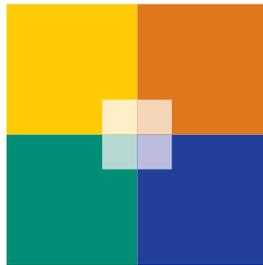


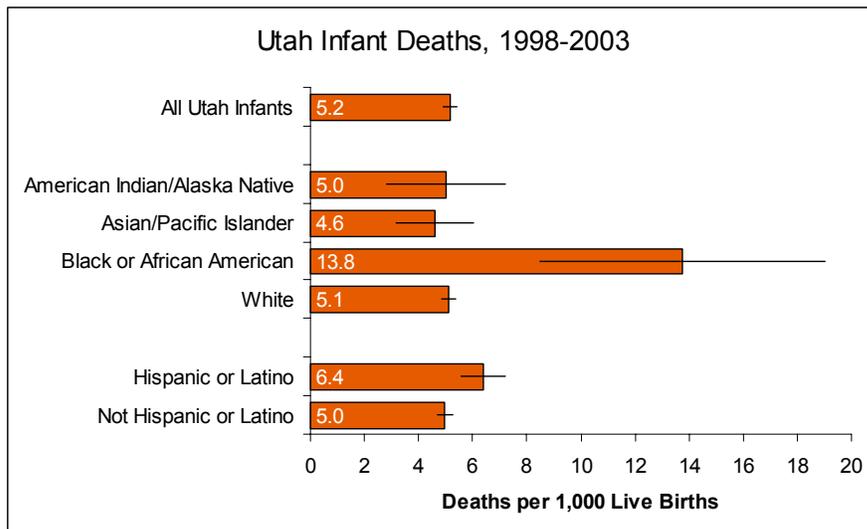
HEALTH PROBLEMS OF MOTHERS AND INFANTS



Infant Mortality

Why Is It Important?

The infant death rate is an important measure of a nation's health and a worldwide indicator of health status and social well-being. It is a critical indicator of the health of a population. Three causes account for more than half of all infant deaths: birth defects, conditions in the perinatal period (includes disorders of short gestation and can reflect the overall state of maternal health, as well as the quality and accessibility of primary health care for pregnant women), and SIDS. Infant mortality, when resulting from a complicated delivery, is associated with increased risk of maternal mortality.



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How Are We Doing?

- From 1998 through 2003, there were 5.2 infants who died during their first year of life in Utah per 1,000 infants born. During 2003, 248 Utah infants died during their first year of life.
- From 1998 through 2003, the infant death rates for infants born to Black/African American and Hispanic/Latina mothers were higher than the overall state rate at 13.8 and 6.4 per 1,000 live births, respectively.

How Can We Improve?

Infant mortality rates are slightly higher in the Utah Hispanic/Latino population than in the population overall. However, the infant mortality rate for Black/African American infants is dramatically higher than other racial and ethnic groups. Conditions in the perinatal period account for the largest proportion of deaths in Black/African American infants. These conditions include disorders of short gestation and can reflect the overall state of maternal health, as well as the quality and accessibility of primary health care for pregnant women. Analysis of data to identify risk factors associated with infant mortality in Utah is complicated by the fact that our population numbers are small. However, case review of infant

deaths is accomplished through several Utah Department of Health, Community and Family Health Services programs. These programs utilize a mortality review process which is aimed at identifying and examining the factors that contributed to the infant deaths in order to identify public health strategies to improve outcomes.

Utah Infant Mortality, 1998-2003

Race/Ethnicity	Avg Annual # of Deaths	Total Live Births	Rate per 1,000 Births (95% CI Range)	Sig.**
All Utah Infants	245	47,599	5.2 (4.9 - 5.4)	n/a
American Indian/Alaska Native	3	665	5.0 (2.8 - 7.2)	
Asian/Pacific Islander	7	1,445	4.6 (3.2 - 6.0)	
Black or African American	4	315	13.8 (8.5 - 19.0)	↑
White	229	44,782	5.1 (4.9 - 5.4)	
Hispanic or Latino	40	6,163	6.4 (5.6 - 7.2)	↑
Not Hispanic or Latino	206	41,436	5.0 (4.7 - 5.2)	

