Analysis of the 2008 Delaware Birth Defects Registry

DESIGNED BY

APS HEALTHCARE
Healthy Together

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

May 21, 2012

CONTACT

Alisa Olshefsky
Chief, Family Health Management Systems Section
Delaware Department of Health and Social Services, Division of Public Health
417 Federal Street, Jesse Cooper Building
Dover, DE 19901
302.744.4551 Office
302.739.6653 Fax
alisa.olshefsky@state.de.us

Kimberly Swanson
Project Manager
44 South Broadway, Suite 12
White Plains, NY 10601
914.288.4700 Office
kswanson@apshealthcare.com

Vikrum Vishnubhakta
Consultant/Principal, Forward Consultants on behalf of APS Healthcare
350 South Hamilton Street, Suite 506
Madison, WI 53703
608.208.1670 Office
608.338.0426 Fax
vikrum@goforwardconsultants.com

CITATION

The Division of Public Health will be acknowledged when the report is quoted or referenced using the following format: "Delaware Health and Social Services, Division of Public Health. Analysis of the 2008 Birth Defects Registry. May 18, 2012."

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 2008 ("registered infants").
2. To compare the demographic and health attributes of these infants to all infants born to Delaware residents in 2008.

To answer 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 2008, 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 indicate that mothers to infants in the registry had generally the same age, education, race and ethnicity, and gravida as all Delaware residents that gave birth in 2008. Moreover, certain findings paralleled those found in other Delaware-specific maternal health assessments.

TABLE OF CONTENTS

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 2004-2008 period, accounting for 13.2 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 2008 ("registered infants").
2. To compare the demographic and health attributes of these infants to all infants born to Delaware residents in 2008. This may assist in investigations on feto-infant health disparities and on policies relevant to maternal and child health.

These objectives can be answered 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") are identified through a routine review of primary source records. Primary sources currently include, but are 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 are ascertained from multiple sources along three broad paths.

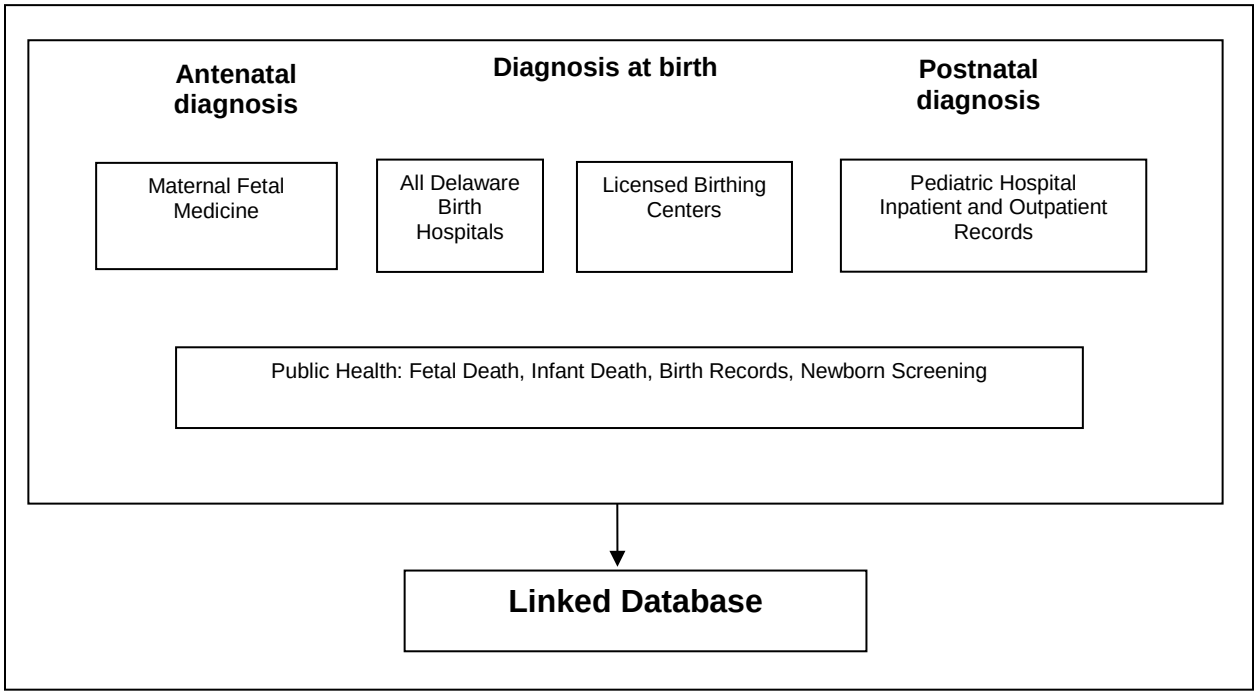
- *First Path*. The records of birth hospitals, licensed birthing centers, and midwives provide the first path for case detection. The frequency of visits to each facility is determined in part by the number of births per year in that facility. The Program Manager requests a list of all patients that were discharged during a specified birth cohort year that have one or more of the codes listed in Appendix A.
- *Second Path*. A second path for case detection involves collecting information from places where children may be prenatally diagnosed or where pregnancies may be terminated. The Program Manager requests 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 involves the review of other sources by the program staff. One of these sources is the Delaware Office of Vital Statistics, which provides a list of names and date of birth or date of death. In addition to these records, staff also review 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 provide 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 are requested by the Program Manager through each institution's medical records department. Lists are created using software to query all births and/or fetal deaths for the ICD-9 codes tracked by the registry. When an institutional list is received it is validated for the appropriate codes and any erroneous codes that are not tracked by the registry are removed. The lists are provided in a vertical

formation in which each case has one line of data for each defect noted in the chart. The Program Manager uses 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 are 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 is used. The infant death list is provided with ICD-10 diagnoses which are translated into ICD-9 for consistency in the registry. The newborn screening list provides 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 provide potential case defect descriptions through cytogenic reports and fetal therapy lists which are 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 are 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 uses 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 are different for each institution, the potential cases are 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.

Mother's date of birth is not always available, especially from the pediatric hospital, in which case only the mother's name is used to match. When lists are matched together the data from institution #1 is linked to institution #2. If the same mother/child pair exists in both datasets that pair is 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 is 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 uploads all potential case information into the Delaware Birth Defects Registry Access database housed within Christiana Care Health System. The Program Assistants/Chart Abstractors use the unduplicated list in the Microsoft Access database to complete their case confirmation and abstraction. The Program Manager can sort 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 appear during the case finding process, the medical record undergoes a full review for any reportable defects that may be associated with these conditions. A Case Abstraction Form is then completed on all medical records where a reportable condition is confirmed. Once a Case Abstraction Form is completed on a confirmed case, additional information is entered in the Access Database. If the case is confirmed as a non-case, Program Assistants code this as "not a case" in the database and no further information is collected for that case. A clinical geneticist makes the confirmation of whether a case was a case or a non-case. All cases and non-cases are documented on the Delaware Birth Defects Progress Sheet for that cohort year.

Analysis of the Registry

Christiana Care Health System submitted the complete 2008 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 2008 Delaware Birth Defects Registry. The registry consists of 500 unique infants. It is important to note that many of the fields listed in Appendix B do not have

data for each of the 500 infants. For this reason, the counts may not add to 500 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	388
Christiana Care Hospital	188
CCHS Maternal Fetal Medicine	118
CCHS NICU	85
DE Office of Vital Statistics	45
DPH Newborn Screening Program	31
Kent General Hospital	29
Beebe Hospital	15
Nanticoke Memorial Hospital	13
St. Francis Hospital	12
Milford Memorial Hospital	2

Source: State of Delaware 2008 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.

County	2008 Registry	All 2008 Events	Percentage of All 2008 Births in Registry
Kent	98	2,333	4.20%
New Castle	307	7,298	4.21%
Sussex	95	2,459	3.86%
Delaware	**500**	**12,090**	**4.14%**

Source: State of Delaware 2008 Birth Defects Registry.

Of the 307 infants' mothers that resided in New Castle County, 125 infants' mothers resided 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	7	25	34	21	8	3
New Castle (w/o Wilmington)	9	37	47	53	27	9
Sussex	9	30	25	21	9	1
Wilmington	14	21	32	38	17	3
Delaware	**39**	**113**	**138**	**133**	**61**	**16**

Source: State of Delaware 2008 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 168 of the 500 infants' mothers (33.60% 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	2	8	25	12	15
New Castle (w/o Wilmington)	3	11	32	23	60
Sussex	8	8	24	9	6
Wilmington	3	9	18	20	36
Delaware	**16**	**36**	**99**	**64**	**117**

Source: State of Delaware 2008 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.[A]

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

County/State	White Non-Hispanic	Black Non-Hispanic	Hispanic
Kent	67	23	6
New Castle (w/o Wilmington)	99	39	23
Sussex	57	19	17
Wilmington	65	35	20
Delaware	**288**	**116**	**66**

Source: State of Delaware 2008 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 2008.[6] The graphs are stratified by

[A] The race and ethnicity investigation was limited to "White Non-Hispanics", "Black Non-Hispanics", and "Hispanics". These three race and ethnicity designations represented 470 out of the 500 entries (94.00% of entries).

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 2008 in the race and ethnicity categories.[B] It is essential to note that the reported number of mothers in the registry that were Hispanic in Kent County is 6; therefore, caution should be exercised as some of the results may be affected by a small sample size.[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 2008.[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. With the exceptions of Sussex County at a gravida of 1, a gravida of 2, a gravida of 5, and a gravida of 6, no statistically significant differences exist between the gravida of mothers in the registry and mothers that gave birth in the other counties in 2008.B These differences in gravida are unknown.

Previous Infant Death

Three 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.

[B] Statistical significance was established using 95% confidence intervals (CI). If the 95% CI do not overlap, the difference between the two percentages is statistically significant. This does not necessarily mean that no statistically significant difference exists if the 95% CI overlap (this would result in type II error). However, if the standard error (SE) of the percentages overlap, the difference is not statistically significant. Each tail of the 95% CI is 1.96 times larger than each tail of the SE. Given these facts, if the tails of one of the 95% CI bars are wholly in the tails of the other 95% CI bar, then it can be stated that no statisticaly significant difference exists (a variation of the "rule of eye" test).

[C] 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	43 (43.88%)	32 (32.65%)	14 (14.29%)	3 (3.06%)	6 (6.12%)
New Castle (w/o Wilmington)	73 (40.11%)	59 (32.42%)	34 (18.68%)	11 (6.04%)	5 (2.75%)
Sussex	38 (40.00%)	28 (29.47%)	15 (15.79%)	5 (5.26%)	9 (9.47%)
Wilmington	54 (43.20%)	47 (37.60%)	13 (10.40%)	7 (5.60%)	4 (3.20%)
Delaware	**208 (41.60%)**	**166 (33.20%)**	**76 (15.20%)**	**26 (5.20%)**	**24 (4.80%)**

Source: State of Delaware 2008 Birth Defects Registry.

Vitamin Use

As shown in Table 7, roughly 4 out of 5 registered infants' mothers reported regular use of vitamins.

TABLE 7. Vitamin Use by Mothers in Registry.

Vitamin Use	Count	Percent
Yes	424	84.80%
No	2	0.40%
Not Stated	74	14.80%

Source: State of Delaware 2008 Birth Defects Registry.

Prenatal Care

As indicated by Table 8, the overwhelming majority of mothers received prenatal care during pregnancy; specifically, 490 infants (98.00% 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	96	0	2
New Castle (w/o Wilmington)	178	3	1
Sussex	92	3	0
Wilmington	124	1	0
Delaware	**490**	**7**	**3**

Source: State of Delaware 2008 Birth Defects Registry.

Table 9 shows that the majority of infants in the registry – 389 infants (77.80% 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 74.16% in Sussex to 85.63% in New Castle (excluding Wilmington); Kent was 83.70% and Wilmington was 80.17%. 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, 13 infants (2.60% of infants) were to mothers that initiated prenatal care in the third trimester. Roughly half of these mothers – 6 out of 13 – resided in Sussex County.

TABLE 9. Initiation of Prenatal Care during Pregnancy.

County/State	1st Trimester	2nd Trimester	3rd Trimester	Unknown
Kent	77	13	2	6
New Castle (w/o Wilmington)	149	23	2	8
Sussex	66	17	6	6
Wilmington	97	21	3	4
Delaware	**389**	**74**	**13**	**24**

Source: State of Delaware 2008 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 18.20% of infants have a mother that did not have any conditions. These findings reveal that the clear majority of infants in the registry – 57.20% of infants – have a mother with multiple conditions.

TABLE 10. Count of Maternal Conditions by Registry Entry.

Count of Conditions	Count of Infant Entries	Percent of Total Infant Entries
0	91	18.20%
1	123	24.60%
2	111	22.20%
3	75	15.00%
4	55	11.00%
5	22	4.40%
6	16	3.20%
7	3	0.60%
8	2	0.40%
9	2	0.40%

Source: State of Delaware 2008 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	221	Bipolar Disorder	8
Surgery-Gynecologic	133	Diabetes Mellitus Type II	8
Obesity	114	Eclampsia	8
Tobacco	108	Genital Herpes	8
Alcohol	85	Diabetes Mellitus Type I	6
Depression	66	Hepatitis C	6
Hypertension (PIH)	58	Coagulopathy	5
Diabetes Gestational	53	Rubella Immune Status-Non-Immune	3
Illicit drugs	33	Varicella-Chicken Pox	3
Chronic Hypertension	23	Lupus	2
Placenta Previa	23	Substance Abuse	2
Toxemia/Preeclampsia	21	Other Psychiatric Disorders	2
Seizure Disorder	13	Cytomegalovirus (CMV)	1
Thyroid Disease	12	Hepatitis B	1
Weight Loss	12	HIV/AIDS	1
Heart Disease	11	Inflammatory Bowel Disease	1

Source: State of Delaware 2008 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[A] 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 supplies these denominator values. For example, in Table 12, fifteen (15) 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 15 infant entries represent 22.39% 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 was reported as having used some form of tobacco. According to this table, 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[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	15 (22.39%)	4 (17.39%)	0 (0.00%)
New Castle (w/o Wilmington)	29 (29.29%)	5 (12.82%)	3 (13.04%)
Sussex	20 (35.09%)	4 (21.05%)	0 (0.00%)
Wilmington	18 (27.69%)	9 (25.71%)	0 (0.00%)
Delaware	**82 (28.47%)**	**22 (18.97%)**	**3 (4.55%)**

Source: State of Delaware 2008 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[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	11 (16.42%)	3 (13.04%)	1 (16.67%)
New Castle (w/o Wilmington)	29 (29.29%)	7 (17.95%)	2 (8.70%)
Sussex	4 (7.02%)	1 (5.26%)	0 (0.00%)
Wilmington	19 (29.23%)	7 (20.00%)	0 (0.00%)
Delaware	**63 (21.88%)**	**18 (15.52%)**	**3 (4.55%)**

Source: State of Delaware 2008 Birth Defects Registry.

