)	103 (79.2%)	23 (17.7%)	4 (3.1%)	15
Sussex	10 (90.9%)	1 (9.1%)	0 (0.0%)	66
Wilmington	84 (76.4%)	23 (20.9%)	3 (2.7%)	7
Delaware	**215 (78.2%)**	**50 (18.2%)**	**10 (3.6%)**	**145**

Source: State of Delaware 2012 Birth Defects Registry.

Maternal Illnesses, Conditions, and Complications

Table 9 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 13.8% of infants have a mother that did not have any conditions listed. These findings reveal that the clear majority of infants in the registry – 67.1% of infants – have a mother reported as having multiple conditions.

Table 9. Count of Maternal Conditions by Registry Entry.

Count of Conditions	Count of Infant Entries	Percent of Total Infant Entries
0	58	13.8%
1	79	18.9%
2	95	22.7%
3	74	17.7%
4	52	12.4%
5	27	6.4%
6	19	4.5%
7	9	2.1%
8	3	0.7%
9	1	0.2%
10	1	0.2%
11	1	0.2%

Source: State of Delaware 2012 Birth Defects Registry.

Table 10 displays the counts for each of the maternal conditions listed in the registry.

Table 10. Count of Maternal Conditions.

Condition	Count	Condition	Count
Surgery-Non Gynecologic Non Transplant	189	Diabetes Mellitus Type II	10
Surgery-Gynecologic	186	Weight Loss	10
Obesity	112	Seizure Disorder	8
Tobacco	100	Cancer	5
Alcohol	86	Hyperthyroidism	4
Depression	51	Heart Disease	3
Illicit Drugs	47	Hepatitis C	3
Placenta Previa	37	Other Psychiatric Disorders	3
Toxemia/Preeclampsia	37	Abdominal Trauma	2
Hypertension (PIH)	33	Diabetes Mellitus Type I	2
Diabetes Gestational	32	Cytomegalovirus (CMV)	1
Chronic Hypertension	29	Hemorrhage-Uterine	1
Genital Herpes	25	Hepatitis B	1
Hypothyroidism	23	Inflammatory Bowel Disease	1
Bi-Polar Disorder	12	Lupus	1
Coagulopathy	10	Thyroid Disease	1

Source: State of Delaware 2012 Birth Defects Registry.

Tables 11-12 and Tables 14-18 provide the count of infant entries that correspond to a set of the most common conditions listed in Table 10. 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 4 displays these denominator values. For example, in Table 12, seven (7) 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 7 infant entries represent 12.3% 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 11 outlines the count of infants who have a mother that used some form of alcohol.

Table 11. Alcohol Use among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	6 (10.5%)	2 (13.3%)	0 (0.0%)
New Castle (w/o Wilmington)	25 (32.5%)	17 (47.2%)	3 (17.6%)
Sussex	5 (9.6%)	0 (0.0%)	0 (0.0%)
Wilmington	17 (29.8%)	9 (22.0%)	0 (0.0%)
Delaware	**53 (21.8%)**	**28 (28.0%)**	**3 (6.1%)**

Source: State of Delaware 2012 Birth Defects Registry.

Table 12 on the following page 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.

Note that 39 infants (9.3% of infants) in the registry have a mother that was documented as having used *both* alcohol and tobacco. Also, 147 infants (35.0% of infants) have a mother documented as having used *either* alcohol or tobacco.

Table 12. Tobacco Use among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	7 (12.3%)	2 (13.3%)	0 (0.0%)
New Castle (w/o Wilmington)	21 (27.3%)	5 (13.9%)	3 (17.6%)
Sussex	19 (36.5%)	2 (25.0%)	0 (0.0%)
Wilmington	21 (36.8%)	13 (31.7%)	2 (15.4%)
Delaware	**68 (28.0%)**	**22 (22.0%)**	**5 (10.2%)**

Source: State of Delaware 2012 Birth Defects Registry.

Table 13 delineates alcohol use by whether the registered infant's mother used alcohol *only before* pregnancy ("Only Before") and *before and during* pregnancy ("Before/During"). Table 14 segments tobacco use by whether the registered infant's mother used tobacco *only before* pregnancy ("Only Before") and *before and during* pregnancy ("Before/During"). No mothers stated that they used either substance *only during* pregnancy. The percentages in Tables 13 and 14 were calculated by taking the neighboring count and dividing it by the total number of women in the respective county; Table 1 provides the total number of women in each county. For example, in Table 13, seven (7) registered infants' mothers that resided in Kent County used alcohol only before pregnancy. This represents 8.6% of all registered infants' mothers that resided in Kent County. Finally, the counts in both tables include all race and ethnicity groups.

Table 13. Alcohol Use during Pregnancy among Mothers in the Registry.

County/State[D]	Only Before	Before/During
Kent	7 (8.6%)	2 (2.5%)
New Castle (w/o Wilmington)	39 (26.9%)	7 (4.8%)
Sussex	4 (5.2%)	1 (1.3%)
Wilmington	23 (19.7%)	3 (2.6%)
Delaware	**73 (17.4%)**	**13 (3.1%)**

Source: State of Delaware 2012 Birth Defects Registry.

Table 14. Tobacco Use during Pregnancy among Mothers in the Registry.

County/State[D]	Only Before	Before/During
Kent	1 (1.2%)	10 (12.3%)
New Castle (w/o Wilmington)	12 (8.3%)	18 (12.4%)
Sussex	2 (2.6%)	19 (24.7%)
Wilmington	13 (11.1%)	25 (21.4%)
Delaware	**28 (6.7%)**	**72 (17.1%)**

Source: State of Delaware 2012 Birth Defects Registry.

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

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. 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.[6,7]

Table 15. Obesity among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	17 (29.8%)	4 (26.7%)	0 (0.0%)
New Castle (w/o Wilmington)	26 (33.8%)	10 (27.8%)	5 (29.4%)
Sussex	14 (26.9%)	3 (37.5%)	3 (20.0%)
Wilmington	12 (21.1%)	13 (31.7%)	3 (23.1%)
Delaware	**69 (28.4%)**	**30 (30.0%)**	**11 (22.4%)**

Source: State of Delaware 2012 Birth Defects Registry.

Table 16 lists the counts and percentages of registered infants' mothers with pregnancy-induced hypertension (PIH).

Table 16. Hypertension (PIH) among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	3 (5.3%)	2 (13.3%)	0 (0.0%)
New Castle (w/o Wilmington)	6 (7.8%)	6 (16.7%)	0 (0.0%)
Sussex	2 (3.8%)	1 (12.5%)	0 (0.0%)
Wilmington	5 (8.8%)	7 (17.1%)	1 (7.7%)
Delaware	**16 (6.6%)**	**16 (16.0%)**	**1 (2.0%)**

Source: State of Delaware 2012 Birth Defects Registry.

Table 17 on the following page lists the counts and percentages of registered infants' mothers documented as having depression.

Table 17. Depression among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	5 (8.8%)	0 (0.0%)	0 (0.0%)
New Castle (w/o Wilmington)	10 (13.0%)	4 (11.1%)	1 (5.9%)
Sussex	4 (7.7%)	0 (0.0%)	0 (0.0%)
Wilmington	17 (29.8%)	5 (12.2%)	3 (23.1%)
Delaware	**36 (14.8%)**	**9 (9.0%)**	**4 (8.2%)**

Source: State of Delaware 2012 Birth Defects Registry.

Finally, Table 18 supplies the counts and percentages of registered infants' mothers reported as having gestational diabetes.

Table 18. Gestational Diabetes among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	6 (10.5%)	0 (0.0%)	0 (0.0%)
New Castle (w/o Wilmington)	3 (3.9%)	3 (8.3%)	1 (5.9%)
Sussex	2 (3.8%)	1 (12.5%)	1 (6.7%)
Wilmington	4 (7.0%)	2 (4.9%)	5 (38.5%)
Delaware	**15 (6.2%)**	**6 (6.0%)**	**7 (14.3%)**

Source: State of Delaware 2012 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 10.

Table 19. Multiple Conditions of Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	33 (57.9%)	6 (40.0%)	0 (0.0%)
New Castle (w/o Wilmington)	61 (79.2%)	29 (80.6%)	9 (52.9%)
Sussex	33 (63.5%)	6 (75.0%)	7 (46.7%)
Wilmington	48 (84.2%)	28 (68.3%)	8 (61.5%)
Delaware	**175 (72.0%)**	**69 (69.0%)**	**24 (49.0%)**

Source: State of Delaware 2012 Birth Defects Registry.

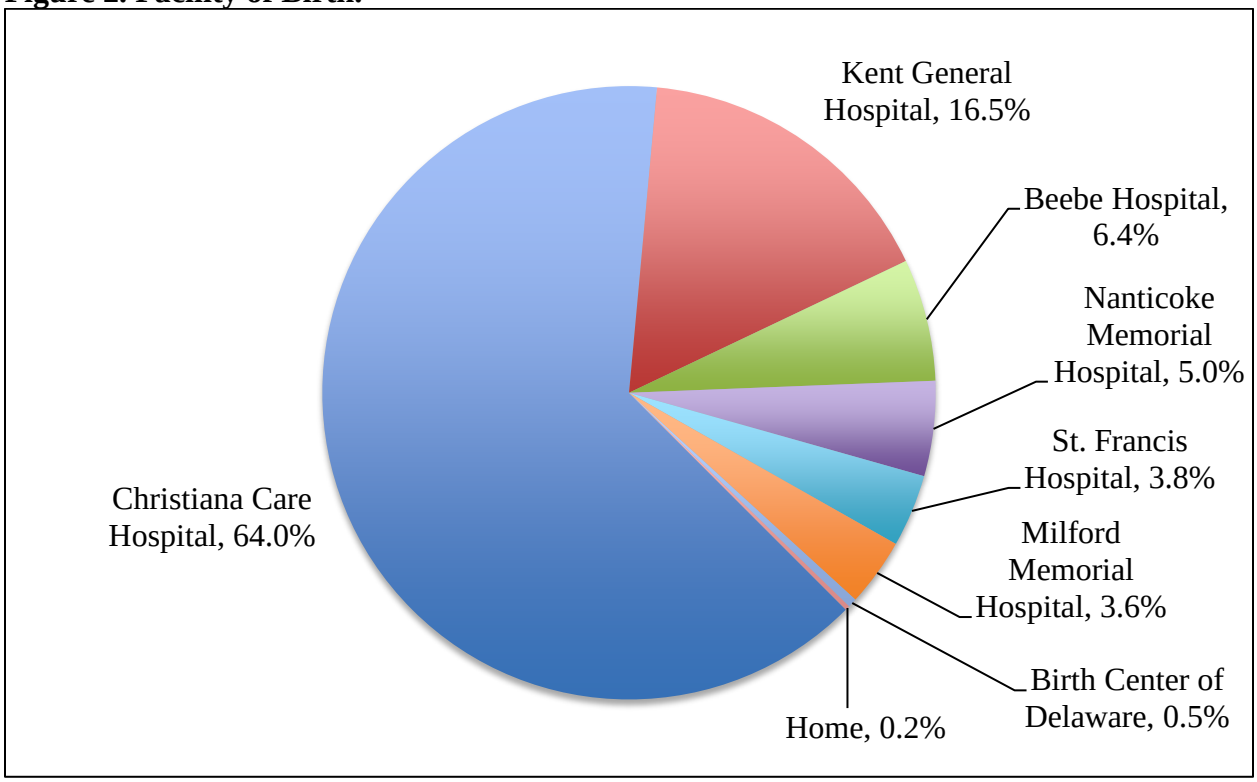
The results from Table 19 are not surprising given that these registered infants' mothers may have interrelated co-morbidities such as obesity, pregnancy-induced hypertension, and gestational diabetes. In addition, some of the counts and percentages may be due to the high count of registered infants'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

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 2012 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 2012.[5] 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 all geographies, 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 2012. Moreover, for all counties, the percentage of infants born at or above 37 weeks was consistently lower among infants in the registry as compared to infants born in 2012. These findings align with research that suggests an association exists between preterm birth and birth defects.[8,9]

Pregnancy Outcome

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

Table 20. Pregnancy Outcome for Registry Entries.

County	Live Birth		Fetal or Infant Death	
	Count	Percentage	Count	Percentage
Kent	79	97.5%	2	2.5%
New Castle (w/o Wilmington)	131	90.3%	14	9.7%
Sussex	73	94.8%	4	5.2%
Wilmington	112	95.7%	5	4.3%
Delaware	**395**	**94.0%**	**25**	**6.0%**

Source: State of Delaware 2012 Birth Defects Registry.

Plurality

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

Table 21. Plurality for Infants in the Registry.

Plurality	Count	Percentage
Singleton	404	96.2%
Twin	16	3.8%

Source: State of Delaware 2012 Birth Defects Registry.

Of the 16 infants that are part of a set of twins, 10 were the first-born twin and 6 were the second-born twin.

Gender

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

Table 22. Gender of Infants in the Registry.

County	Female	Male
Kent	42 (51.9%)	39 (48.1%)
New Castle (w/o Wilmington)	68 (46.9%)	77 (53.1%)
Sussex	37 (48.1%)	40 (51.9%)
Wilmington	50 (42.7%)	67 (57.3%)
Delaware	**197 (46.9%)**	**223 (53.1%)**

Source: State of Delaware 2012 Birth Defects Registry.