Source: UDOH, Office of Vital Records and Statistics, Death Certificate Database

** The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.



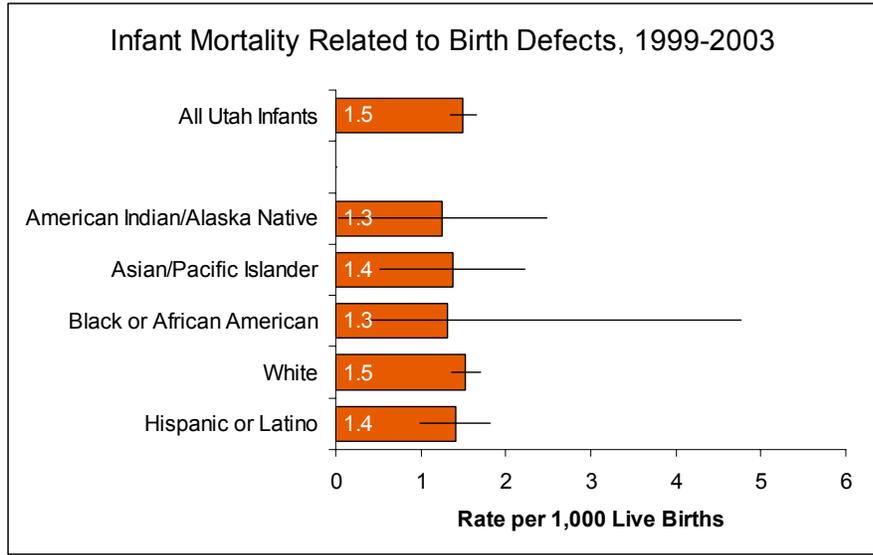
Health Problems of Mothers/Infants

Infant Mortality Related to Birth Defects

Why Is It Important?

Birth defects are the leading cause of infant mortality. They are directly associated with one of every four deaths among infants in Utah. Thus, preventing birth defects is a key to improving children's survival and health. Preventing birth defects requires a combination of surveillance to track and assess these conditions, research to find their causes, and direct prevention services, to ensure that all women and their providers know of effective primary prevention already available,

such as periconceptional folic acid to prevent neural tube defects (see page 47). It is also important that families have the resources to help them in the difficult times following the tragic loss of their child with a birth defect. The Utah Birth Defect Network (UBDN) is engaged in activities to help prevent birth defects through surveillance and services, as well as to provide resource information to families who have experienced the death of a baby and their providers.



How Are We Doing?

During 1999–2003, infant mortality among babies with a birth defect was 72 per 1,000, more than 10 times higher than the overall infant mortality in Utah (5 per 1,000). Thus, even if only 3 in 100 babies are born with a birth defect, they contribute to 3 in 10 infant deaths in Utah (1.5 of the 5 infant deaths per 1,000 live births). There was little variation among Utah's racial and ethnic populations.

How Can We Improve?

With improvements in the control and treatment of infection and prematurity, the relative impact of birth defects on infant mortality is likely to increase over time, unless known primary prevention strategies are implemented and others are found. Surveillance, research, and primary prevention services are keys to reducing infant mortality due to birth defects. The UBDN currently contributes to tracking and

assessing impact, trends, and disparities related to birth defects-related mortality. Organizations that offer resources and support to families who have experienced the death of an infant include the SHARE Pregnancy and Infant Loss Support, Inc. (www.nationalshareoffice.com), The Compassionate Friends, Inc. (www.compassionatefriends.org), and Bereaved Parents of the USA (www.bereavedparentsusa.org).

Infant Mortality Related to Birth Defects, Utah, 1999-2003

Race/Ethnicity	Average Annual #	Total Live Births	Rate per 1,000 Births (95% CI Range)	Sig.*
All Utah Infants	72	48,046	1.5 (1.3 - 1.6)	n/a
American Indian/Alaska Native	1	640	1.3 (0.0 - 2.5)	
Asian/Pacific Islander	2	1,459	1.4 (0.5 - 2.2)	
Black or African American	<1	305	1.3 (0.4 - 4.8)	
White	60	38,989	1.5 (1.4 - 1.7)	
Hispanic or Latino	9	6,411	1.4 (1.0 - 1.8)	

Source: UDOH, Utah Birth Defect Network

Note: Individuals were classified into only one race/ethnic category.