Note that 28 infants (5.60% of infants) in the registry have a mother that used both alcohol and tobacco. Also, 163 infants (32.60% 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 White non-Hispanic mother in New Castle County (excluding Wilmington) used tobacco only during pregnancy and one Black non-Hispanic mother in Kent County 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, twelve (12) registered infants' mothers that resided in Kent County used alcohol only before pregnancy. This represents 12.24% of all registered infants' mothers that resided in Kent County. Finally, the counts in Table 14 include all race and ethnicity groups.

[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.

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

County/State[D]	Alcohol Use		Tobacco Use	
	Only Before	Before/During	Only Before	Before/During
Kent	12 (12.24%)	2 (2.04%)	2 (2.04%)	17 (17.35%)
New Castle (w/o Wilmington)	36 (19.78%)	3 (1.65%)	17 (9.34%)	20 (10.99%)
Sussex	3 (3.16%)	2 (2.11%)	3 (3.16%)	21 (22.11%)
Wilmington	23 (18.40%)	3 (2.40%	13 (10.40%)	14 (11.20%)
Delaware	**74 (14.80%)**	**10 (2.00%)**	**35 (7.00%)**	**72 (14.40%)**

Source: State of Delaware 2008 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[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	16 (23.88%)	6 (26.09%)	3 (50.00%)
New Castle (w/o Wilmington)	21 (21.21%)	12 (30.77%)	2 (8.70%)
Sussex	14 (24.56%)	7 (36.84%)	2 (11.76%)
Wilmington	15 (23.08%)	9 (25.71%)	6 (30.00%)
Delaware	**66 (22.92%)**	**34 (29.31%)**	**13 (19.70%)**

Source: State of Delaware 2008 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[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	10 (14.93%)	3 (13.04%)	1 (16.67%)
New Castle (w/o Wilmington)	14 (14.14%)	3 (7.69%)	5 (21.74%)
Sussex	4 (7.02%)	1 (5.26%)	0 (0.00%)
Wilmington	10 (15.38%)	3 (8.57%)	1 (5.00%)
Delaware	**38 (13.19%)**	**10 (8.62%)**	**7 (10.61%)**

Source: State of Delaware 2008 Birth Defects Registry.

TABLE 17. Depression among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	12 (17.91%)	1 (4.35%)	1 (16.67%)
New Castle (w/o Wilmington)	14 (14.14%)	8 (20.51%)	4 (17.39%)
Sussex	5 (8.77%)	1 (5.26%)	0 (0.00%)
Wilmington	9 (13.85%)	5 (14.29%)	4 (20.00%)
Delaware	**40 (13.89%)**	**15 (12.93%)**	**9 (13.64%)**

Source: State of Delaware 2008 Birth Defects Registry.

TABLE 18. Gestational Diabetes among Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	2 (2.99%)	1 (4.35%)	1 (16.67%)
New Castle (w/o Wilmington)	12 (12.12%)	2 (5.13%)	7 (30.43%)
Sussex	8 (14.04%)	3 (15.79%)	3 (17.65%)
Wilmington	4 (6.15%)	3 (8.57%)	1 (5.00%)
Delaware	**26 (9.03%)**	**9 (7.76%)**	**12 (18.18%)**

Source: State of Delaware 2008 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. These results 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 is especially true for White non-Hispanic women when taking the results from Tables 12 and 13 into consideration.

TABLE 19. Multiple Conditions of Mothers in the Registry.

County/State[D]	White Non-Hispanic	Black Non-Hispanic	Hispanic[E]
Kent	38 (56.72%)	10 (43.48%)	3 (50.00%)
New Castle (w/o Wilmington)	69 (69.70%)	24 (61.54%)	10 (43.48%)
Sussex	34 (59.65%)	9 (47.37%)	4 (23.53%)
Wilmington	49 (75.38%)	23 (65.71%)	5 (25.00%)
Delaware	**190 (65.97%)**	**66 (56.90%)**	**22 (33.33%)**

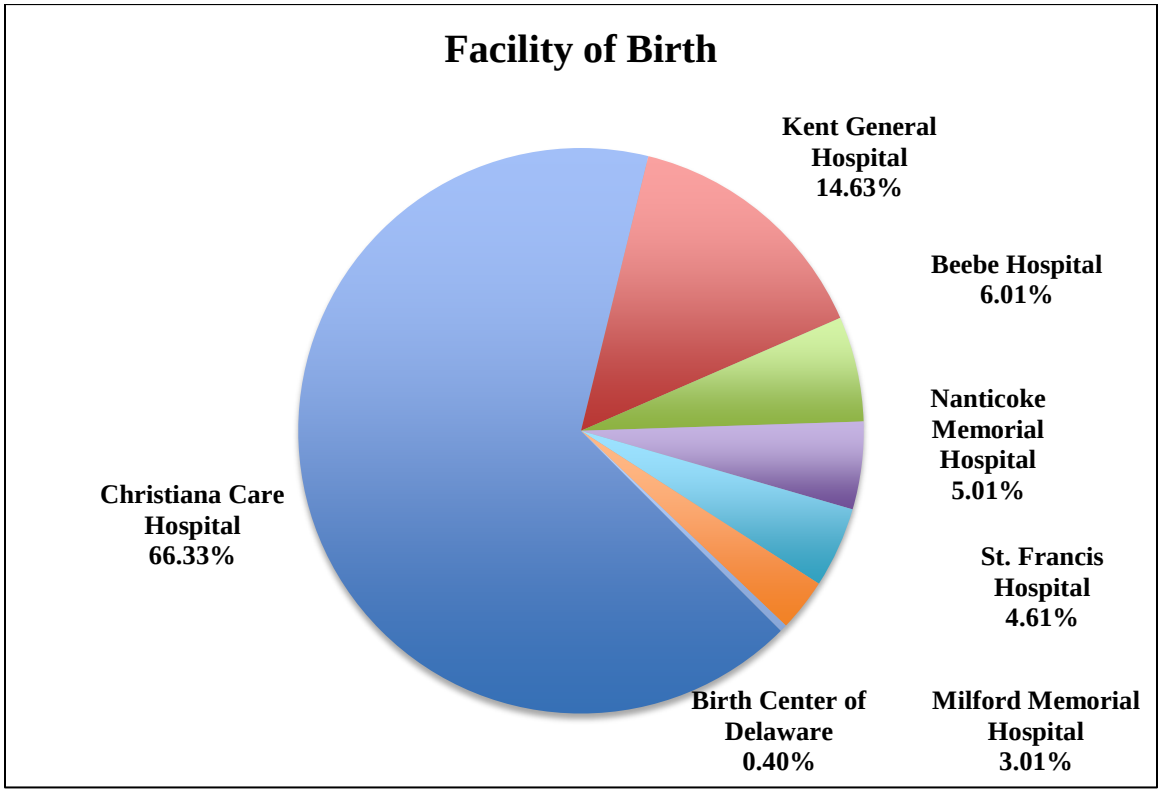
Source: State of Delaware 2008 Birth Defects Registry.

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 2008 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 2008.6 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 2008. Moreover, for New Castle County and the State of Delaware, the percentage of infants born at or above 37 weeks was significantly lower among infants in the registry as compared to infants born in 2008. These findings align with research that suggests an association exists between preterm birth and birth defects.[9,10] However, these significant differences are not at all present in Sussex County.

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. A relatively higher proportion of fetal death cases – 7 of 18 – occurred among mothers residing in Kent County.

TABLE 20. Pregnancy Outcome for Registry Entries.

County	Live Birth		Fetal Death	
	Count	Percentage	Count	Percentage
Kent	91	92.86%	7	7.14%
New Castle (w/o Wilmington)	177	97.25%	5	2.75%
Sussex	92	96.84%	3	3.16%
Wilmington	122	97.60%	3	2.40%
Delaware	**482**	**96.40%**	**18**	**3.60%**

Source: State of Delaware 2008 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	470	94.00%
Twin	28	5.60%
Triplet	2	0.40%

Source: State of Delaware 2008 Birth Defects Registry.

Of the 28 infants that are part of a set of twins, 10 were the first-born twin and 18 were the second-born twin. For the triplets, the first-born in one set of triplets and the third-born in another set of triplets were the infants diagnosed with a birth defect.

Gender

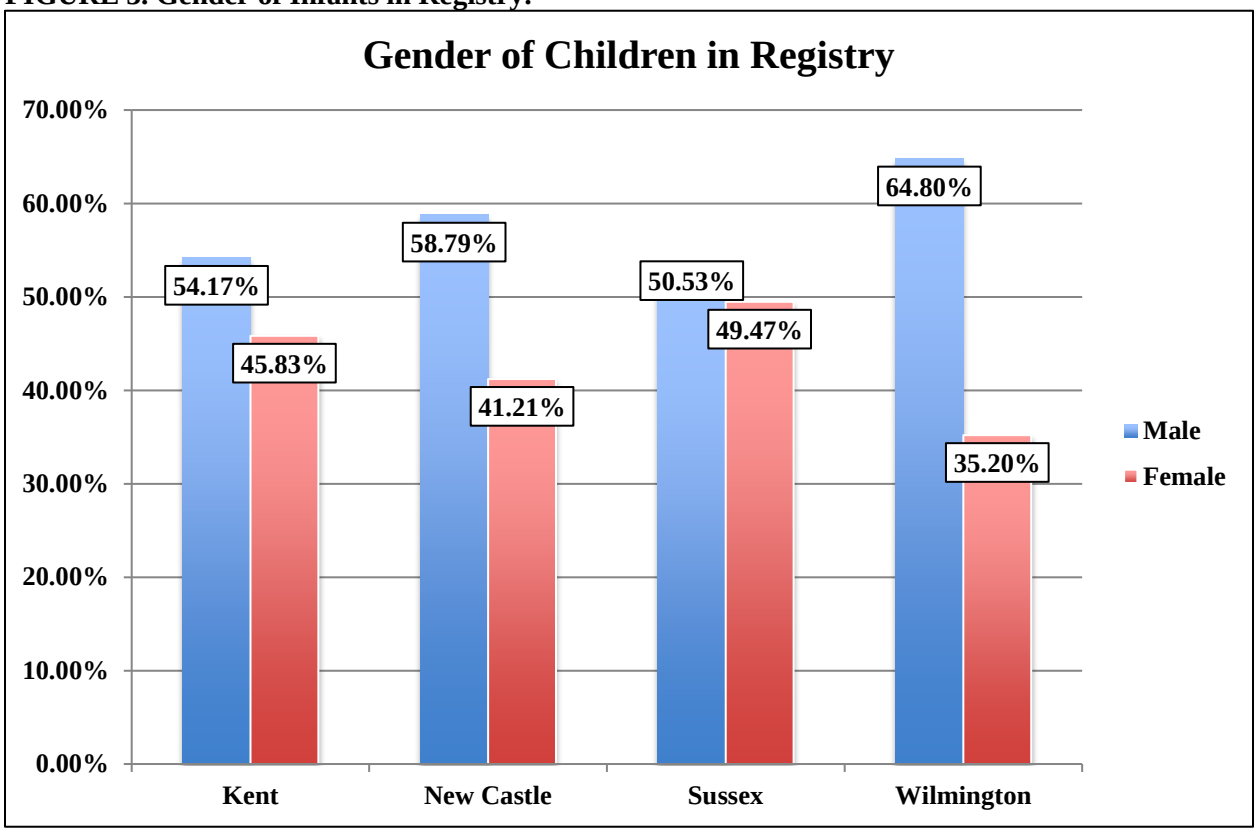
As indicated in Table 22 and Figure 3, the majority of infants in the registry were male.

TABLE 22. Gender of Infants in the Registry.

County	Total	Female	Male
Kent	96	44	52
New Castle	182	75	107
Sussex	95	47	48
Wilmington	125	44	81

Source: State of Delaware 2008 Birth Defects Registry.

FIGURE 3. Gender of Infants in Registry.



Source: State of Delaware 2008 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	42.71%	41.67%	15.63%
New Castle w/o Wilmington	39.01%	39.56%	21.43%
Sussex	40.00%	45.26%	14.74%
Wilmington	41.94%	42.74%	15.32%
Delaware	**40.64%**	**41.85%**	**17.51%**

Source: State of Delaware 2008 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	29.67%	35.16%	35.16%
New Castle w/o Wilmington	29.94%	31.07%	38.98%
Sussex	30.77%	31.87%	37.36%
Wilmington	28.23%	31.45%	40.32%
Delaware	**29.61%**	**32.09%**	**38.30%**

Source: State of Delaware 2008 Birth Defects Registry

Head Circumference Percentiles

Table 25 suggests that approximately 8 out of 9 infants in the registry are below the 75th 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	40.26%	45.45%	14.29%
New Castle w/o Wilmington	35.25%	48.20%	16.55%
Sussex	50.00%	42.05%	7.95%
Wilmington	48.42%	40.00%	11.58%
Delaware	**42.61%**	**44.36%**	**13.03%**

Source: State of Delaware 2008 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, 483 infants (96.60% of infants) had only a "confirmed" diagnosis of a birth defect while 11 infants (2.20% of infants) had only a "possible/probable" diagnosis of a birth defect. Finally, 6 infants (1.20% 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 roughly one-fifth (18.80%) 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	406	81.20%
2	55	11.00%
3	23	4.60%
4	4	0.80%
5	5	1.00%
6	4	0.80%
7	2	0.40%
11	1	0.20%
Total	**500**	**100.00%**

Source: State of Delaware 2008 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
753	Congenital anomalies of urinary system	125
745	Bulbus cordis anomalies and anomalies of cardiac septal closure	122
754	Certain congenital musculoskeletal deformities	58
752	Congenital anomalies of genital organs	47
746	Other congenital abnormalities of the heart	37
742	Other congenital anomalies of nervous system	32
756	Other congenital musculoskeletal anomalies	32
758	Chromosomal anomalies	28
747	Other congenital anomalies of circulatory system	24
744	Congenital anomalies of ear, face, and neck	20
751	Other congenital anomalies of digestive system	20
759	Other and unspecified congenital anomalies	15
282	Hereditary hemolytic anemias	14
743	Congenital anomalies of eye	13
749	Cleft palate and cleft lip	12
755	Other congenital anomalies of limbs	10
Other	-	67
Total		**676**

Source: State of Delaware 2008 Birth Defects Registry

A substantial number of codes are associated with congenital anomalies of the circulatory system (ICD-9 745, 746, and 747; 183 diagnoses or 27.07% of all diagnoses) or congenital urinary tract abnormalities (ICD-9 753; 125 or 18.49% 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	213	31.51%
Echocardiogram	169	25.00%
Clinical	136	20.12%
Laboratory	39	5.77%
Genetics	31	4.59%
X-ray	30	4.44%
Audiogram	18	2.66%
Surgical Observation	11	1.63%
Ophthalmologic Exam	10	1.48%
MRI	9	1.33%
Autopsy	6	0.89%
CT Scan	4	0.59%
Total	**676**	**100.00%**

Source: State of Delaware 2008 Birth Defects Registry

Of the 676 birth defect diagnoses, 178 (26.33%) were confirmed at a prenatal visit while the remaining 498 (73.67%) 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.