Growth Percentiles

The WHO Child Growth Standards[10] 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 above the 75th 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	10 (12.3%)	14 (17.3%)	57 (70.4%)
New Castle w/o Wilmington	25 (17.2%)	30 (20.7%)	90 (62.1%)
Sussex	11 (14.3%)	16 (20.8%)	50 (64.9%)
Wilmington	20 (17.1%)	24 (20.5%)	73 (62.4%)
Delaware	**66 (15.7%)**	**84 (20.0%)**	**270 (64.3%)**

Source: State of Delaware 2012 Birth Defects Registry

Length (Stature) Percentiles

Of the 420 infants in the registry, 411 (97.9%) had a head circumference reported. As shown in Table 24, the counties generally 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	15 (18.8%)	28 (35.0%)	37 (46.3%)
New Castle w/o Wilmington	39 (27.9%)	52 (37.1%)	49 (35.0%)
Sussex	19 (25.7%)	25 (33.8%)	30 (40.5%)
Wilmington	37 (31.6%)	42 (35.9%)	38 (32.5%)
Delaware	**110 (26.8%)**	**147 (35.8%)**	**154 (37.5%)**

Source: State of Delaware 2012 Birth Defects Registry

Head Circumference Percentiles

Note that of the 420 infants in the registry, 355 (84.5%) had a head circumference reported. As evidenced by Table 25, a relatively large percentage of the infants in the birth defects registry are at or below the 25th percentile for head circumference at the time of birth.

Table 25. Head Circumference at Time of Birth.

County/State	25th and Below	Between 25th – 75th	75th and Over
Kent	24 (31.2%)	40 (51.9%)	13 (16.9%)
New Castle w/o Wilmington	37 (32.5%)	55 (48.2%)	22 (19.3%)
Sussex	26 (36.1%)	25 (34.7%)	21 (29.2%)
Wilmington	38 (41.3%)	38 (41.3%)	16 (17.4%)
Delaware	**125 (35.2%)**	**158 (44.5%)**	**72 (20.3%)**

Source: State of Delaware 2012 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, 403 infants (96.2% of infants) had only a "confirmed" diagnosis of a birth defect while 7 infants (1.7% of infants) had only a "possible/probable" diagnosis of a birth defect. Finally, 10 infants (2.4% 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.

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	320	76.2%
2	58	13.8%
3	19	4.5%
4	7	1.7%
5	9	2.1%
6	3	0.7%
7	1	0.2%
8	3	0.7%
Total	**420**	**100.0%**

Source: State of Delaware 2012 Birth Defects Registry

Table 26 shows that almost one-quarter (23.8%) of the infants had more than one diagnosed birth defect.

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	84
753	Congenital anomalies of urinary system	81
746	Other congenital abnormalities of the heart	79
754	Certain congenital musculoskeletal deformities	50
758	Chromosomal anomalies	45
747	Other congenital anomalies of circulatory system	37
755	Other congenital anomalies of limbs	37
751	Other congenital anomalies of digestive system	35
742	Other congenital anomalies of nervous system	23
756	Other congenital musculoskeletal anomalies	20
760	Fetus or newborn affected by maternal conditions which may be unrelated to present pregnancy	16
749	Cleft palate	13
744	Congenital anomalies of ear face and neck	12
283	Acquired hemolytic anemias	11
757	Congenital anomalies of the integument	11
759	Other and unspecified congenital anomalies	10
743	Congenital anomalies of eye	9
Other	–	42
Total		**615**

Source: State of Delaware 2012 Birth Defects Registry

A substantial number of codes are associated with congenital anomalies of the circulatory system (ICD-9 745, 746, and 747; 200 diagnoses or 32.5% of all diagnoses).

Table 28 outlines the methods by which the birth defect was diagnosed. Slightly more than half (52.3%) of the reported birth defects were definitively diagnosed by either echocardiogram or clinical (physical exam).

Table 28. Method of Diagnosis for Birth Defect.

Method of Diagnosis	Count of Diagnoses by Method	Percent of All Diagnoses
Echocardiogram	186	30.2%
Clinical	136	22.1%
Ultrasound	109	17.7%
Genetics	70	11.4%
X-ray	30	4.9%
Laboratory	22	3.6%
Surgical Observation	22	3.6%
Ophthalmologic Exam	11	1.8%
Audiogram	10	1.6%
MRI	9	1.5%
Autopsy	7	1.1%
CT Scan	3	0.5%
Total	**615**	**100.0%**

Source: State of Delaware 2012 Birth Defects Registry

Of the 615 birth defect diagnoses, 159 (25.8%) were confirmed at a prenatal visit while the remaining 456 (74.1%) 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
61 (14.5%)	319 (76.0%)	40 (9.5%)

Source: State of Delaware 2012 Birth Defects Registry

This table indicates that 14.5% 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 (76.0%) 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, 92 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	328
1 Family Member	57
2 Family Members	22
3 Family Members	5
4 Family Members	5
5 Family Member	2
9 Family Members	1
Total	**420**

Source: State of Delaware 2012 Birth Defects Registry

Table 31 provides the specific relation between the infant in the registry and the family member documented as having the birth defect. 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
Sibling (Gender Not Stated)	50
Birth Mother	28
Father	18
Aunt (Maternal/Paternal Not Stated)	16
Uncle (Maternal/Paternal Not Stated)	14
Cousin (Gender Not Stated, Maternal/Paternal Not Stated)	12
Grandmother (Maternal/Paternal Not Stated)	11
Grandfather (Maternal/Paternal Not Stated)	6
Total Family Members Reported with Birth Defect	**155**

Source: State of Delaware 2012 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
Circulatory Anomalies	31
Chromosomal Anomalies	21
Musculoskeletal Anomalies	18
Digestive Anomalies	14
Eye, Ear, Face, and Neck Anomalies	14
Nervous System Anomalies	12
Anemia	4
Urinary Anomalies	4
Other	37
Total Family Members Reported with Birth Defect	**155**

Source: State of Delaware 2012 Birth Defects Registry

Based on Table 31 and Table 32, 155 birth defects, at the most, could be analogous between infants in the registry and reported family members.

Table 33 indicates that 61 birth defects (39.4% of the 155 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
Circulatory Anomalies	24
Eye, Ear, Face, and Neck Anomalies	10
Musculoskeletal Anomalies	8
Chromosomal Anomalies	6
Anemia	5
Digestive Anomalies	4
Urinary Anomalies	2
Other	2
Total	**61**

Source: State of Delaware 2012 Birth Defects Registry

Of these 61 birth defects, six were diagnosed in a prenatal care setting and 55 were reported during a postnatal visit. The six birth defects that were reported during a prenatal visit comprised of five diagnoses related to circulatory anomalies and one diagnosis related chromosomal anomalies.

Infant Deaths in the Registry

In the registry, 25 entries (6.0% of entries) show documentation that a fetal or infant death occurred. Of these 25 entries, 10 were fetal deaths (stillbirth and termination of pregnancy) and 15 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 5 of these 25 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 25 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	2
New Castle (w/o Wilmington)	14
Sussex	4
Wilmington	5
Delaware	**25**

Source: State of Delaware 2012 Birth Defects Registry

Among the 15 infant deaths, 5 were female and 10 were male. Moreover, 15 were within one month of birth (neonatal death) with 5 neonatal deaths occurring on the day of birth. The remaining 5 deaths took place between one month after birth and one year after birth (postneonatal death). Seven (7) out of the 15 infants were born at term (greater than or equal to 37 gestational weeks) and 8 were born preterm (at less than or equal to 36 gestational weeks).

Table 35 provides the growth percentile measures for the 15 infant deaths in the registry. The "Total Infant Deaths" column provides the number out of the 15 infant deaths for which there exists data on the growth percentile measure. As evidenced by this table, 3 out of 5 of the expired infants were at or below the 25th percentile for weight at the time of birth. Moreover, the majority of expired infants were at or below the 25th percentile for length (63.6%) at the time of birth. Half of the expired infants were at or below the 25th percentile for head circumference at the time of birth. Finally, 4 of the 15 infants were below the 25th percentile on all three growth percentile measures.

Table 35. Growth Percentile Measures for the Infant Deaths in the Registry.

Growth Percentile Measure	Number Below 25th	Total Infant Deaths	Percentage
Weight	9	15	60.0%
Length (Stature)	7	11	63.6%
Head Circumference	4	8	50.0%

Source: State of Delaware 2012 Birth Defects Registry

Reported Birth Defects of the Infant Deaths in the Registry

Unlike Table 26 where 76.2% of infants in the registry had documentation of one birth defect, Table 36 indicates that only one-fifth of the 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	3	20.0%
2	1	6.7%
4	2	13.3%
5	5	33.3%
6	2	13.3%
7	1	6.7%
8	1	6.7%
Total	**15**	**100.0%**

Source: State of Delaware 2012 Birth Defects Registry

Table 37 on the following page lists all of the ICD-9 codes provided in the registry for the 15 infant deaths.

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	13
746	Other congenital abnormalities of the heart	12
747	Other congenital anomalies of circulatory system	8
758	Chromosomal anomalies	7
742	Other congenital anomalies of nervous system	5
755	Other congenital anomalies of limbs	4
756	Other congenital musculoskeletal anomalies	4
Other	–	12
Total		**65**

Source: State of Delaware 2012 Birth Defects Registry

Family Member with Birth Defect among Infant Deaths in the Registry

The registry documents two of the 15 infants as having a family member with a birth defect. Of the two infants, one infant had nine family relations with a birth defect and the other infant had two family members with a birth defect. This results in 11 [(9•1) + (1•2)] possible linkages in similar birth defects between the expired infants and respective family members. Of these 11 familial relations, 9 were with the infant's sibling, one was with the infant's father, and one was with the infant's uncle. All of these relations shared a similar birth defect: each of the expired infants and their respective family relations had birth defects related to the circulatory system.

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 15 registry entries documented as infant deaths. As shown in this table, only 6.7% of the mothers with an infant death had no reported conditions and 73.3% 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	1	6.7%
1	3	20.0%
2	5	33.3%
3	3	20.0%
4	2	13.3%
7	1	6.7%
Total	**15**	**100.0%**

Source: State of Delaware 2012 Birth Defects Registry

Table 39 provides counts for all of the maternal conditions listed for the 15 infant deaths in the registry.

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

Condition	Count	Condition	Count
Surgery-Gynecologic	10	Diabetes Gestational	2
Obesity	6	Hypothyroidism	2
Surgery-Non Gynecologic Non Transplant	6	Diabetes Mellitus Type II	1
Alcohol	3	Placenta Previa	1
Chronic Hypertension	2	Tobacco	1
Depression	2	Toxemia/Preeclampsia	1

Source: State of Delaware 2012 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 2012. 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 13, a smaller percentage of mothers consumed alcohol during pregnancy as opposed to before pregnancy.

However, Table 14 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.[6,7] Table 40 provides a cursory comparison of the birth defects registry results and the most applicable

Delaware's 2012 Pregnancy Risk Assessment Monitoring System (PRAMS) results for the remaining selected maternal conditions.

Table 40 provides a cursory comparison of the birth defects registry results and the most applicable Delaware's 2012 Pregnancy Risk Assessment Monitoring System (PRAMS) results for the remaining selected maternal conditions.

Table 40. Comparison of 2012 Birth Defects Registry with 2012 PRAMS by Maternal Condition.

Maternal Condition	2012 Birth Defects Registry	2012 PRAMS
Pregnancy-Induced Hypertension	7.9%	14.5%[F]
Depression	12.1%	7.4%[G]
Gestational Diabetes	7.6%	10.1%[H]

Source: State of Delaware 2012 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, it is likely that a higher proportion of infants in the registry – as compared to all infants – were typically at or below the 25th percentile for birth weight, body length, or head circumference.

Furthermore, as indicated in Table 26, approximately three out of four registered infants had documentation of one birth defect with the remaining one out of four having multiple birth defects reported. The registry lists 92 infants as having at least one or more family members with a birth defect, bringing the total count of familial connections to 155. Finally, the registry documented 10 fetal deaths and 15 infant deaths, and in comparison to all infants in the registry, a lower proportion of these 15 infant deaths (3 out of 15) 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, this report may afford some cursory insights about what factors could be modified to reduce the incidence of birth defects in Delaware.

[F] In PRAMS, this is item 35E: "During your most recent pregnancy, did you have a problem with high blood pressure, hypertension (including pregnancy-induced hypertension [PIH]), preeclampsia, or toxemia?"
[G] In PRAMS, this is item 64: "Since your new baby was born, have you often or always felt down, depressed, or sad?"
[H] In PRAMS, this is item 34: "During your most recent pregnancy, were you told by a doctor, nurse, or other health care worker that you had gestational diabetes?"

APPENDIX A. Birth Defects Registry Reportable Diagnoses.