* The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.

Low Birth Weight

Why Is It Important?

Low birth weight increases the risk for infant mortality and morbidity. As birth weight decreases, the risk for death increases. Low birth weight infants who survive often require intensive care at birth, may develop chronic illnesses, and later may require special education services. Health care costs and length of hospital stay are higher for low birth weight infants.

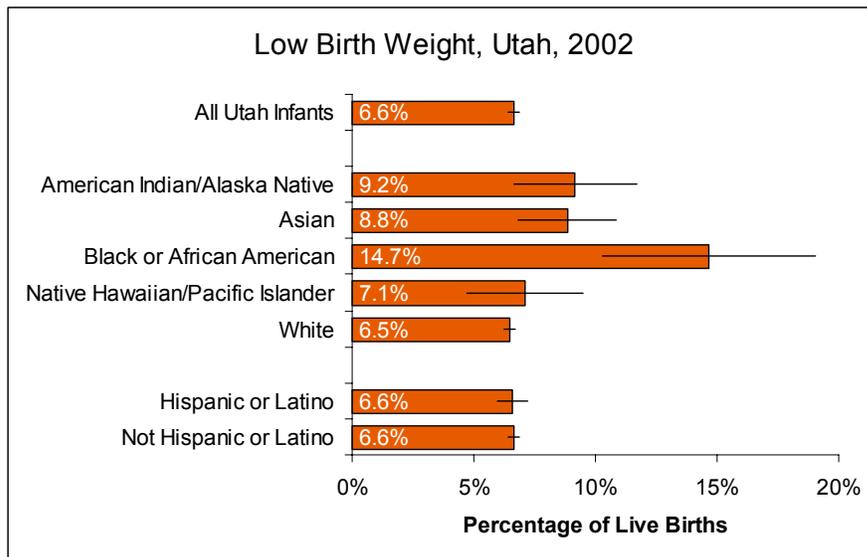
How Are We Doing?

- In 2002, 6.6% of all live births produced infants who weighed less than 2,500 grams (about 5.5 lbs) at birth.
- Babies born to Black/African American, American Indian/Alaska Native, and Asian mothers were at greater-than-average risk of being low birth weight.

How Can We Improve?

Low birth weight rates for Utah's racial minorities are higher than for Utah's White population, with rates for Black women being almost twice that of White women. The etiology of Black-White disparities in low birth weight is complex and is not explained entirely by demographic risk factors such as maternal age, education, or income. Among the factors that might contribute to the disparity is a difference in medical conditions before and during pregnancy. Studies have noted that the higher proportion of Black infants born at very low birth weights (VLBW) was related to an elevated risk in their mothers of major conditions associated with VLBW, primarily chorioamnionitis or premature rupture of the membranes, hypertensive disorders, and hemorrhage. Black women have also been noted to experience higher rates of non-sexually transmitted urogenital tract infections, including bacteriuria, bacterial vaginosis, and Group B streptococcal vaginal colonization, which are risk factors for preterm birth. Risk factors for these non-sexually transmitted

infections are not well understood, however vaginal douching, a health behavior practiced purportedly more frequently in Black than White women, has been linked to alterations in vaginal flora and to ascending urogenital tract infection. Analysis of data to identify risk factors associated with LBW births among Black women in Utah is complicated by the fact that our population numbers are small.



Percentage of Utah Infants With Low Birth Weight, 2002

Race/Ethnicity	# LBW	Total Live Births	Crude Rate (95% CI Range)	Sig.*
All Utah Infants	3,261	49,140	6.6% (6.4% - 6.9%)	n/a
American Indian/Alaska Native	61	666	9.2% (7.1% - 11.7%)	↑
Asian	84	950	8.8% (7.2% - 10.9%)	↑
Black or African American	49	334	14.7% (11.2% - 19.0%)	↑
Native Hawaiian/Pacific Islander	44	619	7.1% (5.3% - 9.5%)	
White	3,002	46,207	6.5% (6.3% - 6.7%)	
Hispanic or Latino	459	6,984	6.6% (6.0% - 7.2%)	
Not Hispanic or Latino	2,785	41,998	6.6% (6.4% - 6.9%)	

Source: UDOH, Office of Vital Records and Statistics, Birth Certificate Database

Note: Low birth weight was defined as less than 2,500 grams (about 5 lbs. 8 oz.)