County/State	Prenatal	Postnatal	Both
Infants	123 (24.60%)	355 (71.00%)	22 (4.40%)

Source: State of Delaware 2008 Birth Defects Registry

This table indicates that 24.60% 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 (71.00%) 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) and that 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, 122 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	378
1 Family Member	83
2 Family Members	26
3 Family Members	10
4 Family Members	3
Total	**500**

Source: State of Delaware 2008 Birth Defects Registry

Table 31 provides the specific relation between the infant in the registry and the family member documented as having the birth of defect. Although the "Sibling" and "Cousin" 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)	33
Cousin (Maternal/Paternal Not Stated)	31
Birth Mother	27
Uncle	17
Father	11
Aunt	10
Grandfather (Maternal/Paternal Not Stated)	7
Grandmother (Maternal/Paternal Not Stated)	2
Other	29
Total Family Members Reported with Birth Defect	**167**

Source: State of Delaware 2008 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	20
Down Syndrome	17
Club Foot	8
Sickle Cell Disease	8
Scoliosis	8
Cleft Lip or Palate	6
Hip Dysplasia	6
Mental Retardation	6
Arthrogryposis	4
Other	84
Total Family Members Reported with Birth Defect	**167**

Source: State of Delaware 2008 Birth Defects Registry

Based on Table 31 and Table 32, at most 167 birth defects could be analogous between infants in the registry and reported family members.

Table 33 indicates that 50 birth defects (29.94% of the 167 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
Other congenital anomalies of limbs	8
Bulbus cordis anomalies and anomalies of cardiac septal closure	8
Congenital anomalies of urinary system	5
Congenital anomalies of ear, face, and neck	5
Acquired hemolytic anemias	5
Other congenital musculoskeletal anomalies	4
Other congenital abnormalities of the heart	4
Certain congenital musculoskeletal deformities	3
Other congenital anomalies of circulatory system	3
Chromosomal anomalies	2
Other congenital anomalies of digestive system	1
Other congenital anomalies of nervous system	1
Congenital hypothyroidism	1
Total	**50**

Source: State of Delaware 2008 Birth Defects Registry

Of these 50 types of birth defects, 15 were diagnosed in a prenatal care setting and 35 were reported during a postnatal visit. The 15 birth defects that were reported during a prenatal visit are quite diverse: five diagnoses of congenital heart defects, five diagnoses of disease related to the kidney or urinary tract, three diagnoses of club foot, one diagnosis arthrogryposis (abnormal muscle development and/or stiff joints), and one diagnosis of hip dysplasia.

Infant Deaths in the Registry

In the registry, 32 entries (6.40% of entries) show documentation that a fetal or infant death occurred. Of these 32 entries, 18 were fetal deaths (stillbirth and termination of pregnancy) and 14 were documented as an infant death (infant with a live birth that expired within the first year after birth).[F] According to the registry, an autopsy was performed on 9 of these 32 deaths while no autopsy was conducted on 16 of the deaths; it is unknown whether an autopsy was performed on the remaining seven 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 32 expired infants and fetal deaths resided.

[F] The remaining 4 entries were fetal or infant deaths that had documentation of expiration but no date of expiration (3 of the 4 entries) or was a death that took place after the first year after birth (1 of the 4 entries).

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

County/State of Residence	Count
Kent	12
New Castle (w/o Wilmington)	11
Sussex	4
Wilmington	5
Delaware	**32**

Source: State of Delaware 2008 Birth Defects Registry

Among the 14 infant deaths, six were female and eight were male. Moreover, seven were within one month of birth (neonatal death) with all seven neonatal deaths occurring on the day of birth. The remaining seven deaths took place between one month after birth and one year after birth (postneonatal death). Four (4) out of the 14 infants were born at term (greater than or equal to 37 gestational weeks) while five were born early preterm (at less than 32 gestational weeks).

Table 35 provides the growth percentile measures for the 14 infant deaths in the registry. The "Total Infant Deaths" column provides the number out of the 14 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 (78.57%), length (91.67%), and head circumference (75.00%) at the time of birth. Moreover, seven out of the eight infants listed in the head circumference measure were 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	11	14	78.57%
Length (Stature)	11	12	91.67%
Head Circumference	6	8	75.00%

Source: State of Delaware 2008 Birth Defects Registry

Reported Birth Defects of the Infant Deaths in the Registry

Unlike Table 26 where 81.20% of infants in the registry had documentation of one birth defect, Table 36 half – 50.00% – 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	7	50.00%
2	3	21.43%
3	2	14.29%
5	1	7.14%
12	1	7.14%
Total	**14**	**100.00%**

Source: State of Delaware 2008 Birth Defects Registry

Table 37 lists all of the ICD-9 codes provided in the registry for the 14 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	8
753	Congenital anomalies of urinary system	7
746	Other congenital abnormalities of the heart	6
756	Other congenital musculoskeletal anomalies	3
758	Chromosomal anomalies	2
754	Certain congenital musculoskeletal deformities	2
740	Anencephalus and similar anomalies	2
759	Other and unspecified congenital anomalies	1
755	Other congenital anomalies of limbs	1
751	Other congenital anomalies of nervous system	1
748	Congenital anomalies of respiratory system	1
742	Other congenital anomalies of nervous system	1
317	Mild mental retardation	1

Source: State of Delaware 2008 Birth Defects Registry

Family Member with Birth Defect among Infant Deaths in the Registry

The registry documents three of the 14 infants as having a family member reported 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, two were to cousins, one was with the infant's sibling, and one was with the infant's birth mother. Two of these four relations shared a similar birth defect: an expired infant and her cousin each had a congenital heart defect and an expired infant and his birth mother each had arthrogryposis (abnormal muscle development and/or stiff joints).

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 14 registry entries documented as infant deaths. As shown in this table, only 28.57% of the mothers with an infant death had no reported conditions and half of the mothers (seven out of 14) 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	4	28.57%
1	3	21.43%
2	3	21.43%
3	1	7.14%
4	3	21.43%
Total	**14**	**100.00%**

Source: State of Delaware 2008 Birth Defects Registry

Table 39 provides counts for all of the maternal conditions listed for the 14 infant deaths listed in the registry.

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

Condition	Count	Condition	Count
Surgery-Non Gynecologic Non Transplant	5	Surgery-Gynecologic	2
Depression	3	Varicella-Chicken Pox	2
Alcohol	2	Heart Disease	1
Diabetes Gestational	2	Illicit Drugs	1
Hypertension (PIH)	2	Thyroid Disease	1
Obesity	2	Toxemia/Preeclampsia	1

Source: State of Delaware 2008 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 2008. 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 2008 Pregnancy Risk Assessment Monitoring System (PRAMS) results for the remaining selected maternal conditions.

TABLE 40. Comparison of 2008 Birth Defects Registry with 2008 PRAMS by Maternal Condition.

Maternal Condition	2008 Birth Defects Registry	2008 PRAMS
Obesity	22.60%	N/A
Pregnancy-Induced Hypertension	11.00%	13.31%[G]
Depression	12.80%	9.33%[H]
Gestational Diabetes	9.40%	8.32%[I]

Source: State of Delaware 2008 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, although some commonly reported birth defects – such as hypospadias – affect males and not females. 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 four out of five registered infants had documentation of one birth defect with the remaining one out of five having multiple birth defects reported. The registry lists 122 infants as having at least one or more family members with a birth defect, bringing the total count of familial connections to 167. Finally, the registry documented 18 fetal deaths and 14 infant deaths, and in comparison to all infants in the registry, a lower proportion of these 14 infant deaths (seven out of 14) had only one birth defect.

[G] In PRAMS, this is item 27G: "During your most recent pregnancy, did you have a problem with high blood pressure, hypertension (including pregnancy-induced hypertension [PIH]), preeclampsia, or toxemia?"
[H] In PRAMS, this is item 72A: "Since your new baby was born, have you always or often felt down, depressed, or hopeless?"
[I] In PRAMS, this is item 27B: "During your most recent pregnancy, did you have a problem with high blood sugar that started during this pregnancy?"

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	ICD-9 Code
Congenital syphilis	090.0-090.3
Neurofibromatosis	237.70
Congenital hypothyroidism	243.00
Congenital adrenal hyperplasia (adrenogenital disorders)	255.2
Multiple carboxylase deficiency	269.2
Phenylketonuria	270.1
Other disturbances of aromatic amino-acid metabolism	270.2
Disturbances of branched-chain amino-acid metabolism	270.3
Disturbances of sulphur-bearing amino-acid metabolism	270.4
Disorder of urea cycle metabolism	270.6
Glutaric aciduria	270.7
3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency	270.9
Galactosemia	271.1
Cystic fibrosis	277.0
Biotinidase deficiency	277.6
Carnitine uptake deficiency	277.81
Disorders of fatty acid oxidation	277.85
Sickle cell disease	282.60
Other hemoglobinopathies	282.63, 282.69, 282.4
Hemoglobinopathies - SS Disease, SC Disease, Variant Hgb	282.7
Developmental language disorder	315.31-315.39
Coordination Disorder	315.40
Mental Retardation/Cognitive delay	317-319
Hearing loss (sensorineural)	389.1-389.18
Known or suspected fetal abnormality affecting management of the mother	655.0-655.5; 655.8
Other fetal and placental problems affecting management of the mother: intrauterine death	656.4
Anencephalus	740.0-740.1
Spina bifida without anencephalus	741, 741.0, 741.9 w/o 740.0-740.10
Encephalocele	742.0
Microcephalus	742.1
Holoprosencephaly/porencephaly	742.2
Hydrocephalus without spina bifida	742.3 w/o 741.0, 741.9
Other congenital anomalies of nervous system	742.4-742.9
Anophthalmia/microphthalmia	743.0, 743.1
Glaucoma	743.20-743.22
Congenital cataract	743.30-743.34
Aniridia	743.45
Coloboma	743.46
Anotia / microtia	744.01, 744.23
Common truncus	745.0
Transposition of great arteries, double outlet right ventricle	745.10, 745.11, 745.12, 745.19
Tetralogy of Fallot	745.2
Single Ventricle	745.3

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	Facility Where Entry was Abstracted
M_MRN_CCHS, M_MRN_KENTGENERAL, M_MRN_STFRANCIS, M_MRN_NANTICOKE, M_MRN_BEEBE, MRN_NICU, M_MRN_MILFORD	Maternal 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
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

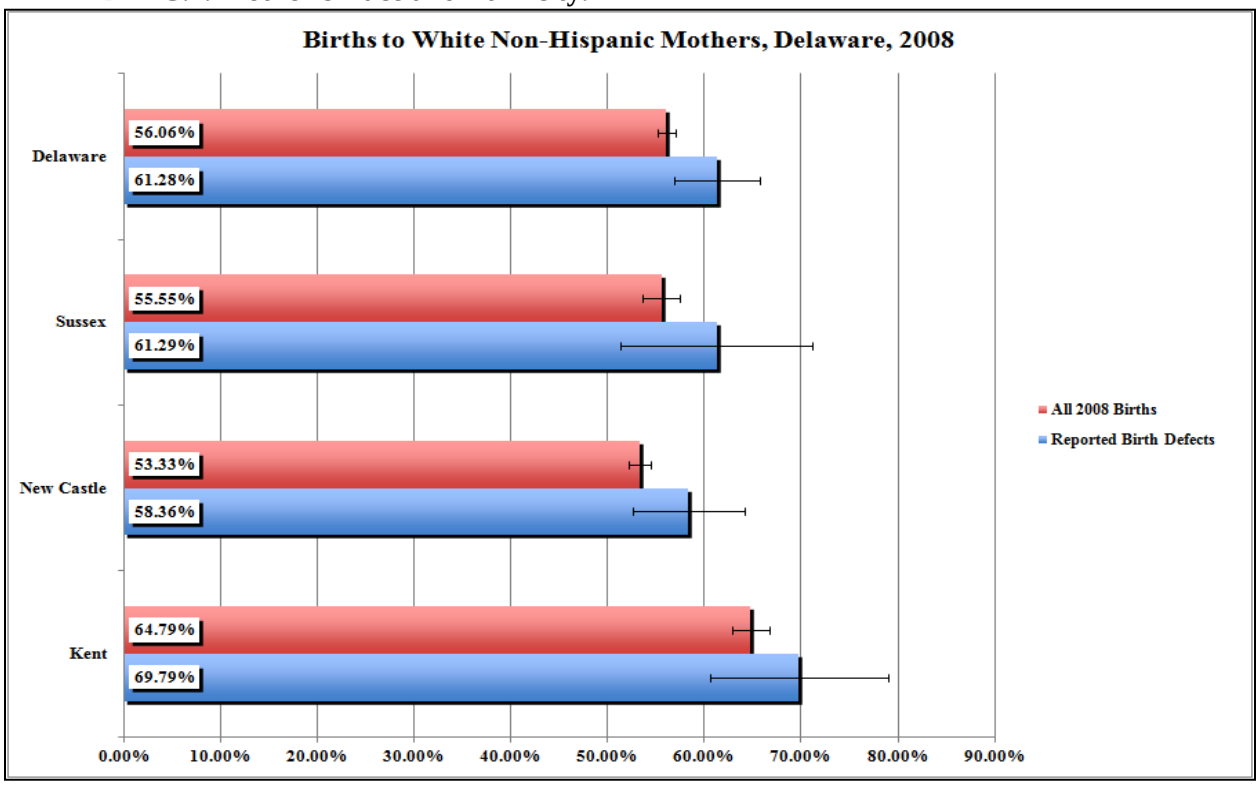
APPENDIX B. Birth Defects Registry Fields. *Continued*

Field	Description
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, MAT_COND.9	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, COND_COM.9	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
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, MALF.9, MALF.10, MALF.11	ICD-9 Code and Description for Birth Defect