ICD-9 Code	Diagnosis
090.2	Congenital syphilis
090.9	Congenital syphilis
237.70	Neurofibromatosis
243.00	Congenital hypothyroidism
270.10	Phenylketonuria
270.7	Glutaric Aciduria, Type I
271.1	Galactosemia
277.00	Cystic Fibrosis
277.6	Biotinidase deficiency
277.85	Disorders of fatty acid oxidation
282.4	Other hemoglobinopathies
282.60	Sickle cell disease
317.0	Developmental delay
318.0	Developmental delay
318.2	Developmental delay
389.15	Sensorineural hearing loss
389.18	Sensorineural hearing loss
740.0	Anencephalus
741.0	Spina bifida
741.9	Spina bifida
742.0	Encephalocele
742.1	Microcephalus
742.2	Agenesis of corpus callosum
742.2	Holoprosencephaly
742.2	Lissencephaly
742.2	Septo-optic dysplasia
742.3	Hydrocephalus
742.4	Other congenital anomalies of nervous system
742.4	Porencephaly
742.59	Tethered cord
743.1	Microphthalmia
743.20	Glaucoma
743.30	Congenital cataract
743.31	Congenital cataract
743.34	Congenital cataract
743.46	Coloboma
744.23	Microtia
745.10	Transposition of great arteries
745.11	Double outlet right ventricle
745.2	Tetralogy of Fallot
745.3	Single ventricle
745.4	Ventricular septal defect
745.5	Atrial septal defect

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

ICD-9 Code	Diagnosis
745.61	Endocardial cushion defect
745.69	Endocardial cushion defect
746.01	Dysplastic pulmonary valve
746.01	Pulmonary valve atresia
746.02	Pulmonary valve stenosis
746.1	Tricuspid valve dysplasia
746.1	Tricuspid valve dysplasia
746.3	Aortic valve stenosis
746.4	Bicuspid aortic valve
746.5	Mitral stenosis
746.6	Mitral atresia
746.7	Hypoplastic left heart syndrome
746.89	Other specified congenital anomalies of heart
747.0	Patent ductus arteriosus
747.10	Coarctation of aorta
747.4	Anomalus pulmonary venous return
747.49	Other anomalies of the great veins
748.0	Choanal atresia
748.4	Congenital cystic adenomatoid malformation
748.5	Lung hypoplasia
749.00	Cleft palate without cleft lip
749.02	Cleft palate without cleft lip
749.1	Cleft lip without cleft palate
749.2	Cleft lip with cleft palate
749.23	Cleft lip with cleft palate
750.3	Tracheoesophageal fistula
750.3	Tracheoesophageal fistula with esophageal atresia
750.5	Pyloric stenosis
751.10	Atresia of intestine
751.2	Anorectal malformation
751.2	Atresia of intestine
751.4	Malrotation of intestine
751.61	Biliary atresia
752.61	Hypospadias
753.0	Renal agenesis
753.15	Cystic/dysplastic kidneys
753.2	Obstructive genitourinary defect
753.3	Horseshoe kidney
753.6	Obstructive genitourinary defect
754.2	Scoliosis
754.30	Developmental hip dysplasia
754.31	Developmental hip dysplasia

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

ICD-9 Code	Diagnosis
754.51	Club foot
754.60	Club foot
754.70	Club foot
754.88	Other specified anomalies of hands
754.89	Arthrogryposis multiplex congenital
755.21	Reduction defect, upper limbs
755.26	Reduction defect, upper limbs
755.27	Reduction defect, upper limbs
755.28	Reduction defect, upper limbs
755.30	Reduction defect, lower limbs
755.39	Reduction defect, lower limbs
755.4	Adactyly
756.0	Craniosynostosis
756.0	Macrocephaly
756.0	Multiple congenital anomaly syndrome
756.1	Vertebrae anomalies
756.3	Other anomalies of rib and sternum
756.4	Achondroplasia
756.51	Osteogenesis imperfecta
756.6	Diaphragmatic hernia
756.7	Gastroschisis
756.9	Other skeletal dysplasia
758.0	Trisomy 21
758.1	Trisomy 13
758.2	Trisomy 18
758.30	Autosomal deletion syndromes
758.50	Other conditions due to autosomal anomalies
758.60	Gonadal dysgenesis
758.80	Other conditions due to sex chromosome anomalies
759.89	Other specified anomalies
762.8	Amniotic band disruption complex
771.1	Congenital cytomegalovirus

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

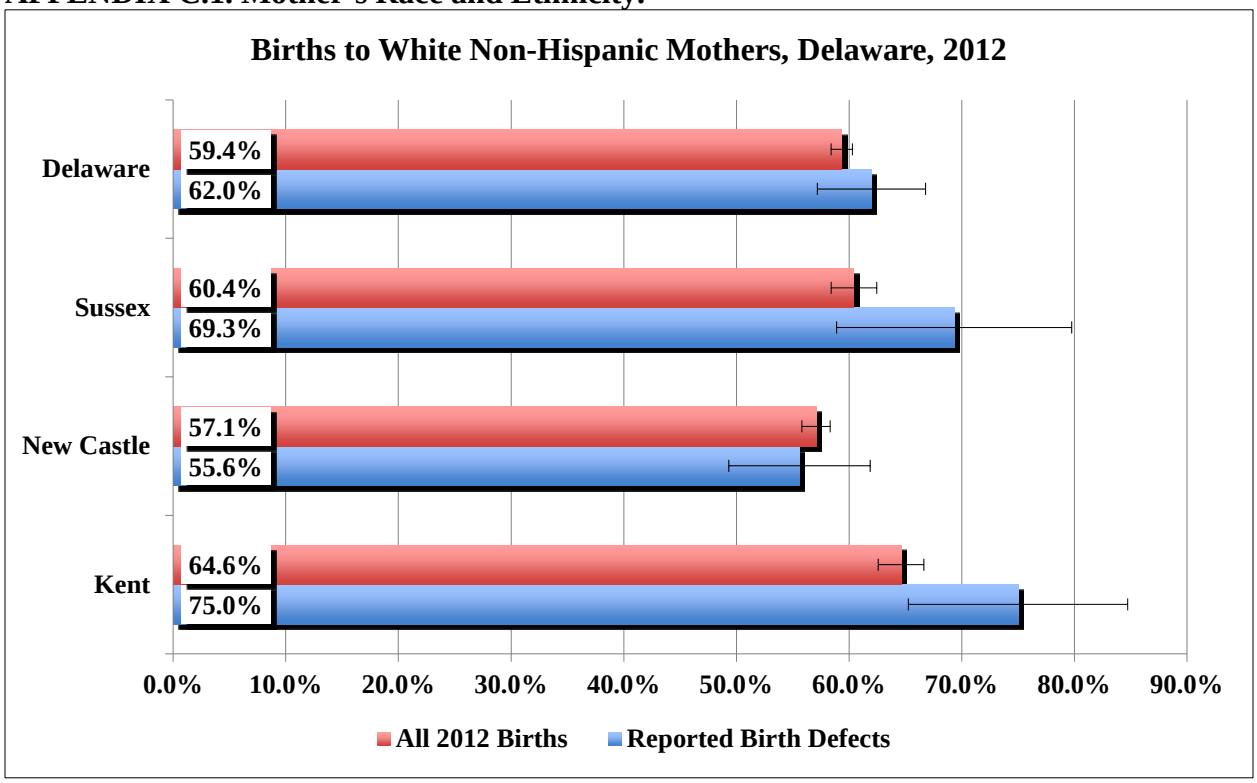
APPENDIX B. Birth Defects Registry Fields. *Continued*

Field	Description
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
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)

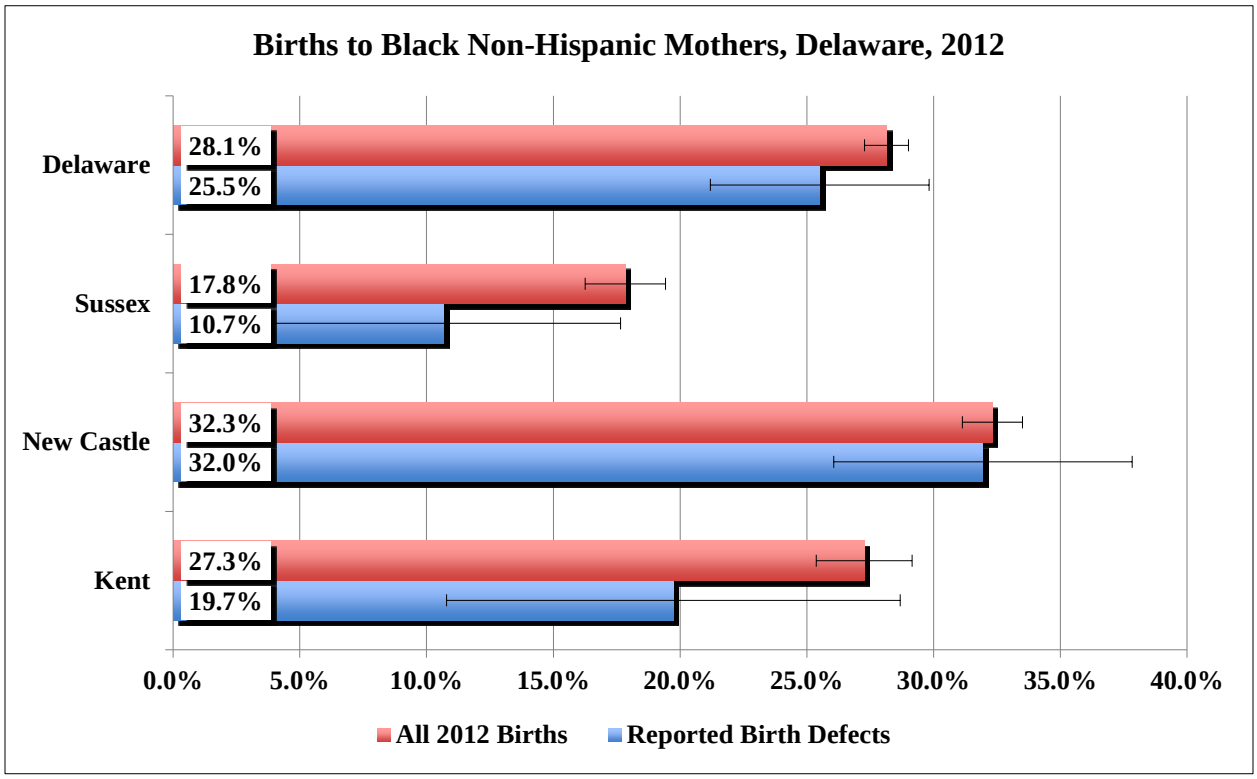
APPENDIX B. Birth Defects Registry Fields. *Continued*

Field	Description
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
FAM_MEM.1, FAM_MEM.2, FAM_MEM.3, FAM_MEM.4, FAM_MEM.5, FAM_MEM.6, FAM_MEM.7, FAM_MEM.8	Family Member with Birth Defect
FAM_MEM_BD.1, FAM_MEM_BD.2, FAM_MEM_BD.3, FAM_MEM_BD.4, FAM_MEM_BD.5, FAM_MEM_BD.6, FAM_MEM_BD.7, FAM_MEM_BD.8	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, MALF_C.9	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, MALF_DXM.9	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, MALF_DATE.9	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, MALF_WHEN.9	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, MALF_CON.9	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, MALF_CD.9	ICD-9 Code for Birth Defect