* The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.

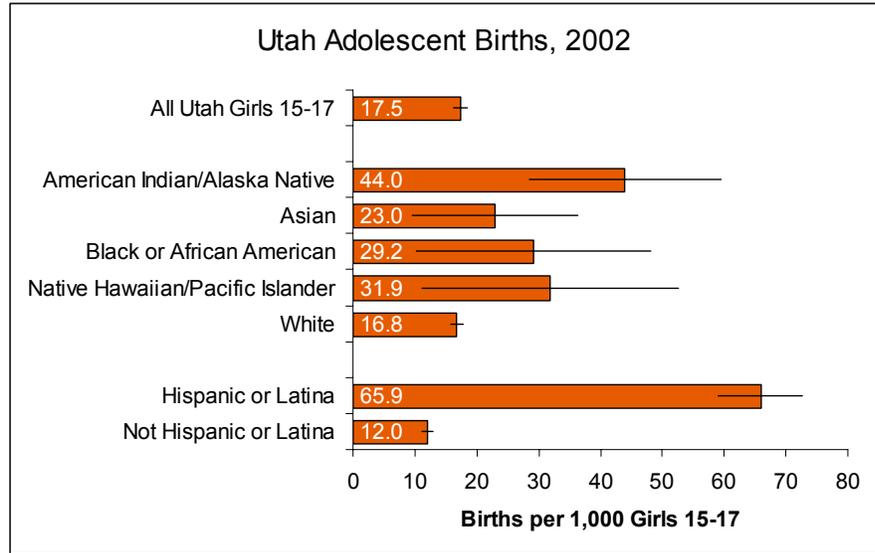


Health Problems of Mothers/Infants

Adolescent Births

Why Is It Important?

Compared to babies born to older mothers, babies born to adolescent mothers, particularly young adolescent mothers, are at higher risk of low birth weight and infant mortality. These babies are more likely to grow up in homes that offer lower levels of emotional support and cognitive stimulation, and they are less likely to earn a high school diploma. For the mothers, giving birth during adolescence is associated with limited educational attainment, which in turn can reduce future employment prospects and earning potential.



How Are We Doing?

- The number of Utah girls aged 15 to 17 who gave birth in 2002 was 17.5 per 1,000 girls.
- Adolescent births were significantly more common among Hispanic/Latina (65.9), American Indian/Alaska Native (44.0), and Native Hawaiian/Pacific Islander Utah girls (31.9 births per 1,000 girls). The rate among Hispanic/Latina girls aged 15 to 17 was nearly four times the overall state rate, with 1 of every 15 girls having given birth in 2002.

How Can We Improve?

Prevention of teen pregnancy includes programs to encourage sexual abstinence for all teens and family planning services for sexually active teens. A detailed report on adolescent pregnancy in Utah has been published by the Utah Department of Health and can be accessed on the Internet (www.health.utah.gov/cash).

The Utah Department of Health funds eight abstinence-only community-based projects for youth aged 9–14 throughout the state with federal abstinence education monies.

Births to Utah Adolescent Girls (Age 15-17), 2002

Race/Ethnicity	# Births to Teens	Total Girls 15-17	Crude Rate per 1,000 (95% CI Range)	Sig.*
All Utah Girls 15-17	998	57,190	17.5 (16.4 - 18.5)	n/a
American Indian/Alaska Native	42	955	44.0 (31.7 - 59.4)	↑
Asian	18	781	23.0 (13.7 - 36.4)	
Black or African American	15	514	29.2 (16.3 - 48.1)	
Native Hawaiian/Pacific Islander	15	470	31.9 (17.9 - 52.6)	↑
White	900	53,508	16.8 (15.7 - 17.9)	
Hispanic or Latina	337	5,116	65.9 (59.1 - 72.7)	↑↑
Not Hispanic or Latino	660	54,894	12.0 (11.1 - 12.9)	↓↓