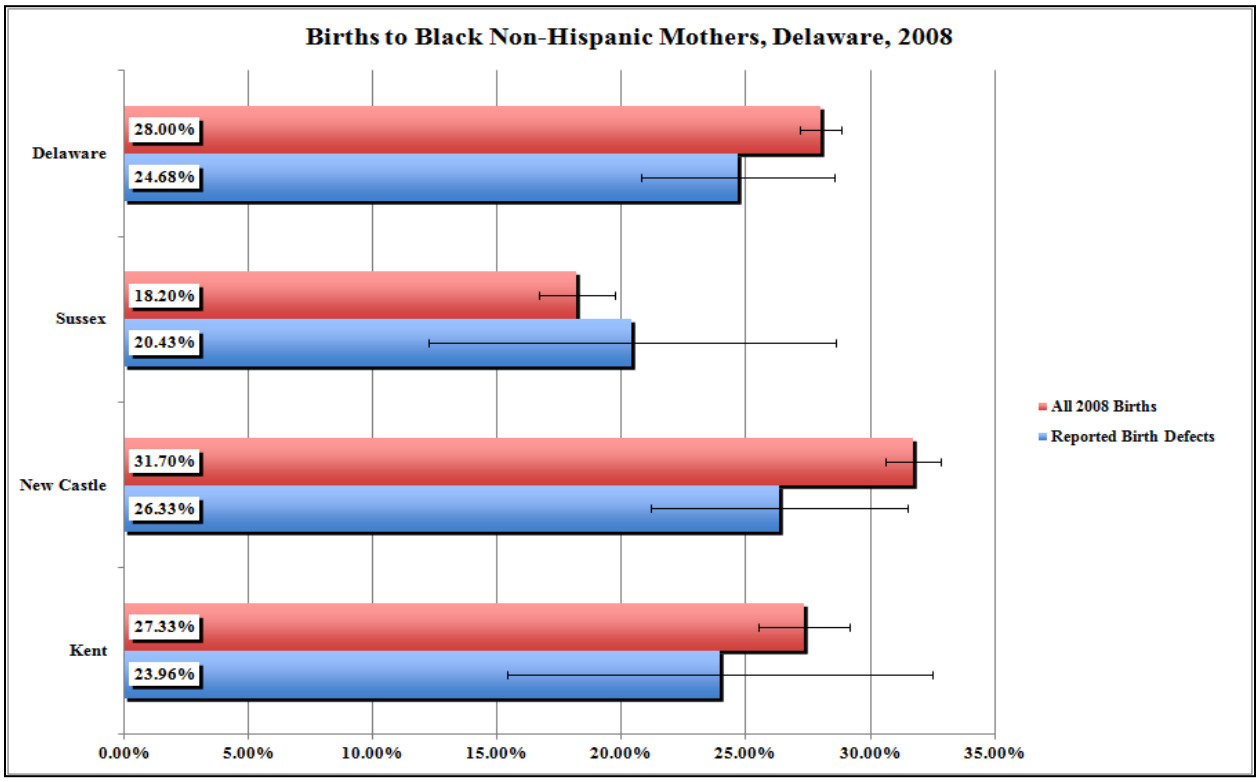
APPENDIX B. Birth Defects Registry Fields. *Continued*

Field	Description
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, MALF_C.10, MALF_C.11	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, MALF_DXM.10, MALF_DXM.11	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, MALF_DATE.10, MALF_DATE.11	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, MALF_WHEN.10, MALF_WHEN.11	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, MALF_CON.10, MALF_CON.11	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, MALF_CD.10, MALF_CD.11	ICD-9 Code for Birth Defect