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

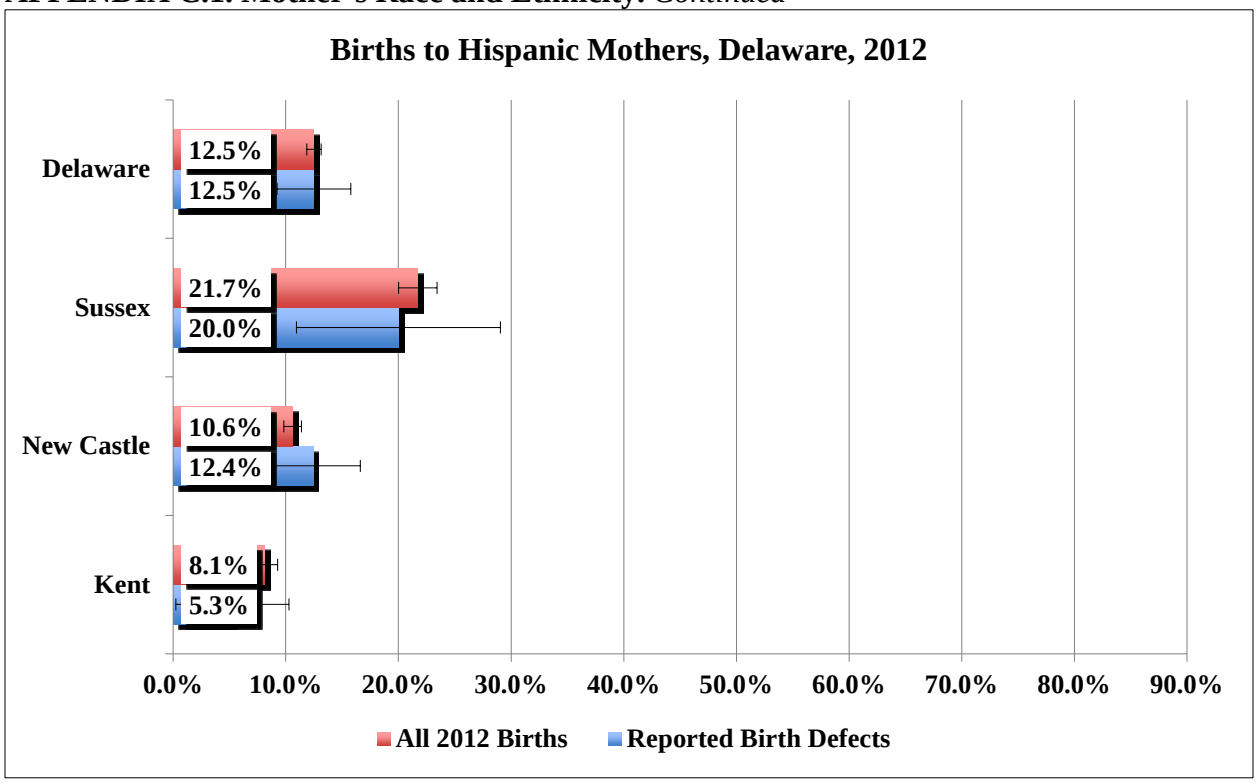


Source: State of Delaware 2012 Birth Defects Registry

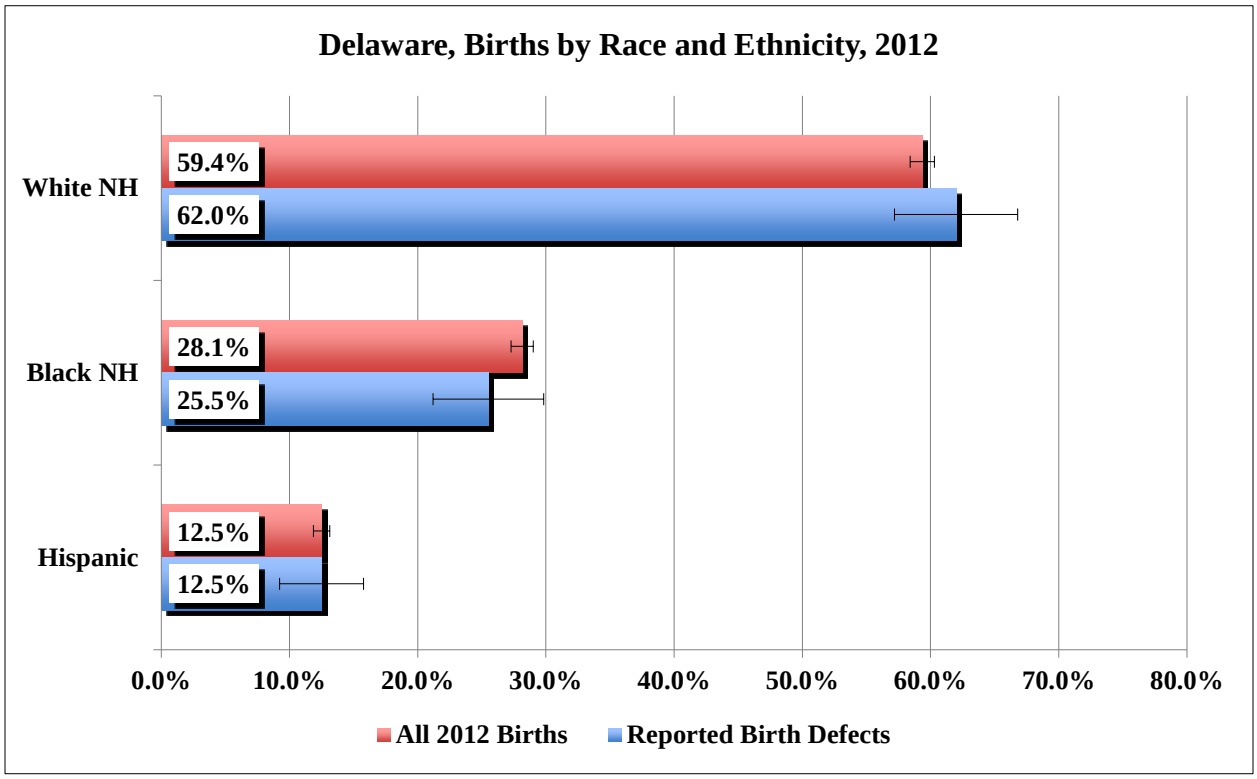


Source: State of Delaware 2012 Birth Defects Registry

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

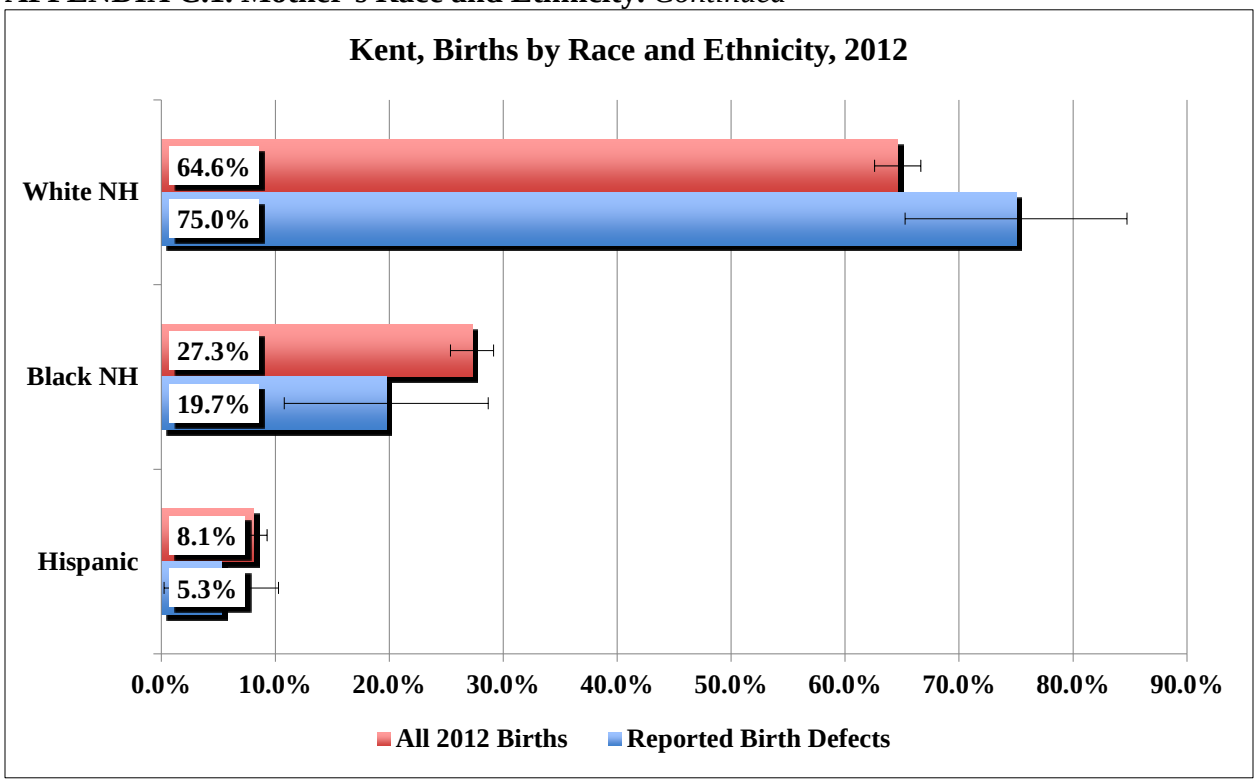


Source: State of Delaware 2012 Birth Defects Registry

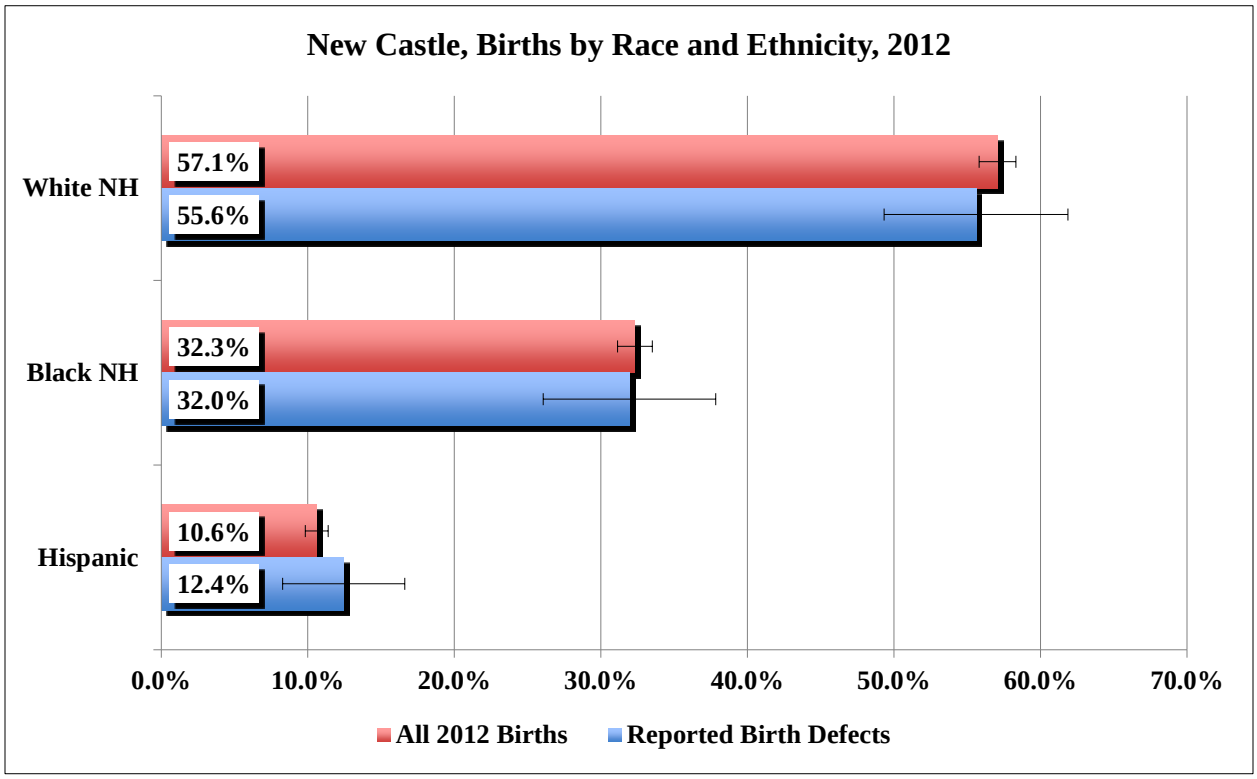