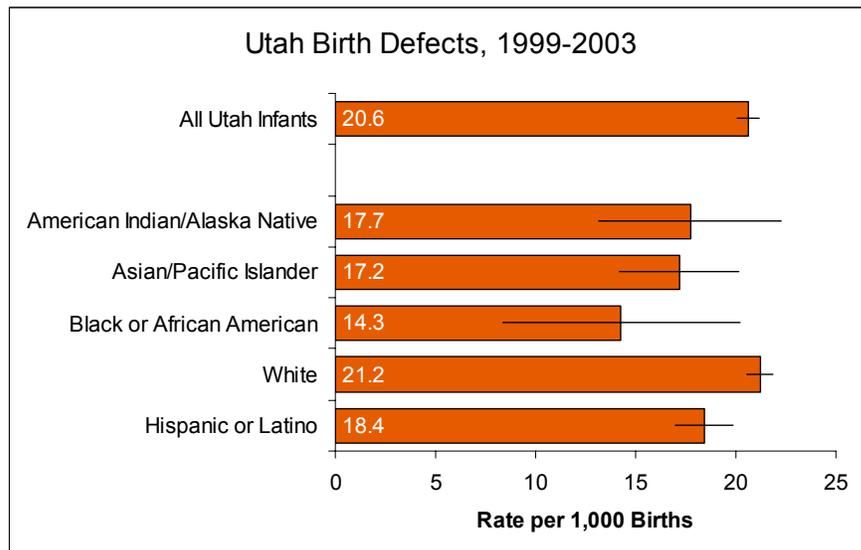
Source: UDOH, Office of Vital Records and Statistics, Birth Certificate Database

* The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.

Overall Birth Defects

Why Is It Important?

Birth defects are a major cause of stillbirths and infant deaths. People with birth defects are also at increased risk for chronic illness, disability, and premature death. Because Utah has the highest birth rate in the nation, birth defects are an especially important issue here. Assessing the distribution of birth defects and their impact over time and in racial/ethnic groups provides crucial evidence to direct health care planning, provide efficient services, identify disparities, and provide inroads into the search of causes.



How Are We Doing?

- During 1999–2003 the overall rate of major structural birth defects was 20.6 per 1,000, or 1 in 48 births. Because the UBDN does not monitor every type of birth defect, this number is actually lower than the actual rate for all birth defects.
- According to the UBDN, 17.7% of birth defects have a genetic origin (a chromosomal or single gene condition), 0.4% have an environmental origin (including maternal illnesses and medications), and 0.1% are due to twinning. In the remaining 81.8%, the cause is unknown.
- Birth defects also contribute to prematurity, another major cause of preventable mortality and disability. In 2003, 20.2% of babies with birth defects were premature compared to 9.5% of all Utah newborns.
- Although overall birth defect rates vary somewhat by race and ethnicity, it is also important to assess rates of individual defects. This report presents such assessment for selected major birth defects.

How Can We Improve?

We can improve with better surveillance, research, and primary prevention services. Currently the UBDN in partnership with local and national organizations is (1) tracking all major birth defects to assess trends, address community concerns, examine clustering, and quantify morbidity and mortality; (2) searching for causes of birth defects in collaboration with and with funding from the U.S. Centers for Disease Control and Prevention (CDC); and (3) promoting and evaluating primary prevention of severe birth defects, including education campaigns among women and health care providers to promote the use of the B-vitamin folic acid to prevent spina bifida and other neural tube defects.

Birth Defects, Utah, 1999-2003

Race/Ethnicity	Average Annual #	Total Births	Rate per 1,000 Births (95% CI Range)	Sig.*
All Utah Infants	990	48,039	20.6 (20.0 - 21.8)	n/a
American Indian/Alaska Native	11	643	17.7 (13.2 - 22.3)	↓
Asian/Pacific Islander	25	1,467	17.2 (14.2 - 20.1)	↓
Black or African American	4	308	14.3 (8.4 - 20.2)	↓
White	830	39,170	21.2 (20.6 - 21.8)	↓
Hispanic or Latino	119	6,450	18.4 (17.0 - 19.9)	↓

Source: UDOH, Utah Birth Defect Network

Note: Individuals were classified into only one race/ethnic category. "Total births" include all live births plus fetal deaths.

* The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.



Folic Acid Consumption

Why Is It Important?

Folic acid, a B-vitamin, can prevent many neural tube defects (NTDs), which are severe defects of the brain and spine (see page 47). The occurrence of NTDs could be reduced by more than half if women consumed adequate folic acid (400 micrograms) daily from at least one month before conception through the first months of pregnancy. Because approximately 50% of pregnancies are unplanned, it is important for every woman to consume a multi-vitamin with folic acid whether contemplating pregnancy or not.