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

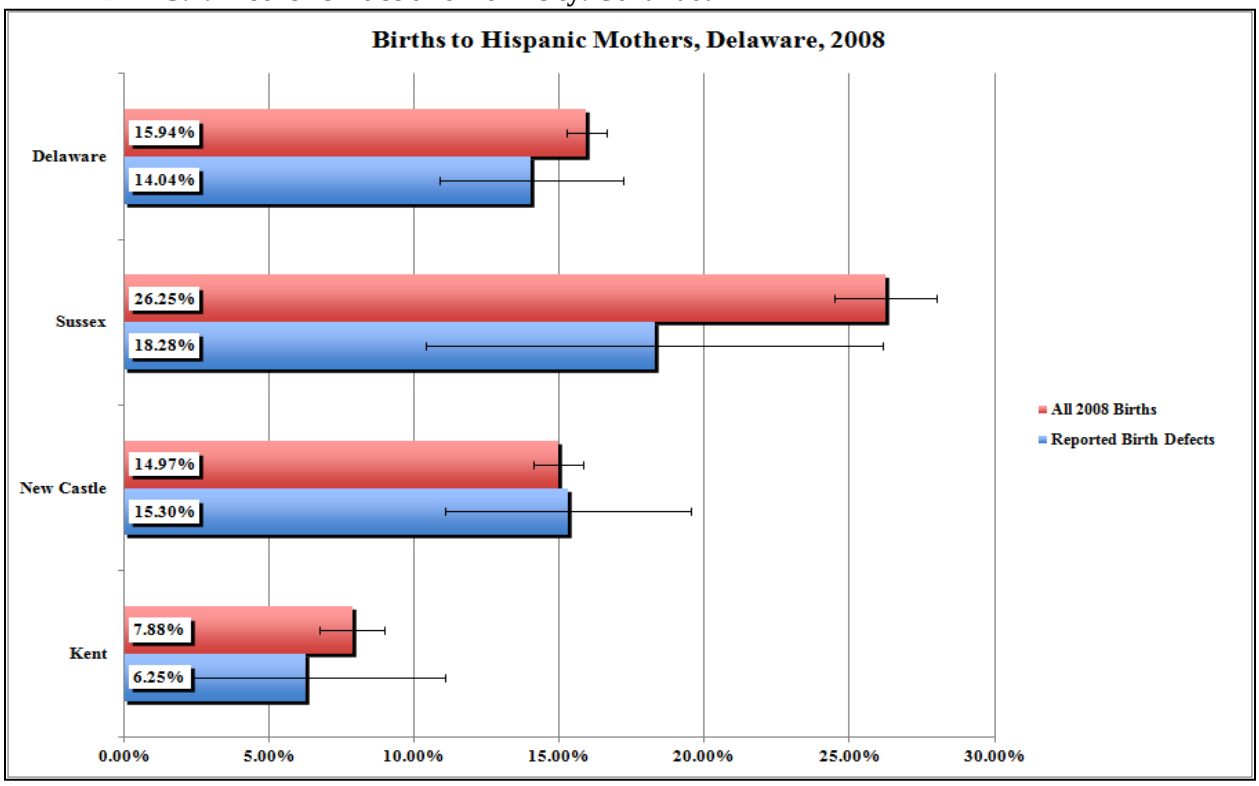


Source: State of Delaware 2008 Birth Defects Registry

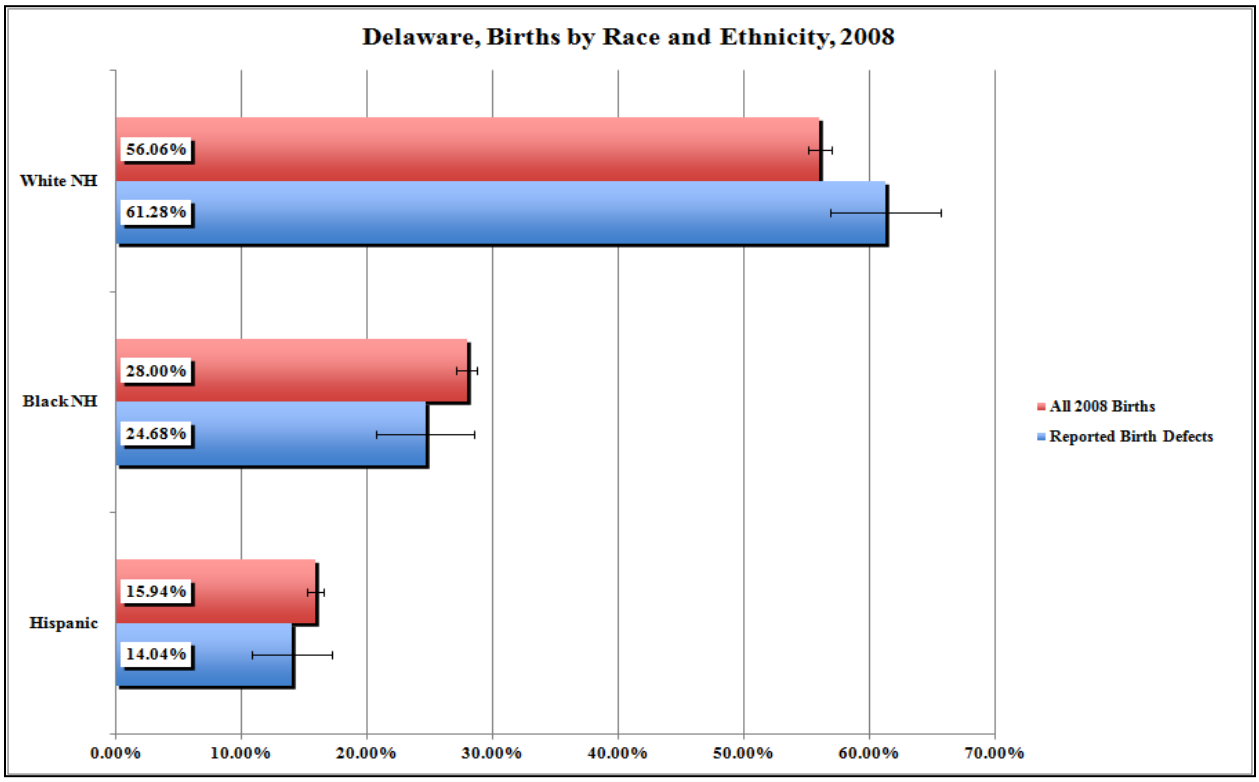


Source: State of Delaware 2008 Birth Defects Registry

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

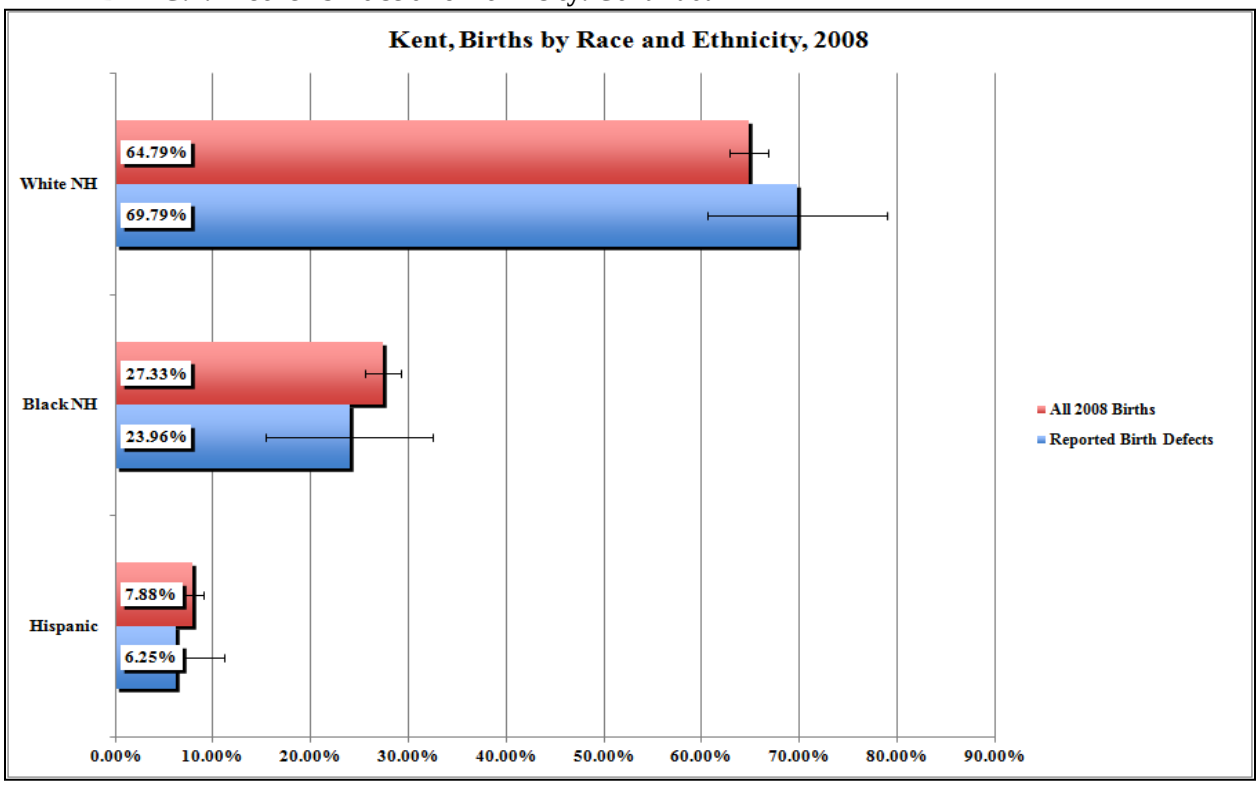


Source: State of Delaware 2008 Birth Defects Registry

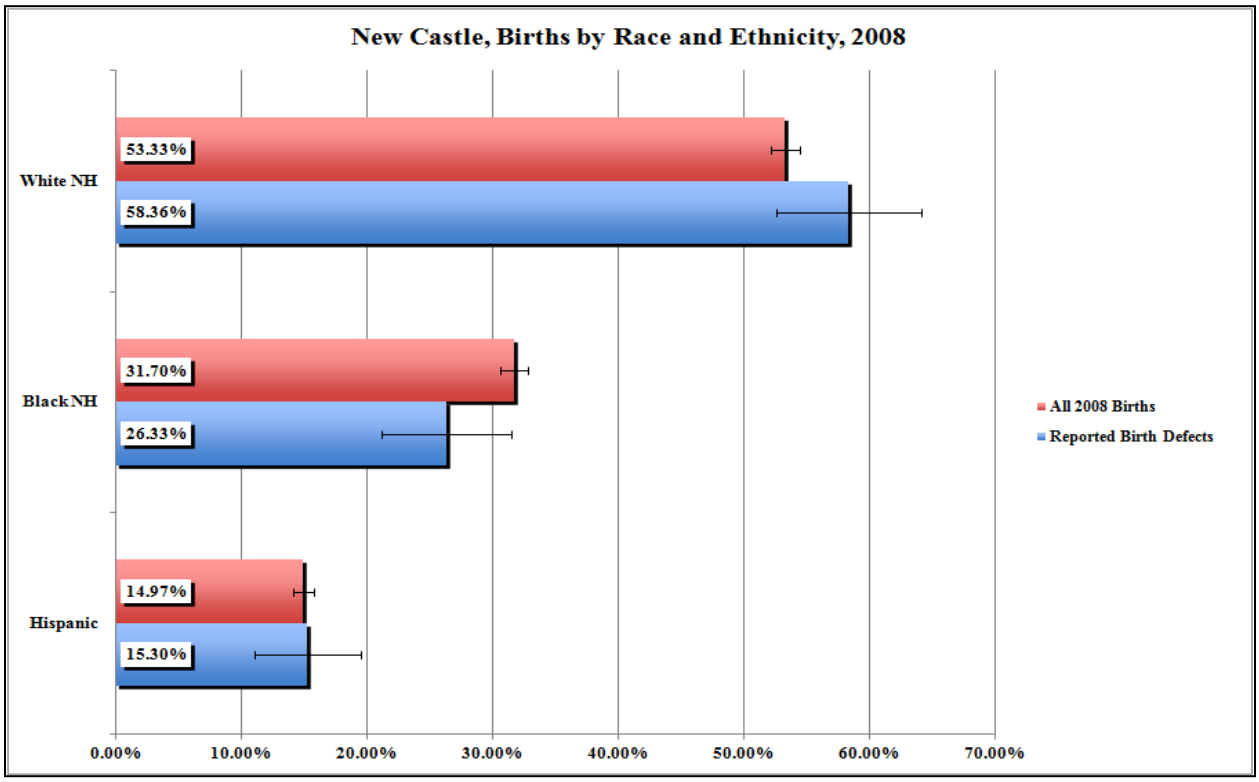


Source: State of Delaware 2008 Birth Defects Registry

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

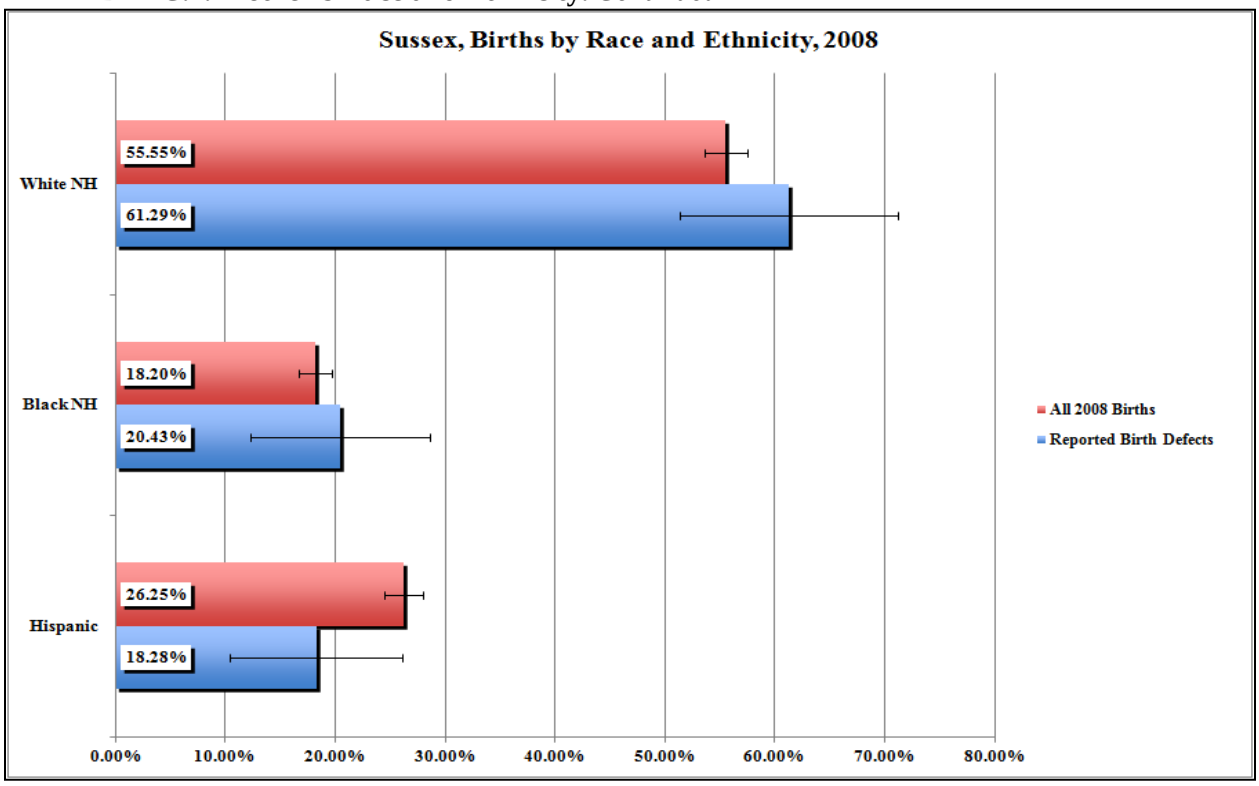


Source: State of Delaware 2008 Birth Defects Registry



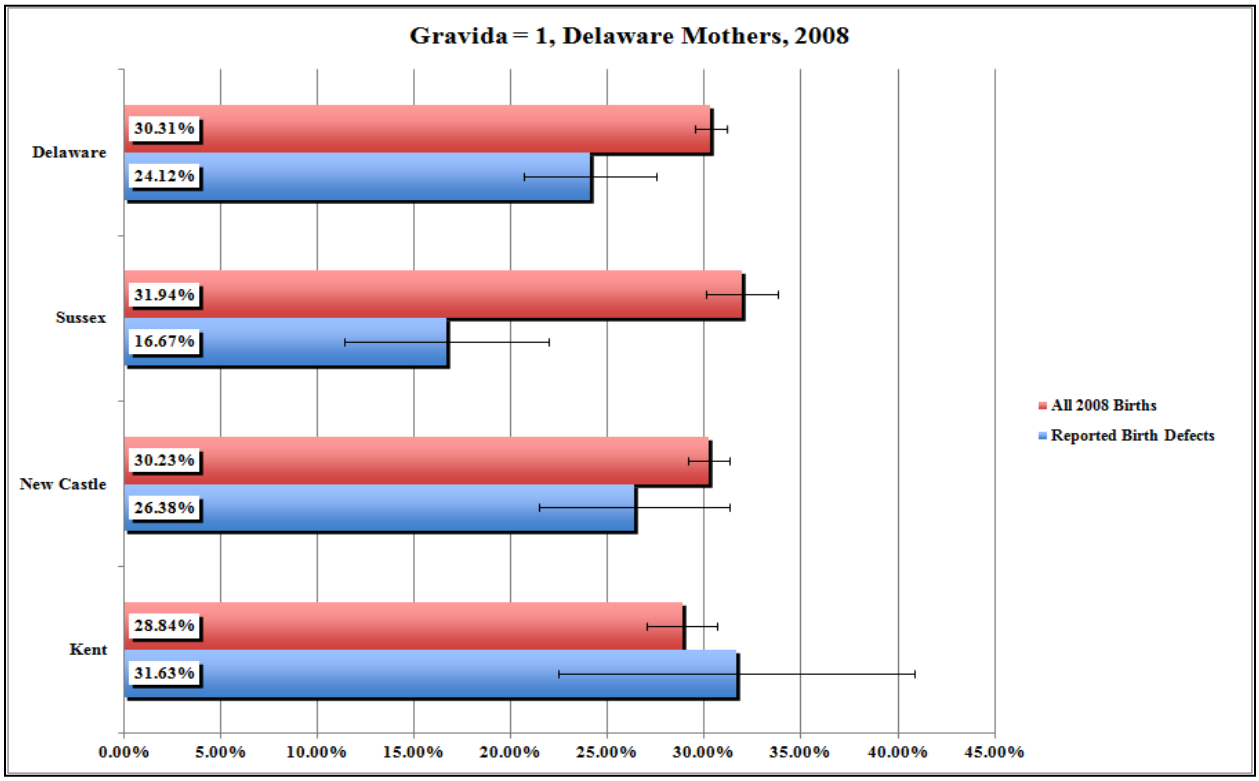
Source: State of Delaware 2008 Birth Defects Registry

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

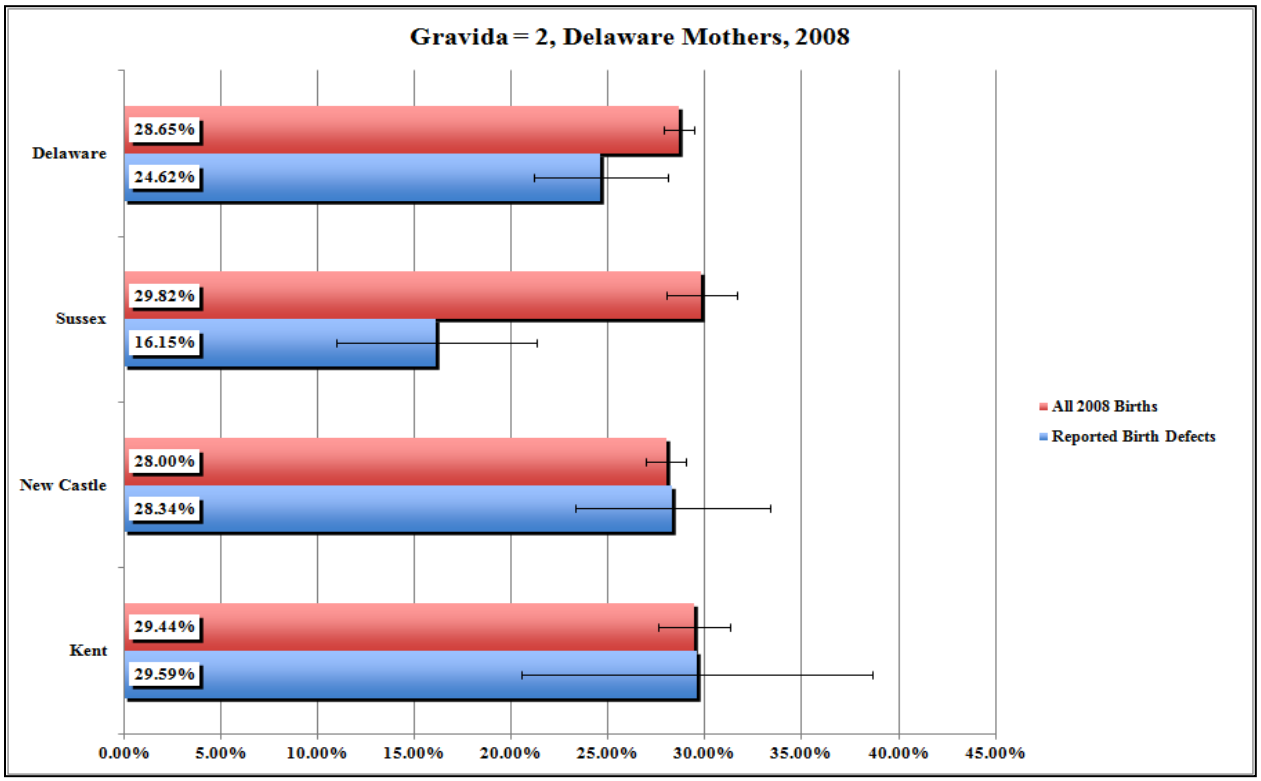


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.2. Gravida.