Source: State of Delaware 2012 Birth Defects Registry

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

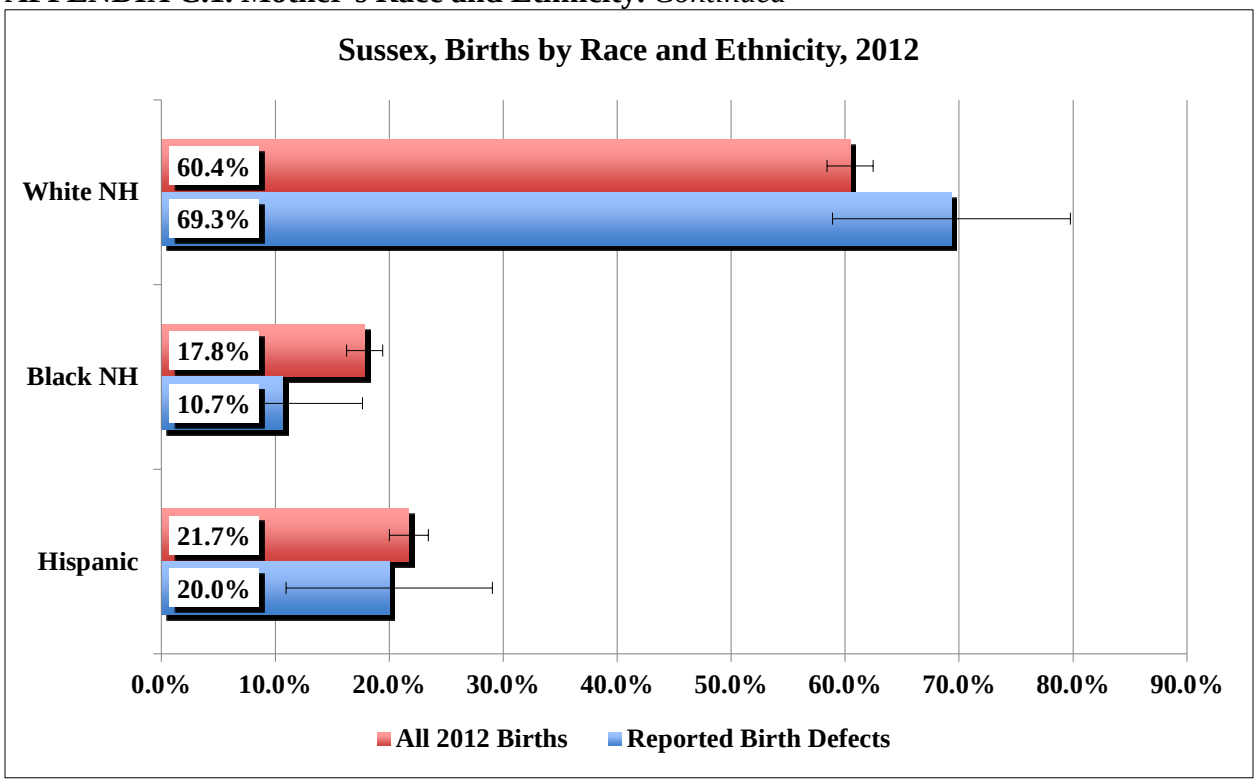


Source: State of Delaware 2012 Birth Defects Registry



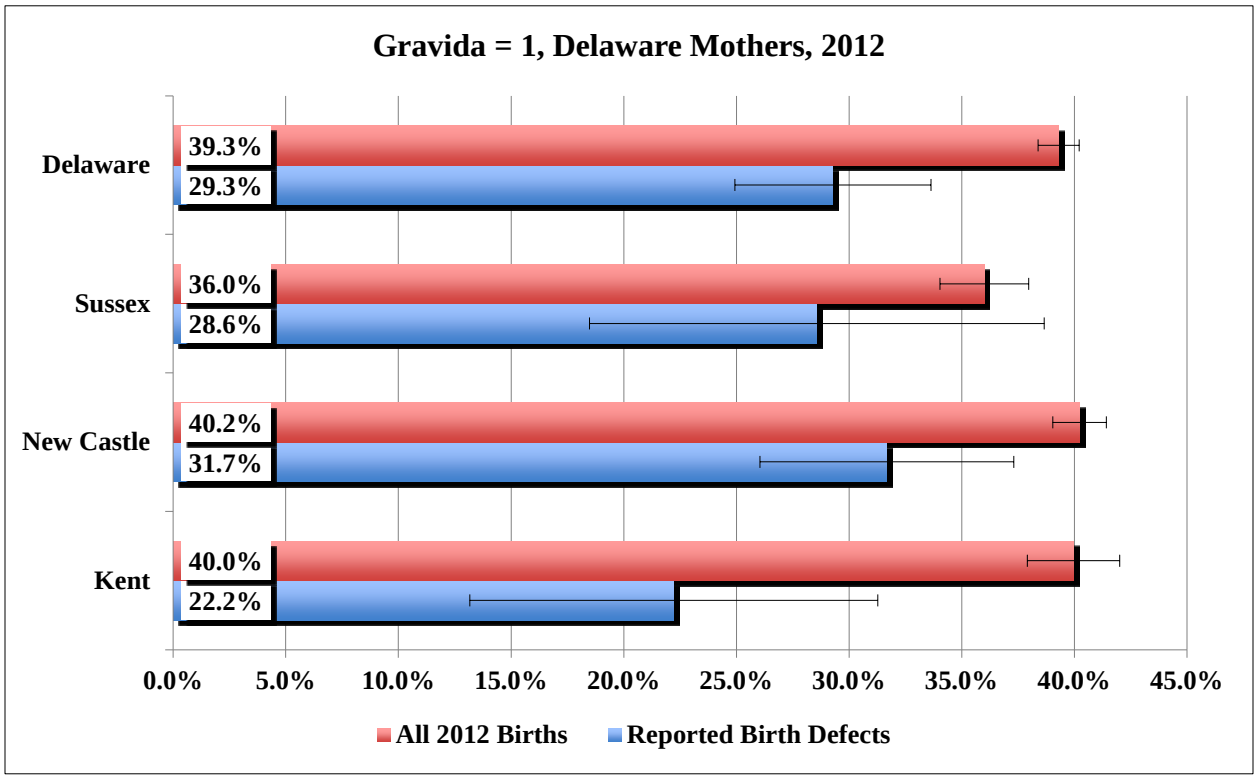
Source: State of Delaware 2012 Birth Defects Registry

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

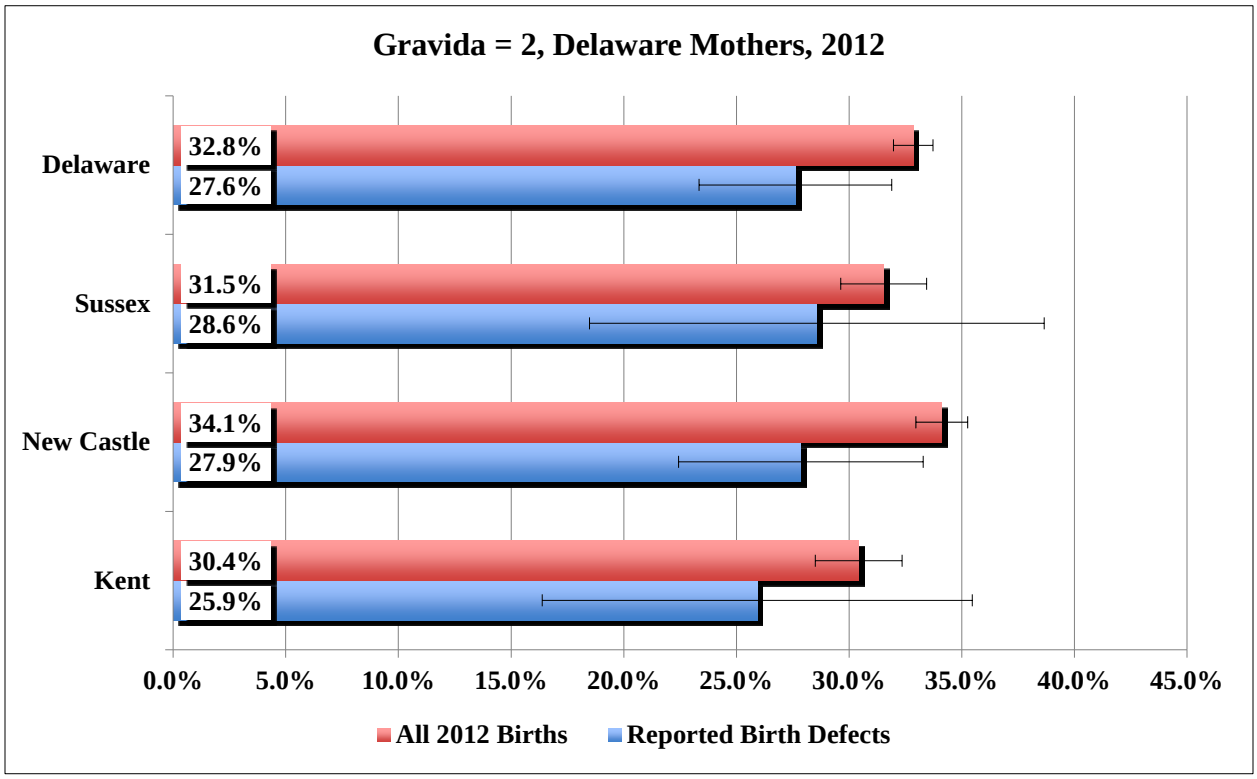


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.2. Gravida.