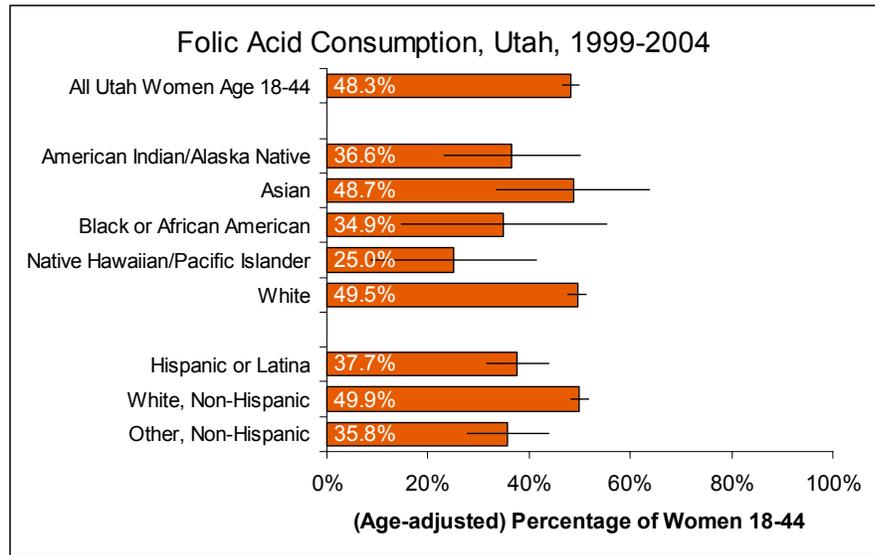
Food fortification with folic acid, mandated in 1998, has increased intake, but does not provide enough folic acid to prevent NTDs for all women of childbearing age.

How Are We Doing?

- Nearly half (48.3%) of all Utah women aged 18 to 44 reported that they were taking vitamins or supplements with 400 micrograms of folic acid daily.
- Folic acid consumption was significantly lower among Native Hawaiian/Pacific Islander and Hispanic/Latina women aged 18–44, and also somewhat lower among those in Utah’s Black/African American and American Indian/Alaska Native communities.

How Can We Improve?

The U.S. Public Health Service recommended in 1992 that all women of childbearing age consume 400 micrograms of folic acid daily. Continuing to educate women, particularly young women entering childbearing years is critical. Educational campaigns need to target minority groups reporting lower rates of folic acid consumption. The effect of these campaigns needs to be assessed regularly through surveys, and the effect on NTD rates needs to be tracked by ongoing birth defects monitoring.



Percentage of Utah Women (Age 18-44) Who Reported Taking Folic Acid Daily, 1999-2004

Race/Ethnicity	Sample Size	# Females 18-44	# Taking Folic Acid	Crude Rate (95% CI Range)	Age-adjusted Rate* (95% CI Range)	Sig.**
All Utah Women Age 18-44	6,397	466,492	223,633	47.9% (46.3% - 49.6%)	48.3% (46.6% - 50.0%)	n/a
American Indian/Alaska Native	86	7,429	2,717	36.6% (23.1% - 50.1%)	36.6% (23.1% - 50.1%)	
Asian	63	11,103	5,107	46.0% (30.2% - 61.8%)	48.7% (33.5% - 63.8%)	
Black or African American	30	4,035	1,695	42.0% (14.2% - 69.8%)	34.9% (14.6% - 55.3%)	
Native Hawaiian/Pacific Islander	36	3,431	883	25.7% (9.2% - 42.3%)	25.0% (8.6% - 41.3%)	↓
White	5,897	440,494	215,966	49.0% (47.3% - 50.7%)	49.5% (47.7% - 51.2%)	
Hispanic or Latina	446	42,870	15,706	36.6% (30.6% - 42.6%)	37.7% (31.7% - 43.8%)	↓
White, Non-Hispanic	5,675	399,654	197,984	49.5% (47.8% - 51.3%)	49.9% (48.1% - 51.7%)	
Other, Non-Hispanic	244	23,968	8,727	36.4% (28.1% - 44.8%)	35.8% (27.8% - 43.8%)	↓