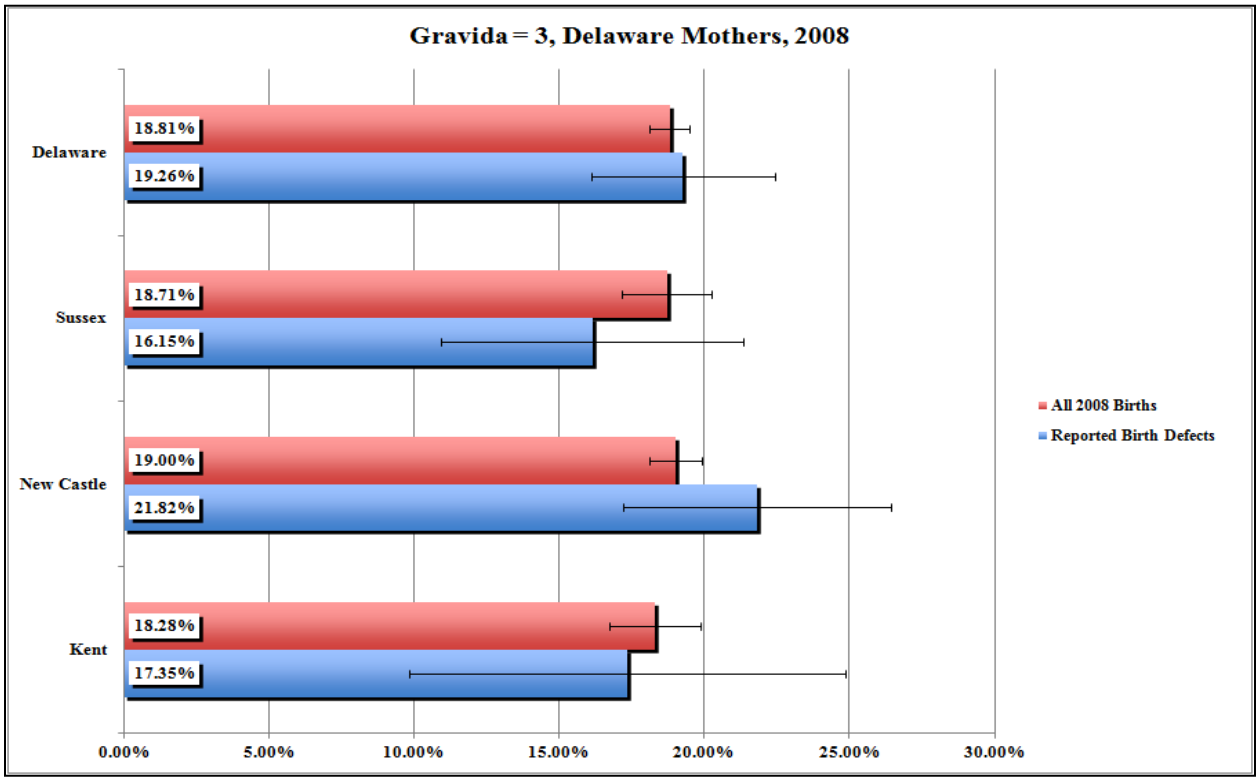


Source: State of Delaware 2008 Birth Defects Registry

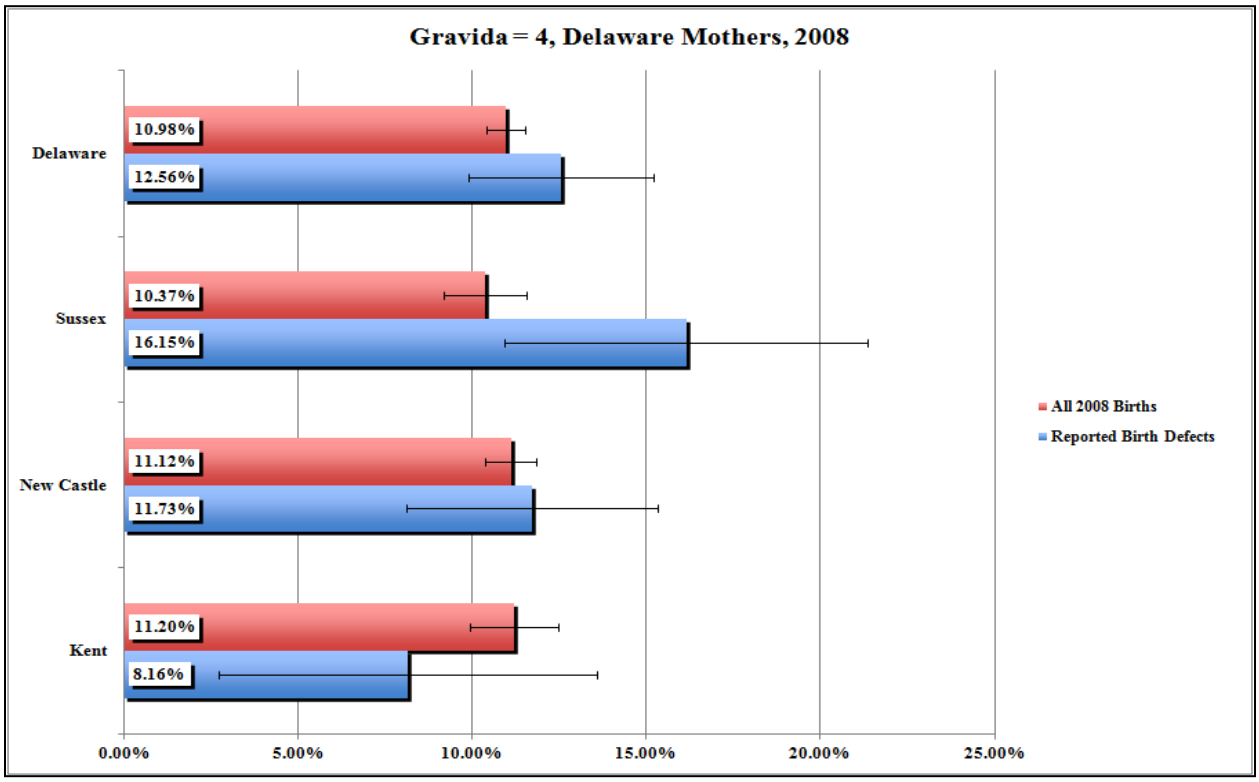


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

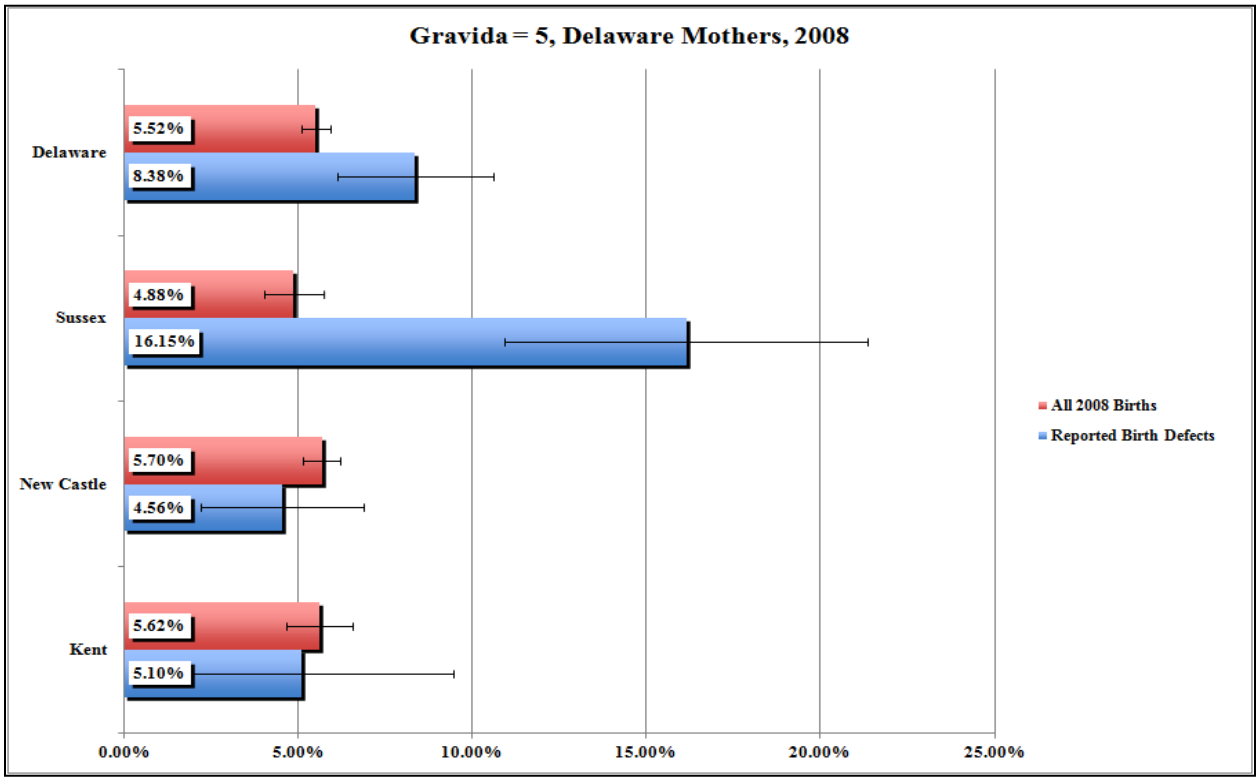


Source: State of Delaware 2008 Birth Defects Registry

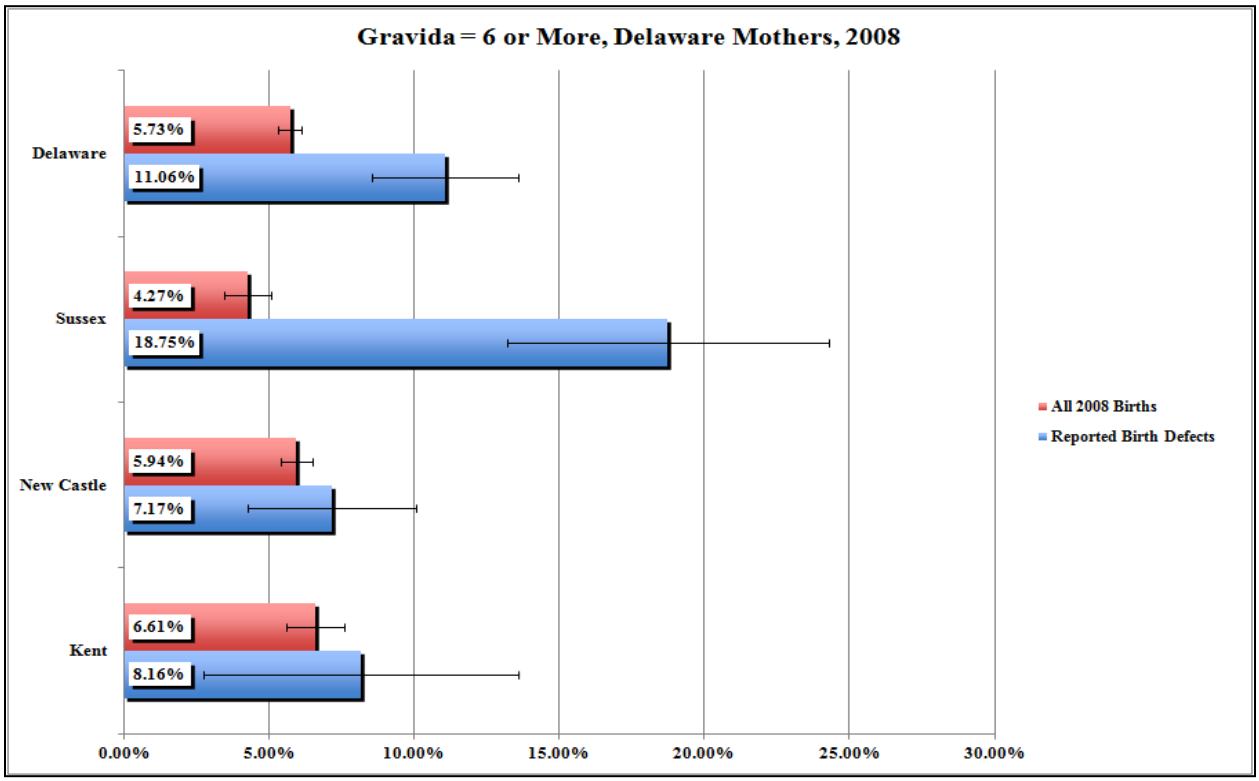


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

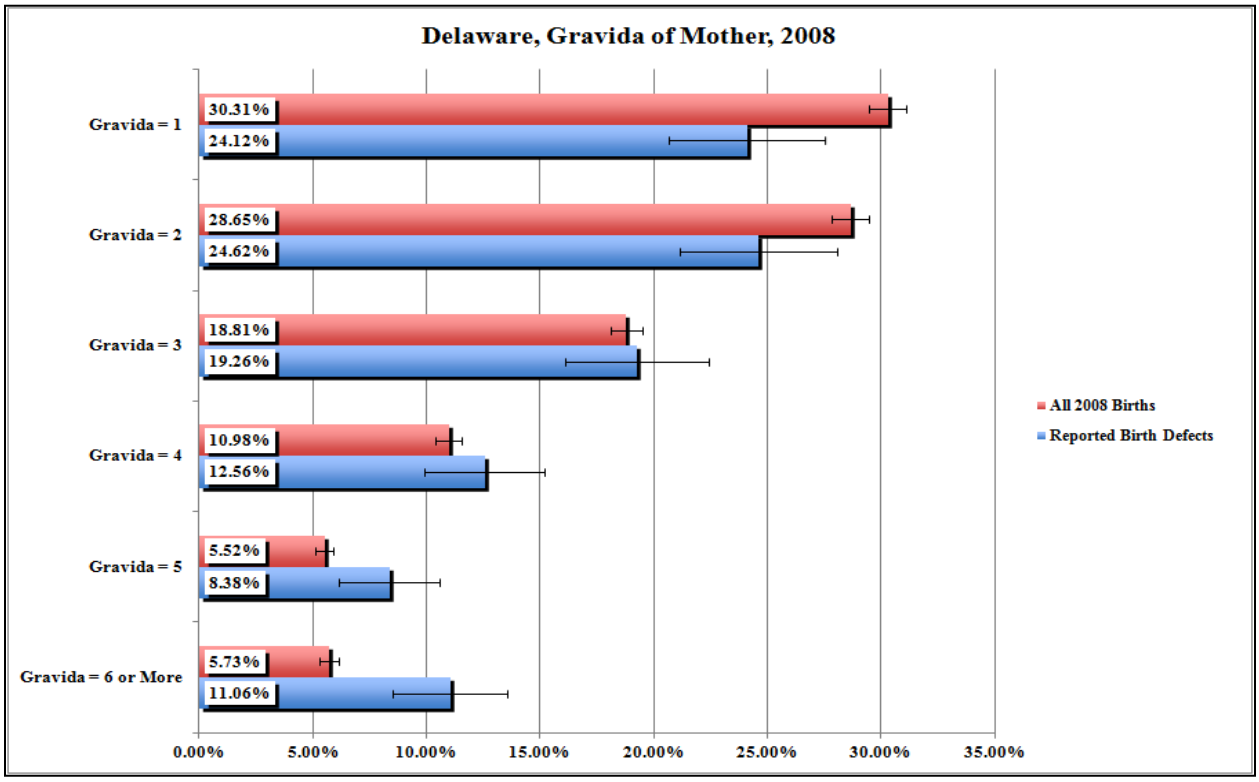


Source: State of Delaware 2008 Birth Defects Registry

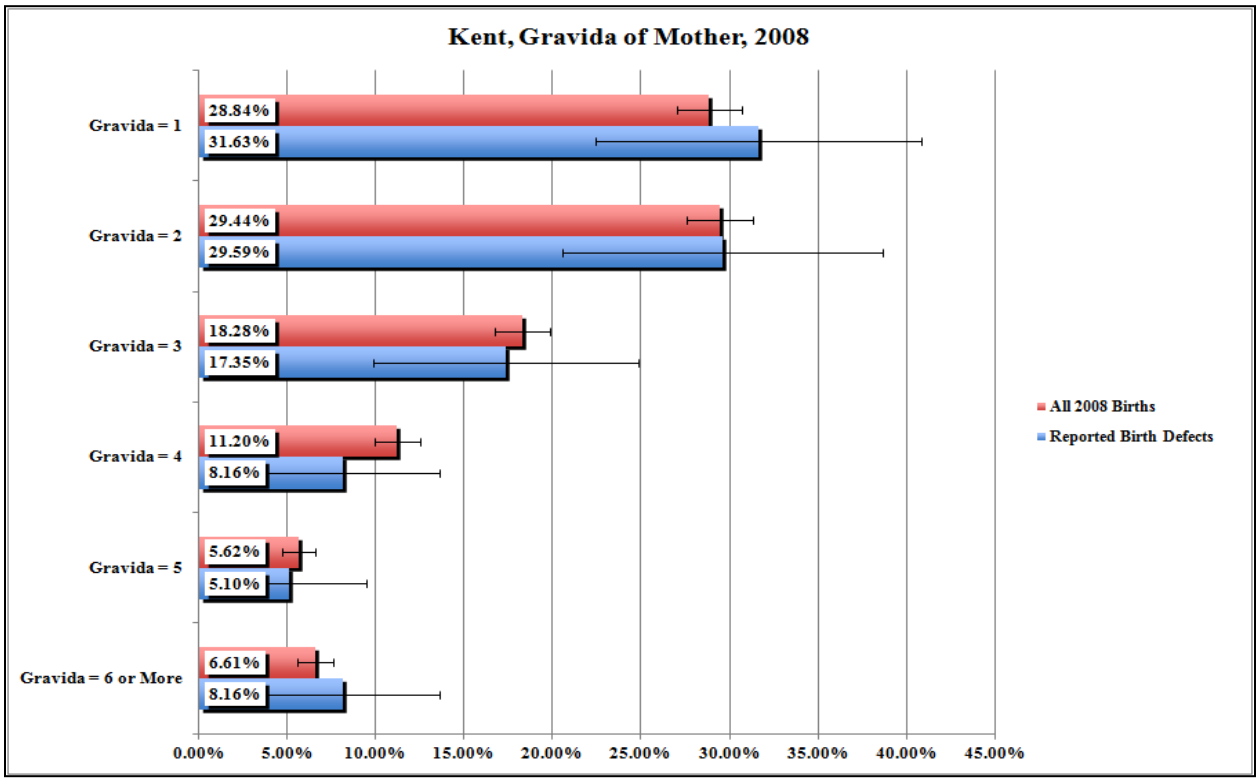