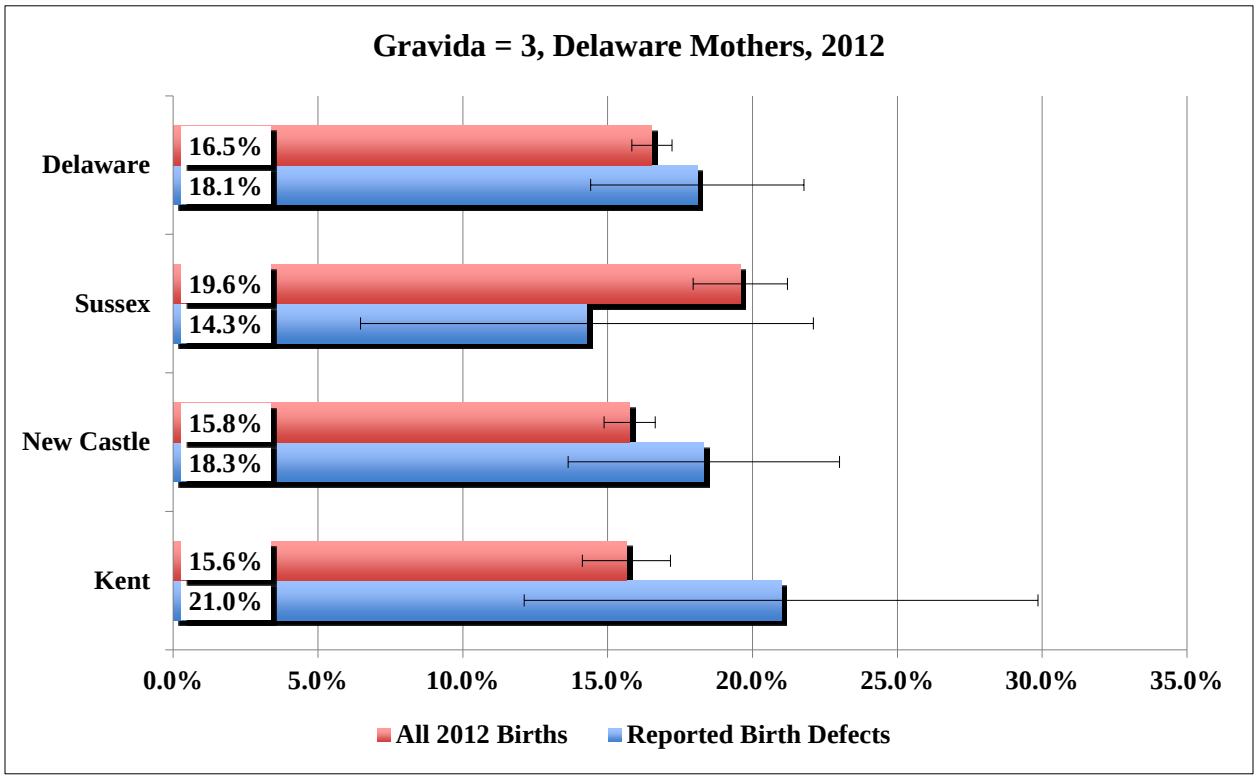


Source: State of Delaware 2012 Birth Defects Registry

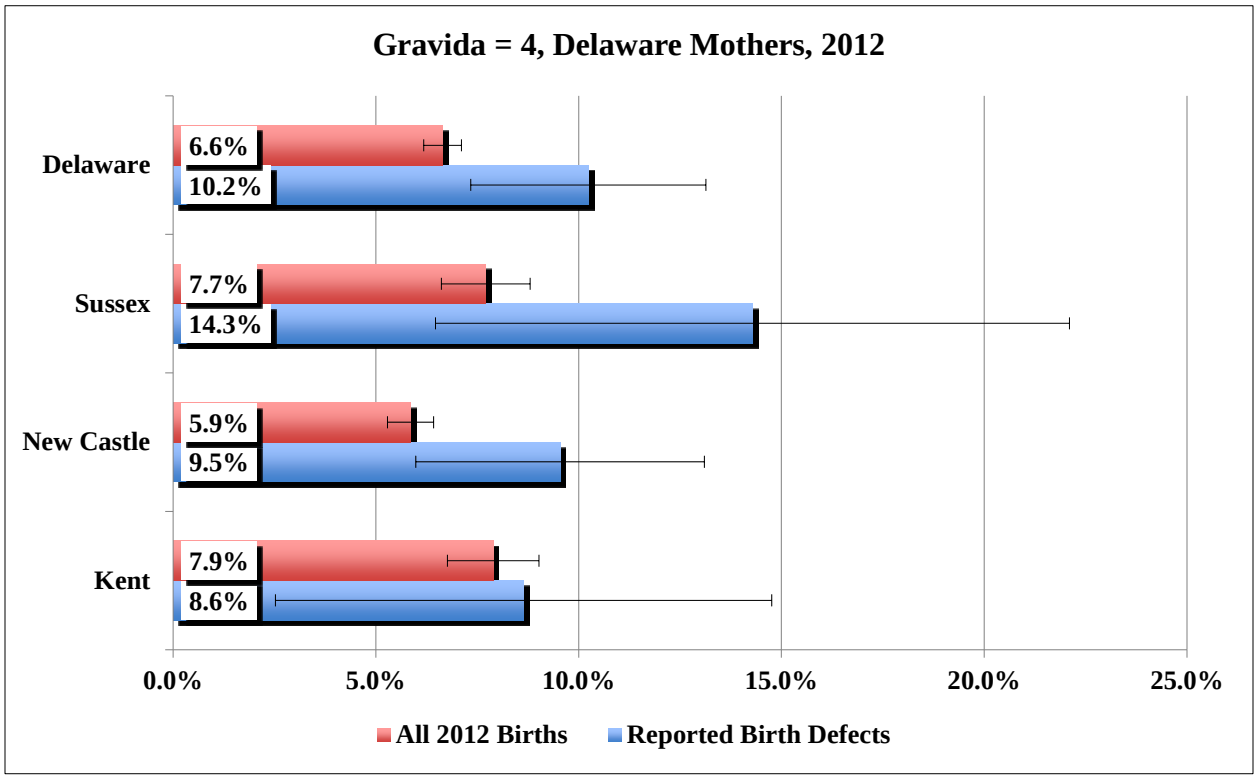


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

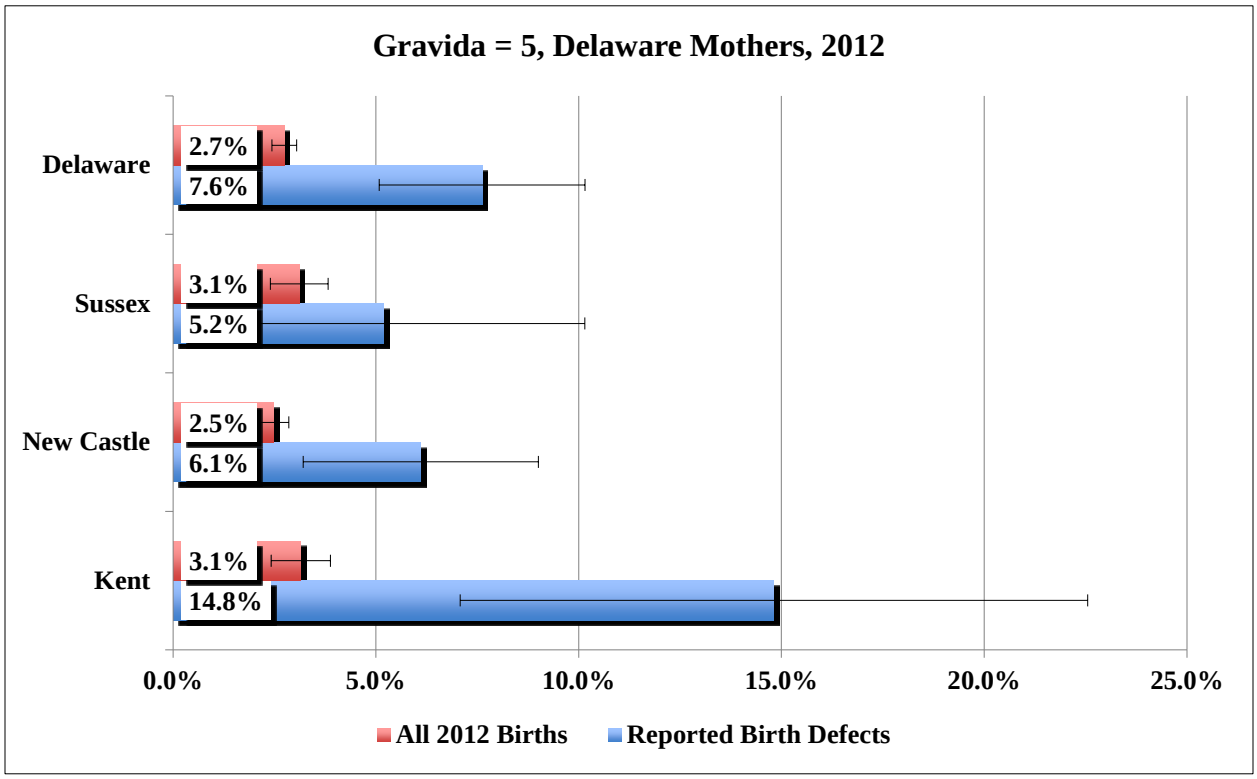


Source: State of Delaware 2012 Birth Defects Registry

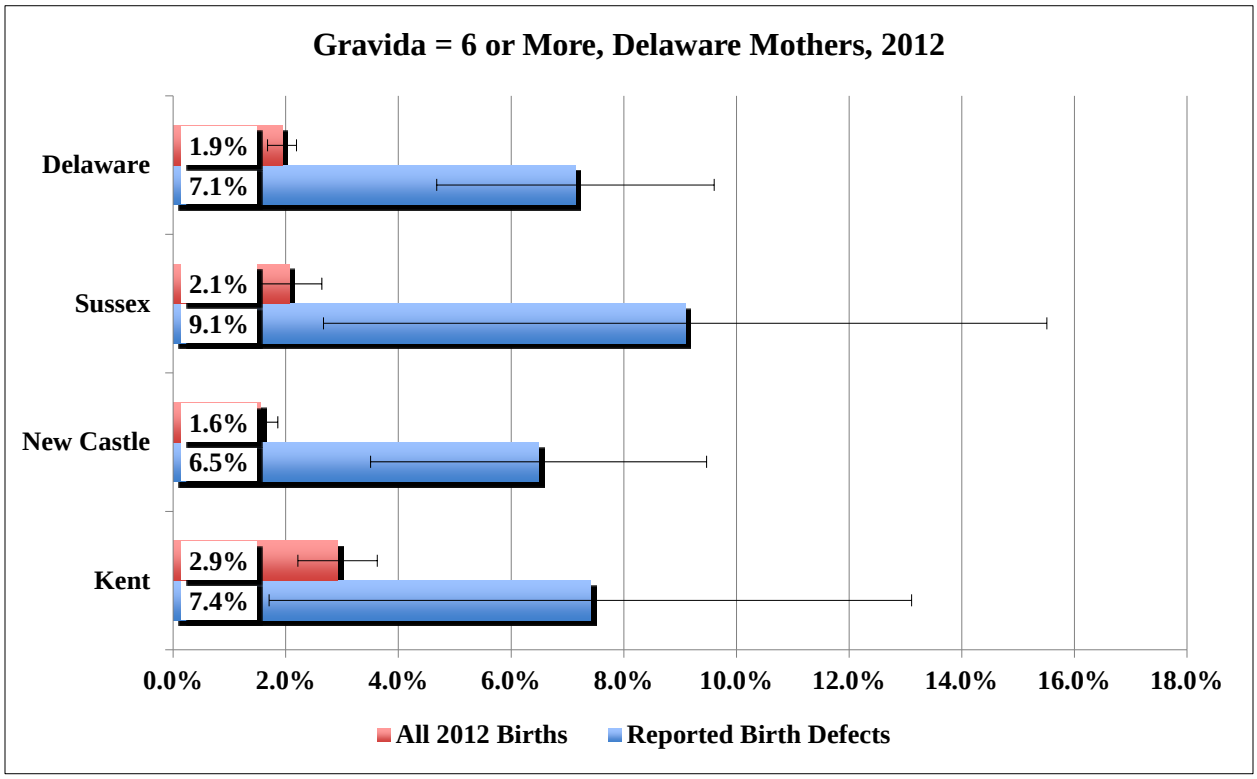


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

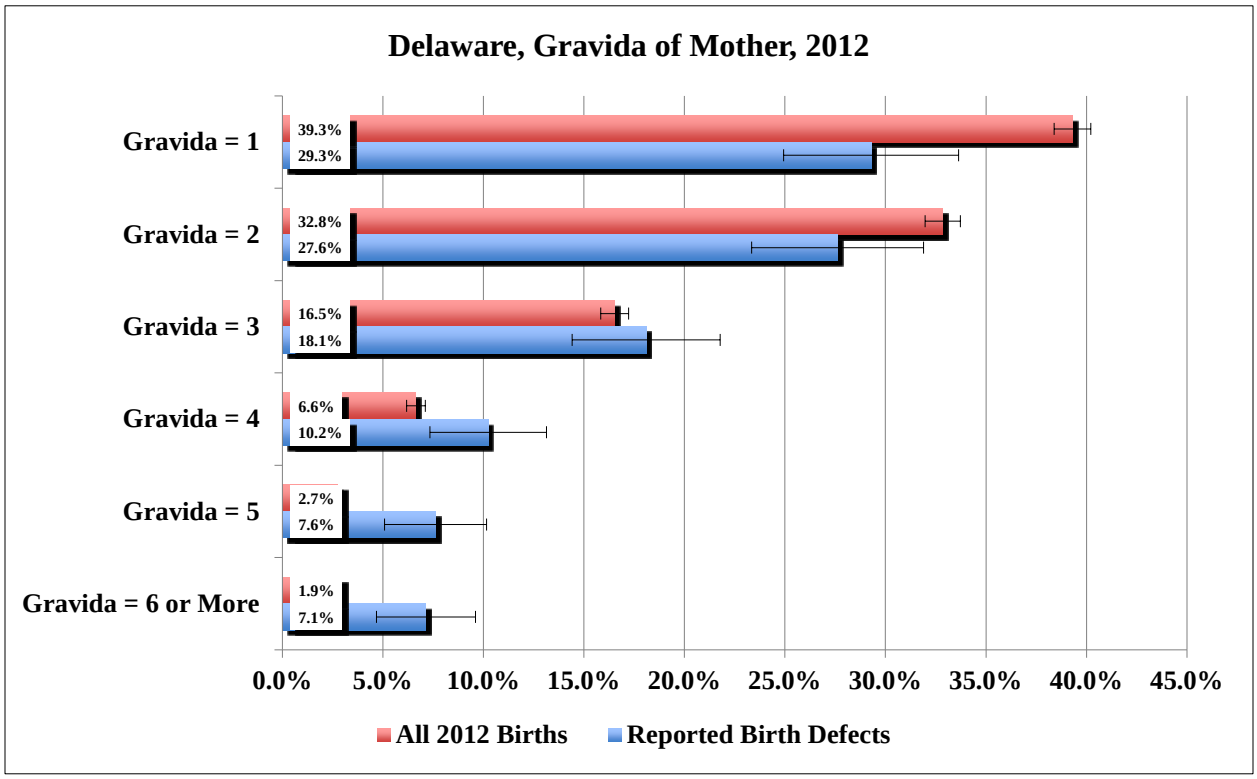


Source: State of Delaware 2012 Birth Defects Registry