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

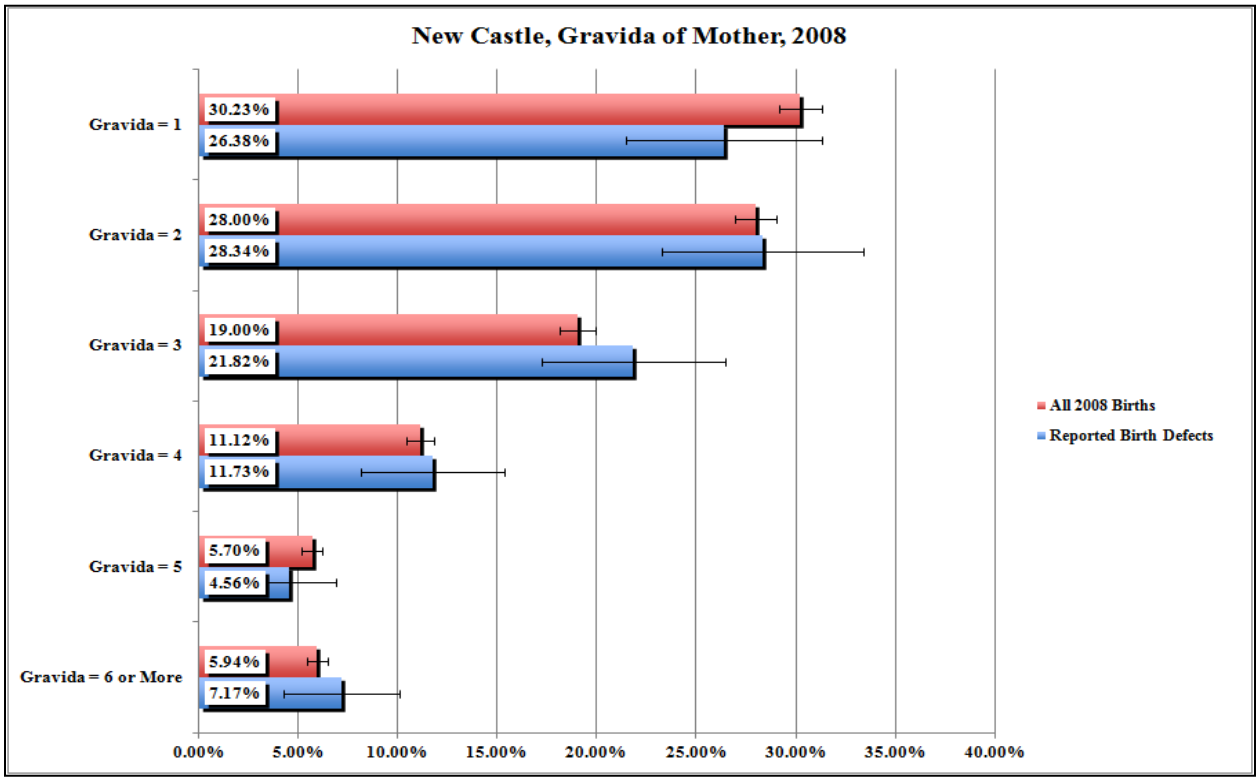


Source: State of Delaware 2008 Birth Defects Registry

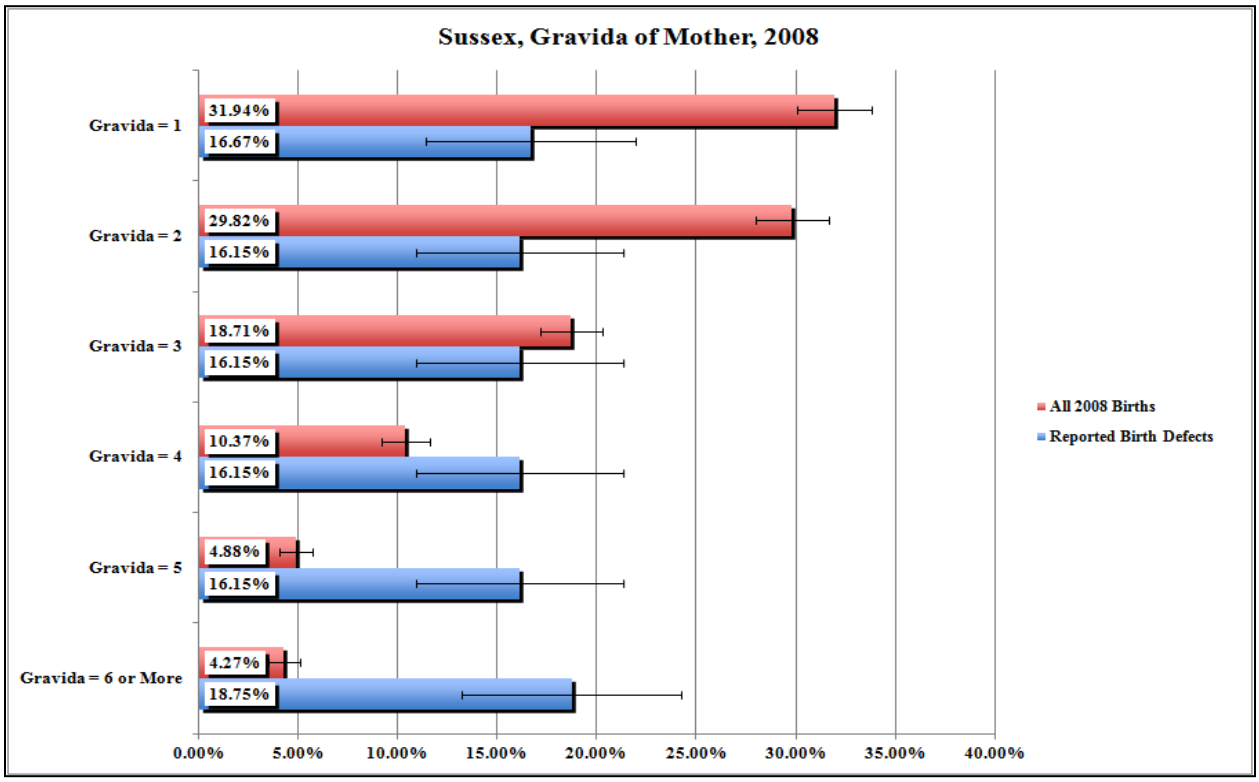


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.2. Gravida. *Continued*

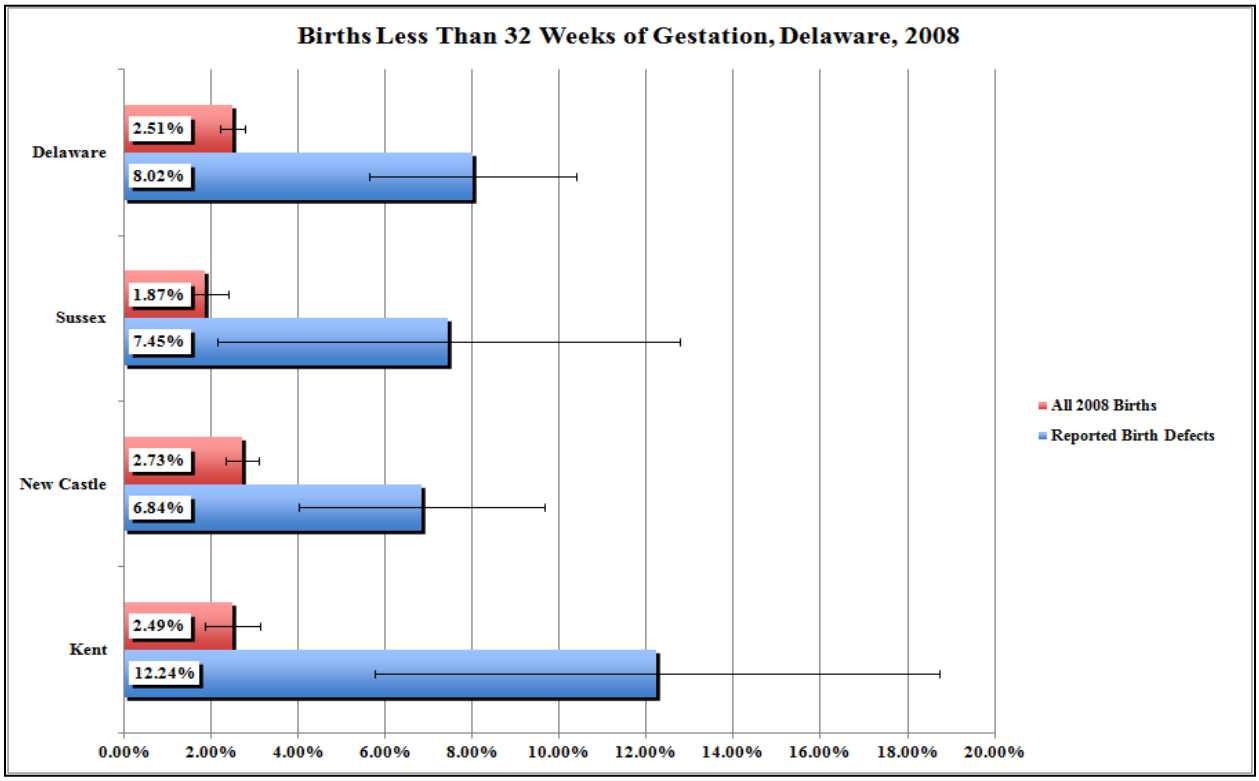


Source: State of Delaware 2008 Birth Defects Registry

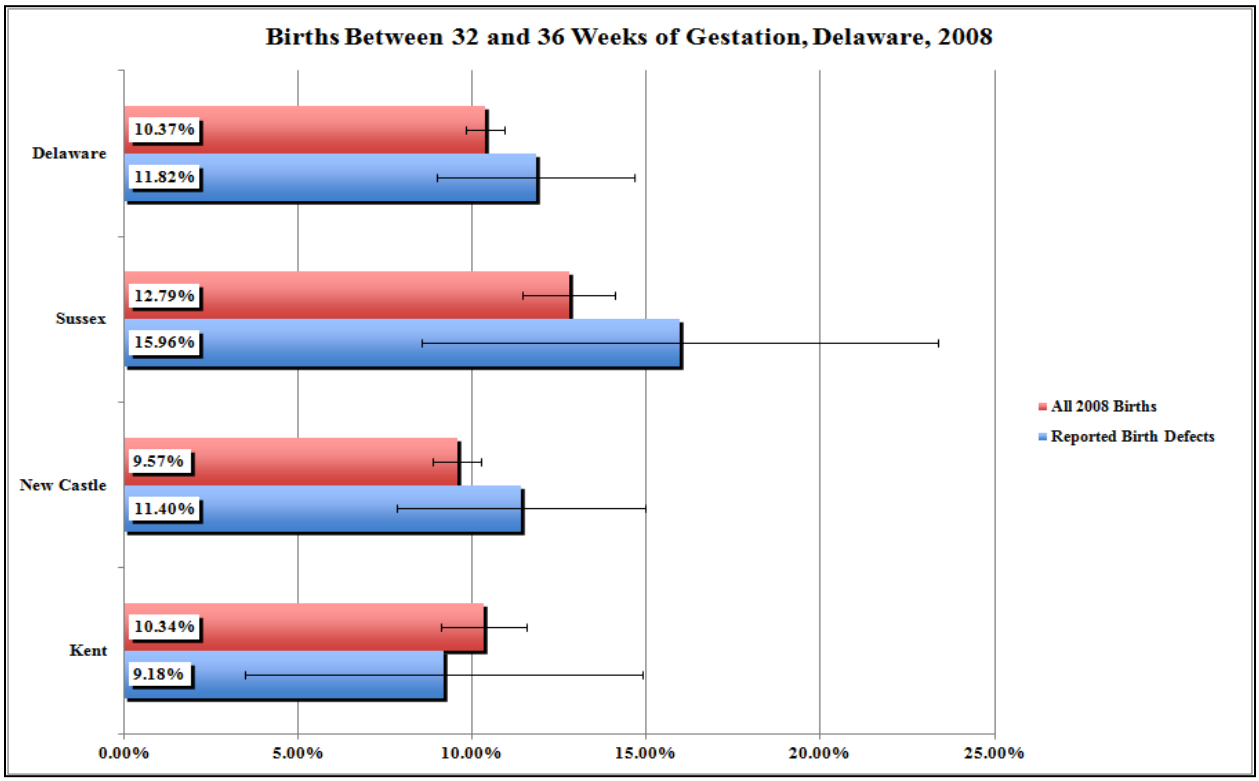


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.3. Gestational Weeks.

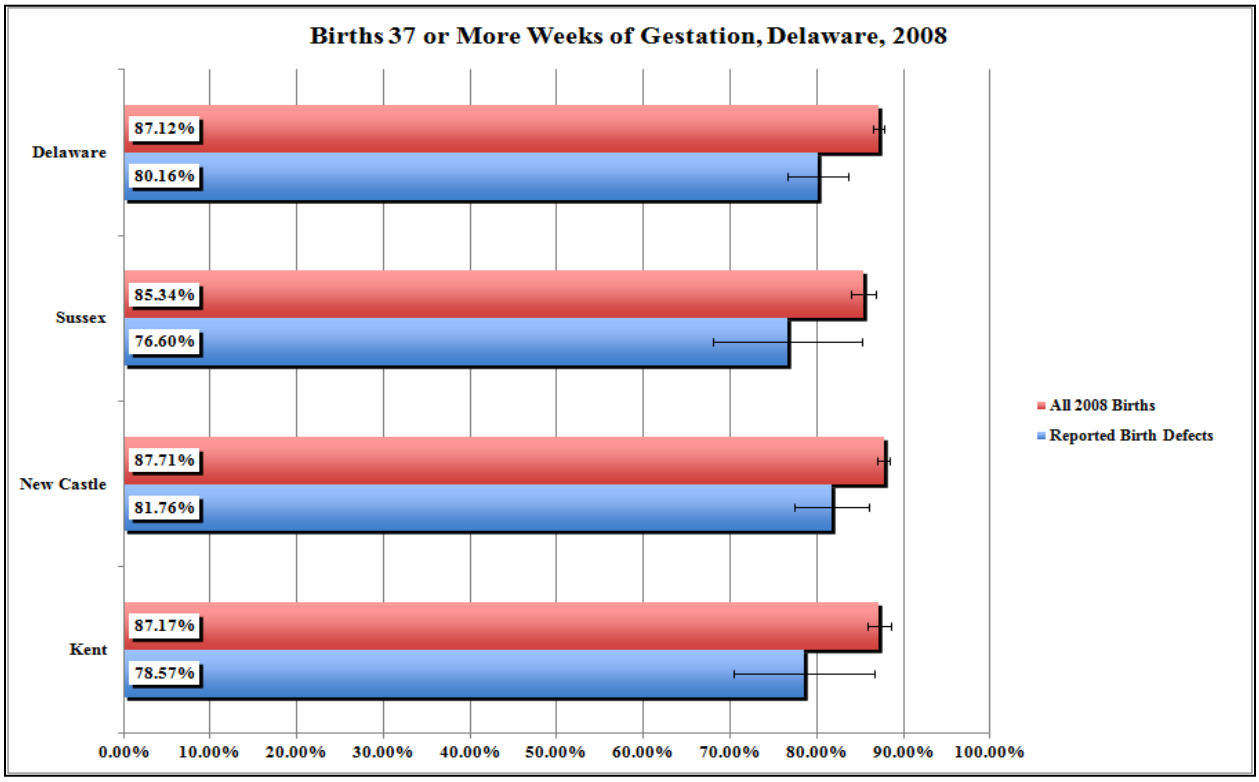


Source: State of Delaware 2008 Birth Defects Registry

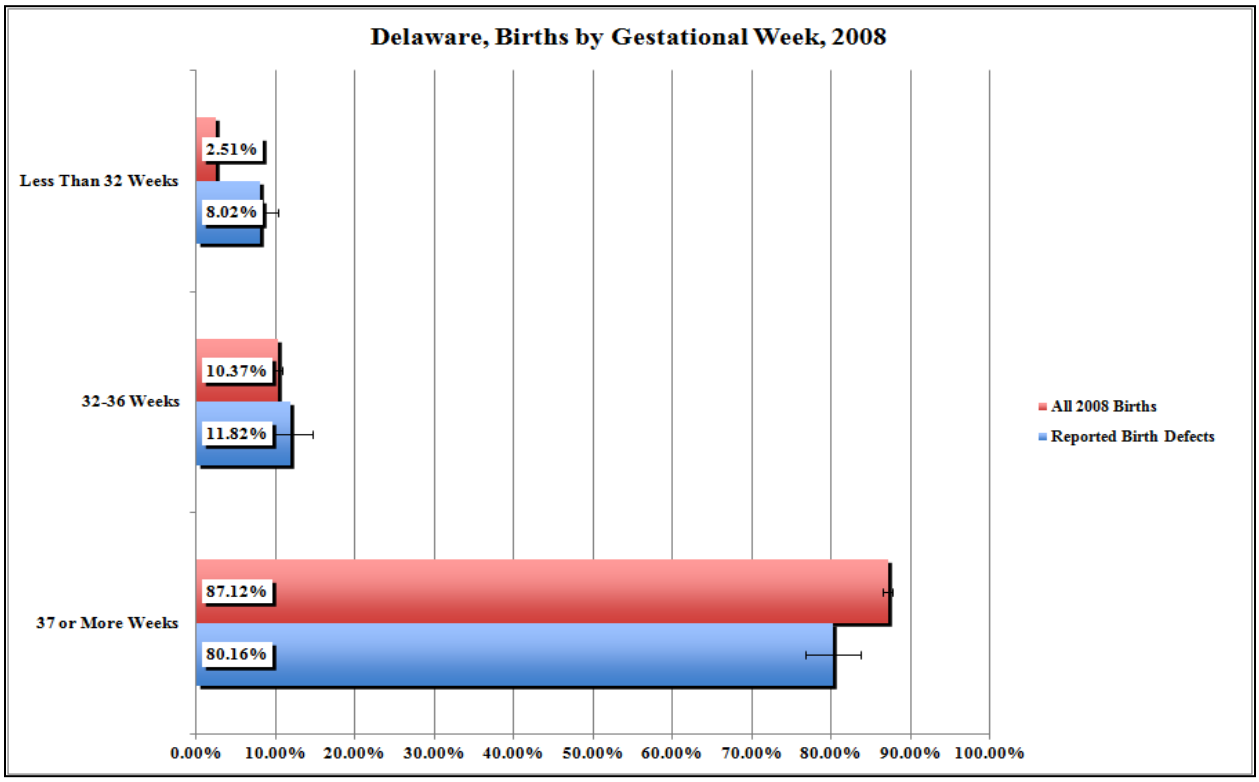


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.3. Gestational Weeks. *Continued*

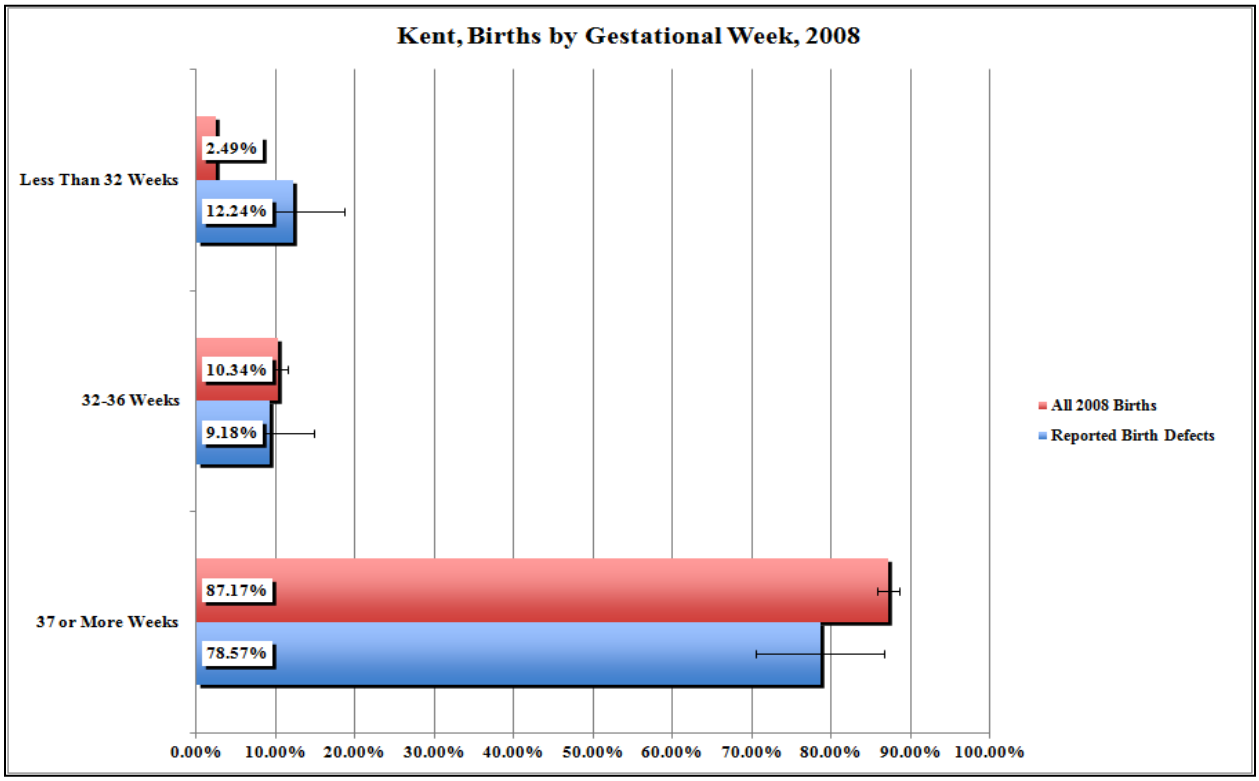


Source: State of Delaware 2008 Birth Defects Registry

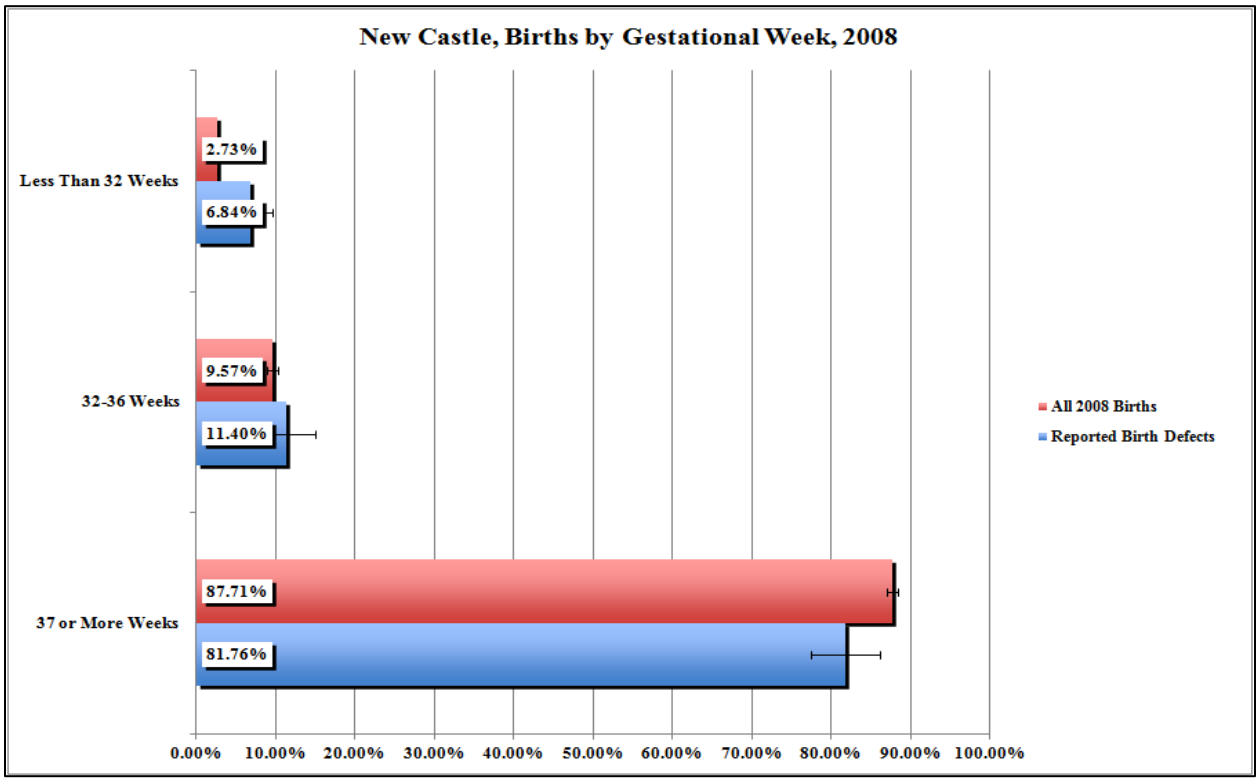


Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.3. Gestational Weeks. *Continued*

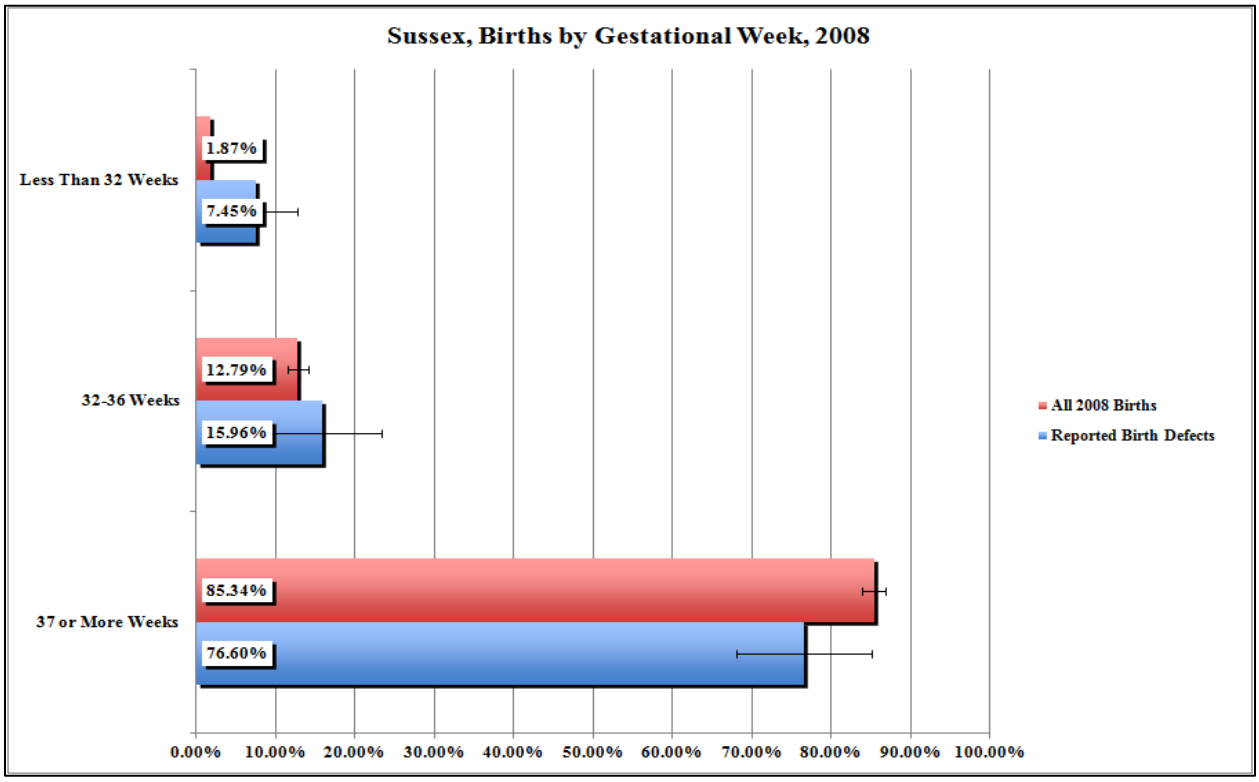


Source: State of Delaware 2008 Birth Defects Registry



Source: State of Delaware 2008 Birth Defects Registry

APPENDIX C.3. Gestational Weeks. *Continued*



Source: State of Delaware 2008 Birth Defects Registry

REFERENCES

[1] March of Dimes. (2011). Birth defects. Retrieved from March of Dimes website: http://www.marchofdimes.com/Baby/birthdefects.html.
[2] Centers for Disease Control and Prevention. (2006). Improved national prevalence estimates for 18 selected major birth defects – United States, 1999-2001. *MMWR*, 54(51,52): 1301-5.
[3] Mathews, T. and MacDorman, M. (2008, July). Infant mortality statistics from the 2005 period linked birth/infant death data set. *Nat Vit Stat Rep*, 57, 2.
[4] Delaware Health Statistics Center. (2011, February). *Delaware Vital Statistics Annual Report, 2008.* Retrieved from Department of Health and Social Services, Division of Public Health website: http://www.dhss.delaware.gov/dhss/dph/hp/annrepvs.html.
[5] Delaware Health and Social Services, Division of Public Health. (2011, April). *Delaware Birth Defects Surveillance Registry Program*. Retrieved from Delaware Health and Social Services, Division of Public Health website: http://dhss.delaware.gov/dph/chca/dphbdr1.html.
[6] Centers for Disease Control and Prevention. National Center for Health Statistics. VitalStats. http://www.cdc.gov/nchs/vitalstats.htm.
[7] Delaware Department of Health and Social Services, Division of Public Health. (2010, June). *Perinatal Periods of Risk Analysis*. Retrieved from Department of Health and Social Services, Division of Public Health website: http://dhss.delaware.gov/dhss/dph/chca/files/perinatalrisk082010.pdf.
[8] Delaware Department of Health and Social Services, Division of Public Health. (2010, September). *Delaware Pregnancy Risk Assessment Monitoring System (PRAMS) 2008 Analysis*. Retrieved from Department of Health and Social Services, Division of Public Health website: http://dhss.delaware.gov/dhss/dph/chca/files/pram2008finaloct20.pdf.
[9] Honein, M. et al. (2009). The association between major birth defects and preterm birth. *Mat Child Health J*, 13(2): 164-75.
[10] Swamy, G., Ostbye, T., Skjaerven, R. (2008). Association of preterm birth with long-term survival, reproduction, and next-generation preterm birth. *JAMA*, 299(12): 1429-36.
[11] Grummer-Strawn, L., Reinold, C., Krebs, N. (2010). Use of World Health Organization and CDC growth charts for children aged 0-59 months in the United States. *MMWR Recomm Rep*, 59(RR-9): 1-15.