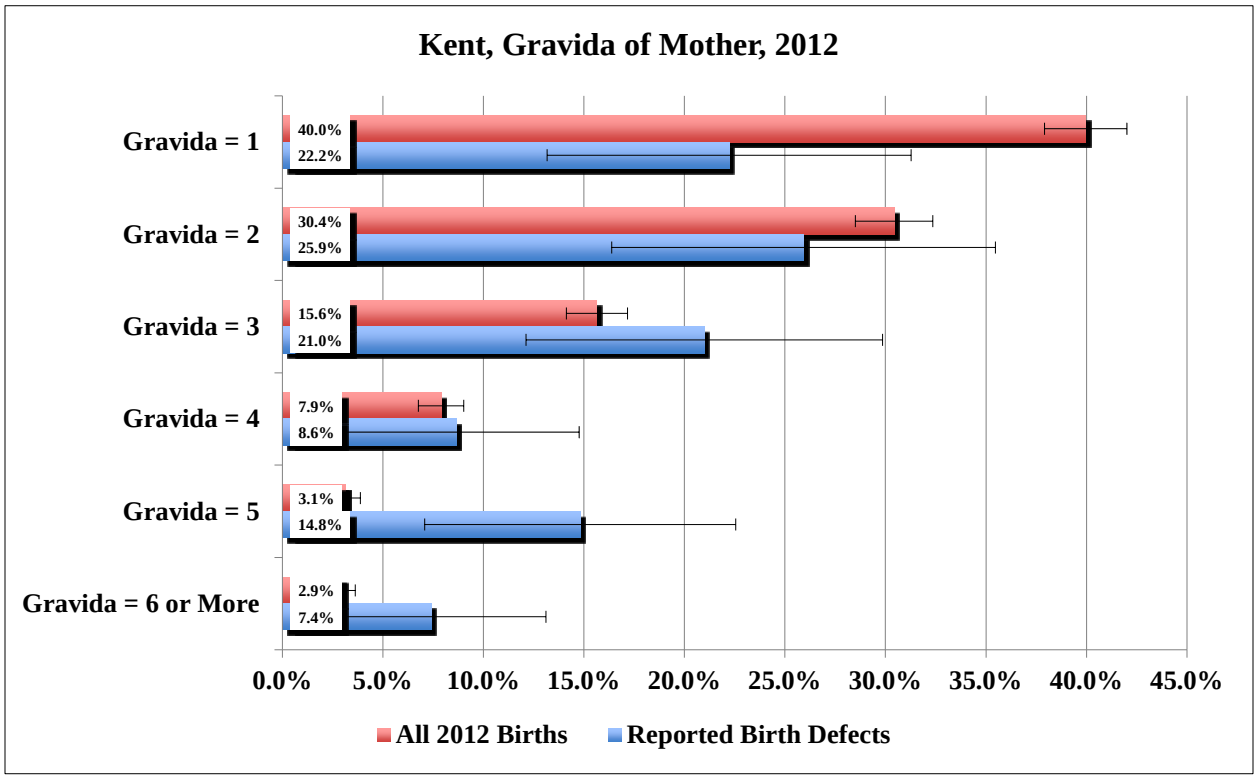


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

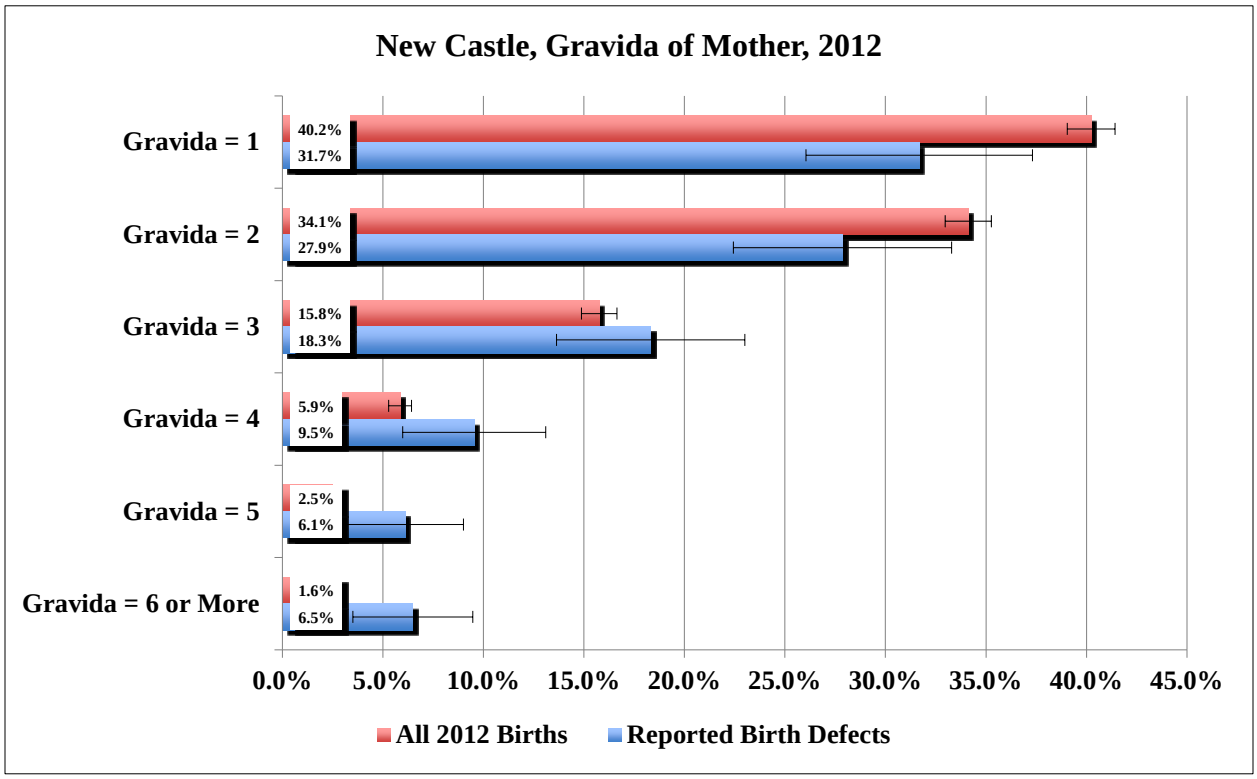


Source: State of Delaware 2012 Birth Defects Registry

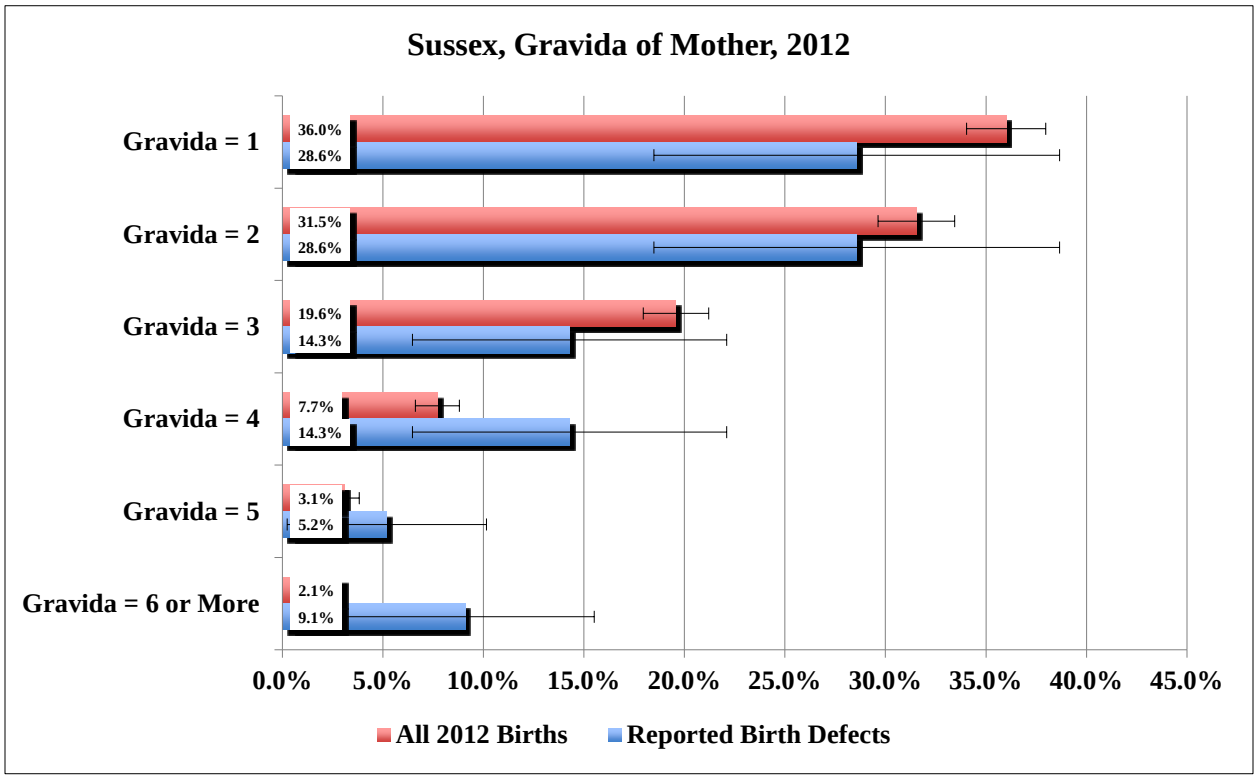


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

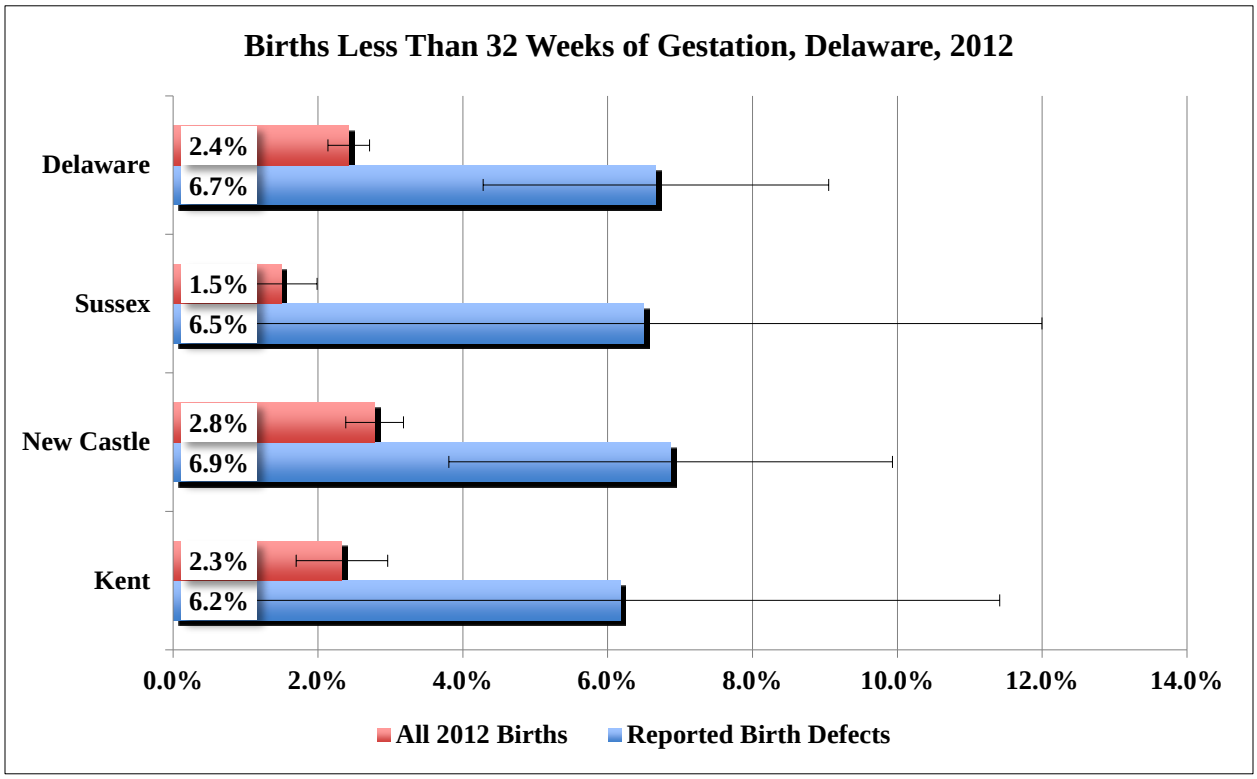


Source: State of Delaware 2012 Birth Defects Registry

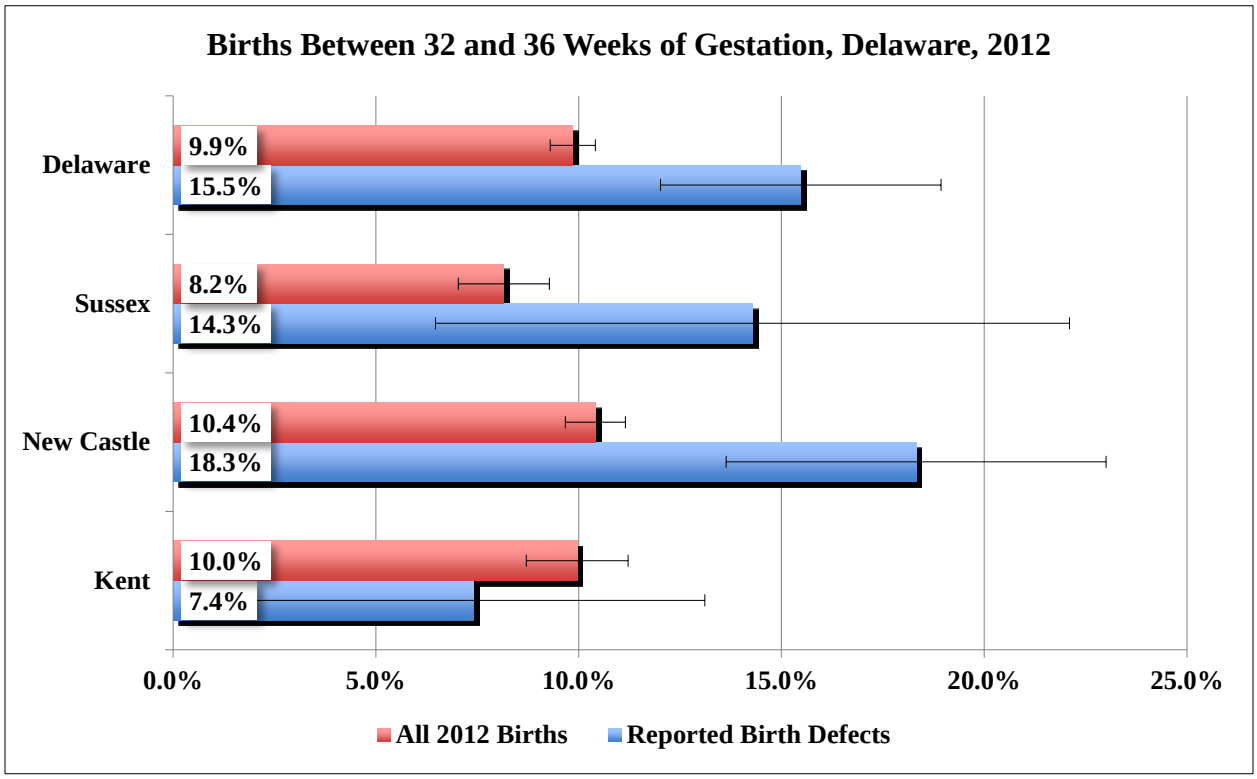


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.3. Gestational Weeks.

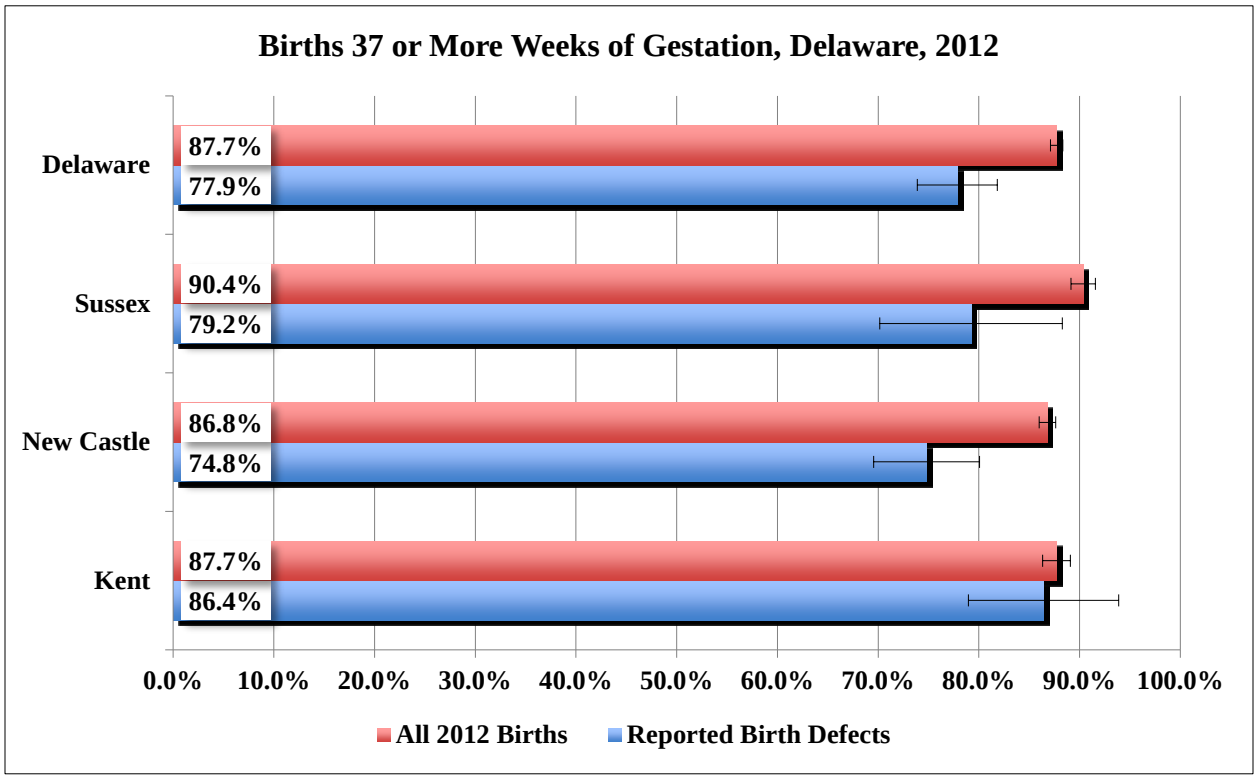


Source: State of Delaware 2012 Birth Defects Registry

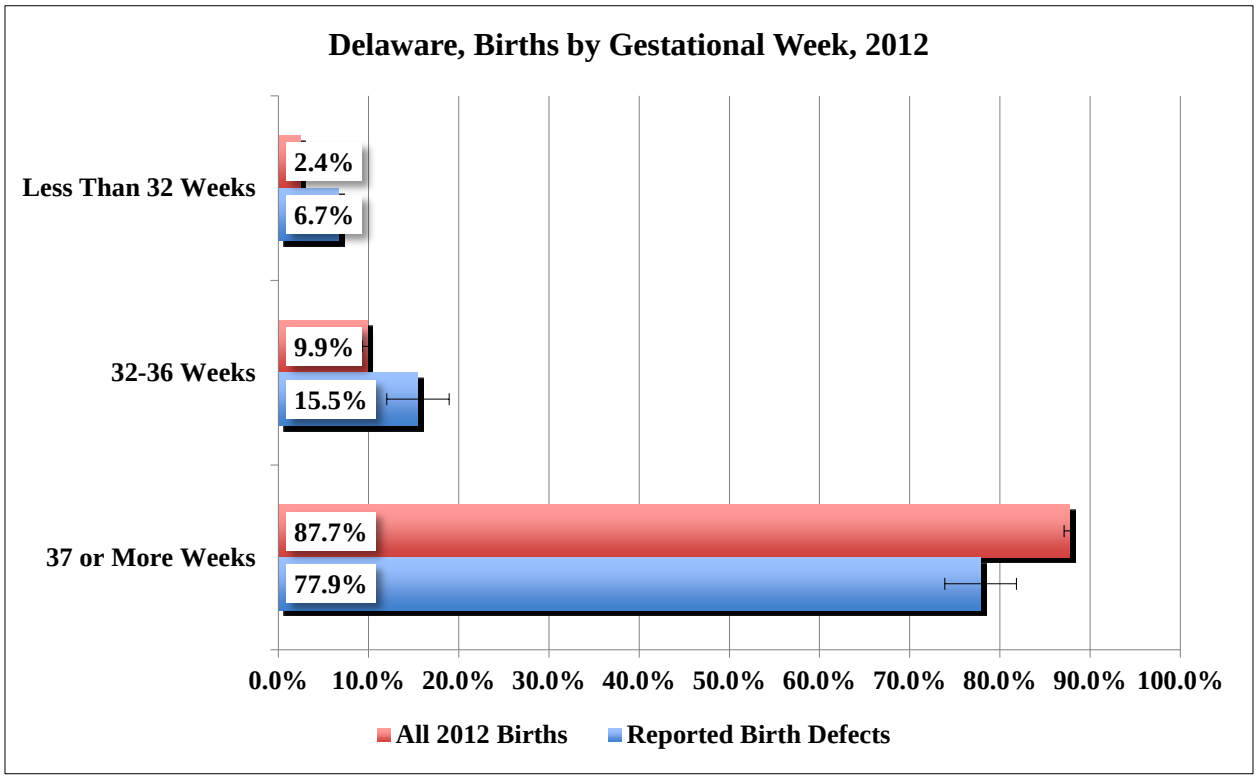


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.3. Gestational Weeks. *Continued*

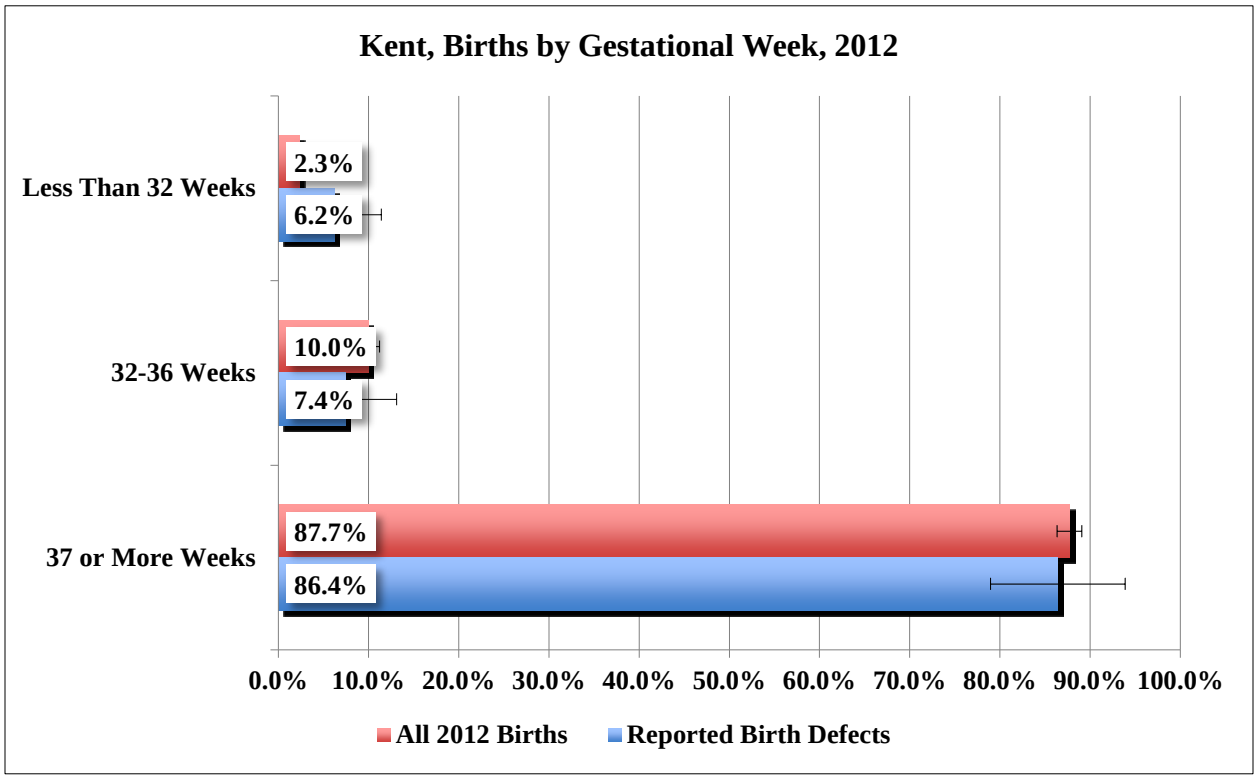


Source: State of Delaware 2012 Birth Defects Registry

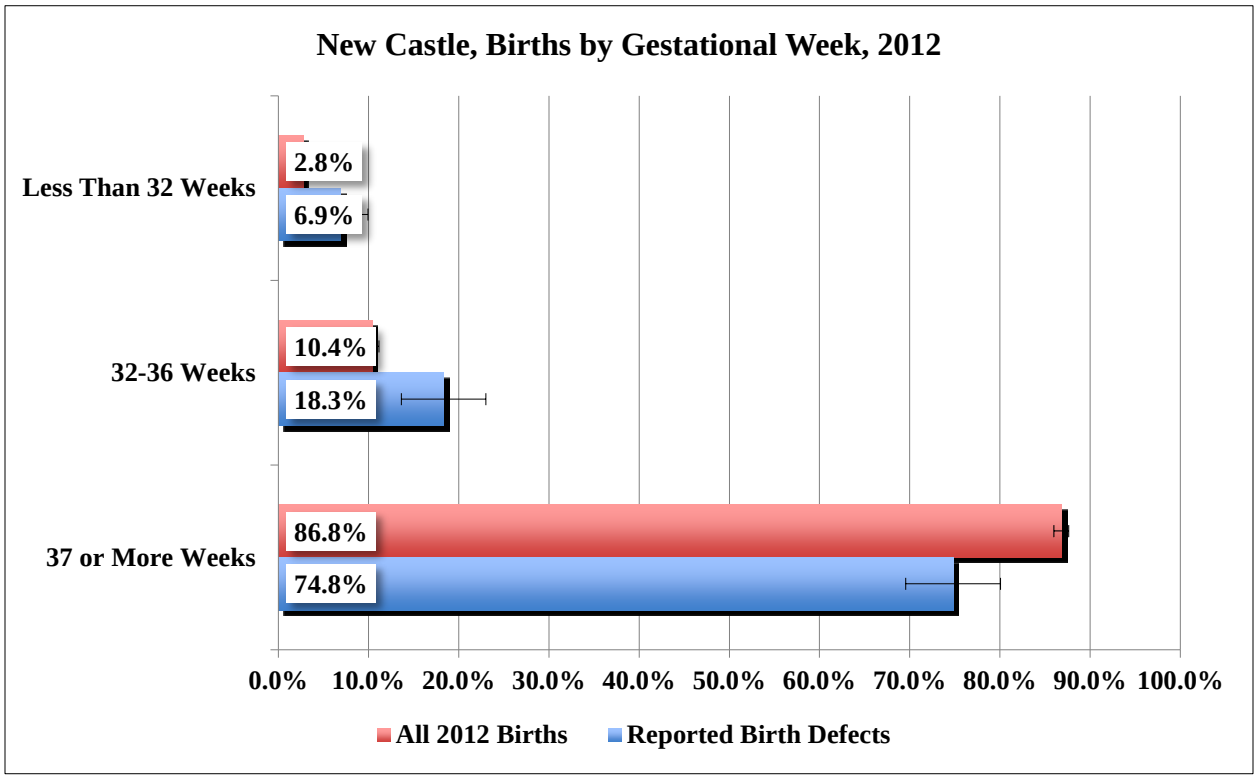


Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.3. Gestational Weeks. *Continued*

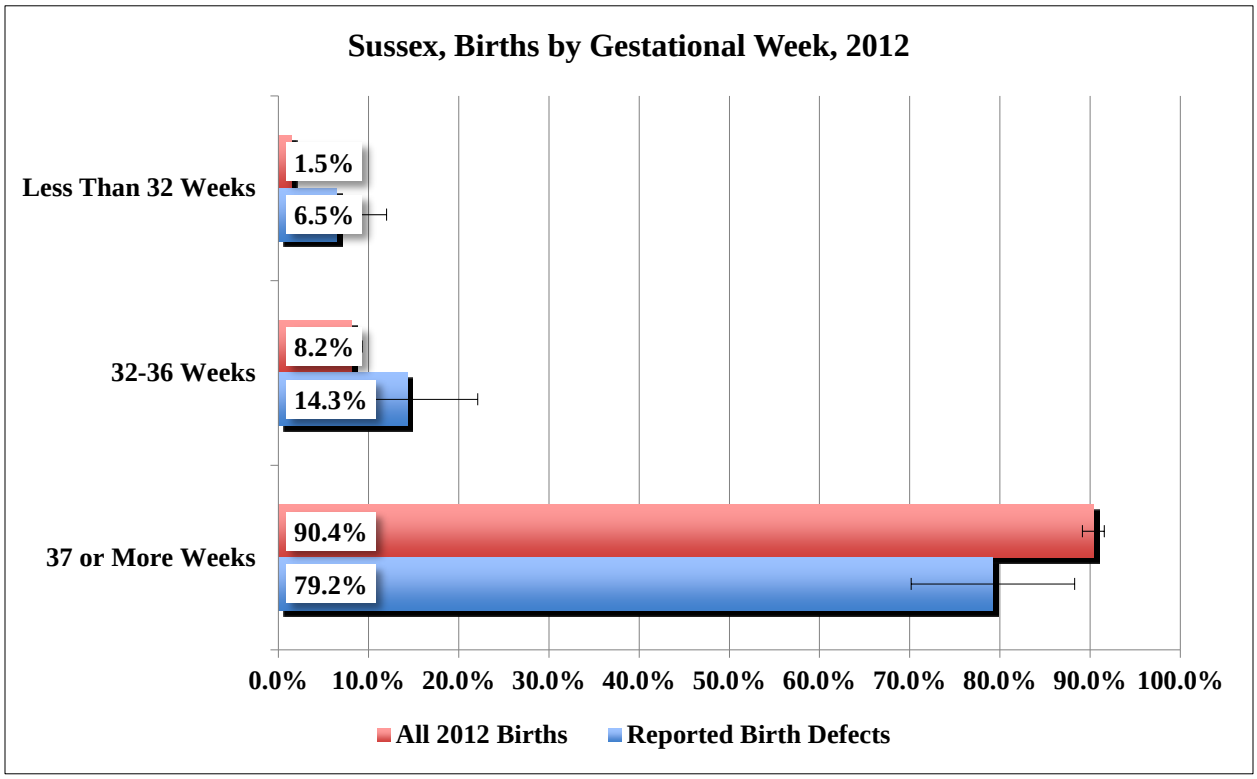


Source: State of Delaware 2012 Birth Defects Registry



Source: State of Delaware 2012 Birth Defects Registry

APPENDIX C.3. Gestational Weeks. *Continued*



Source: State of Delaware 2012 Birth Defects Registry

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