Source: Behavioral Risk Factor Surveillance System

*Age adjusted to the U.S. 2000 standard population

** The age-adjusted rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.



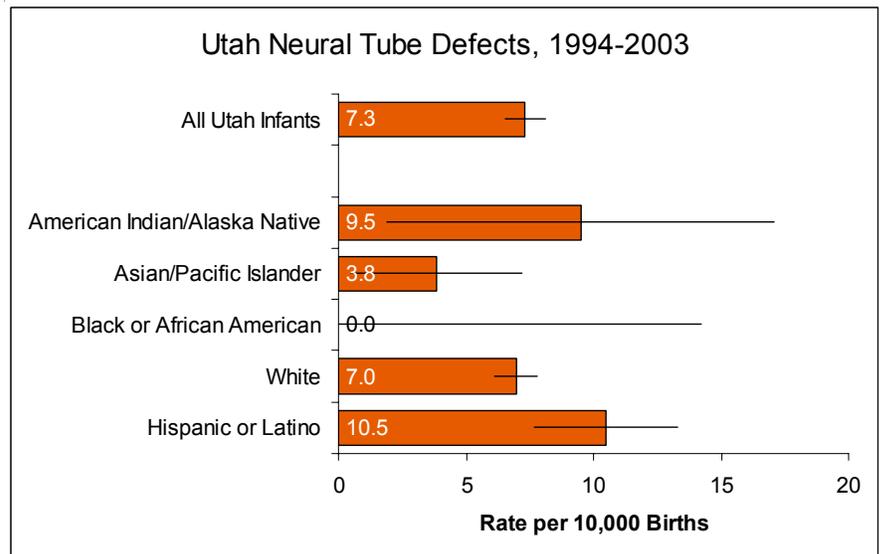
Health Problems of Mothers/Infants

Neural Tube Defects

Why Is It Important?

Neural tube defects (NTDs) are severe malformations of the brain and spine that cause premature death, chronic illness, and disabilities. The two most common NTDs are anencephaly and spina bifida. NTDs occur in the very early weeks of pregnancy, but many can be prevented by women taking the B-vitamin folic acid daily from before conception through early pregnancy. It is crucial that all women and their providers know this information.

Much can be done to improve the health and prevent disabilities in children who are born with NTDs. These children often require long term treatment and rehabilitation services. Tracking the occurrence of these conditions, their distribution, and their outcomes provides much-needed evidence to help plan efficient services and improve outcomes among people with these conditions. The Utah Birth Defect Network (UBDN) together with other public and private partners is engaged both in folic acid prevention efforts as well as in continuing tracking of NTDs.



How Are We Doing?

According to the UBDN data, from 1994–2003, NTDs occurred in 1 in 1,365 births (7.3 per 10,000 births). These rates represent a halving of the rates compared to before 1992. Hispanic Utahns experienced a higher rate of NTDs compared to other groups. The rate for the combined Asian and Pacific Islander populations was significantly lower than the overall state rate.

How Can We Improve?

As of 2003, over half of Utah women of childbearing age still do not use folic acid daily. Thus, a considerable number of additional neural tube defects could be prevented with increased use of folic acid. Such prevention will benefit families and the state by improving health and decreasing personal,

family, and societal burden for these severe conditions. Such efforts have recently been designed and implemented to reach Hispanic women. Complete and timely tracking and evaluation of NTDs is also crucial to assess prevention efforts and evaluate impact.

Neural Tube Defects, Utah, 1994-2003

Race/Ethnicity	Average Annual #	Total Births	Rate per 10,000 Births (95% CI Range)	Sig.*
All Utah Infants	33	45,074	7.3 (6.5 - 8.1)	n/a
American Indian/Alaska Native	1	632	9.5 (1.9 - 17.1)	
Asian/Pacific Islander	1	1,306	3.8 (0.5 - 7.2)	↓
Black or African American	0	271	0.0 (0.0 - 14.2)	
White	26	37,480	7.0 (6.1 - 7.8)	
Hispanic or Latino	5	5,141	10.5 (7.7 - 13.3)	↑

Source: UDOH, Utah Birth Defect Network

Note: Individuals were classified into only one race/ethnic category. "Total births" include all live births plus fetal deaths.

* The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.

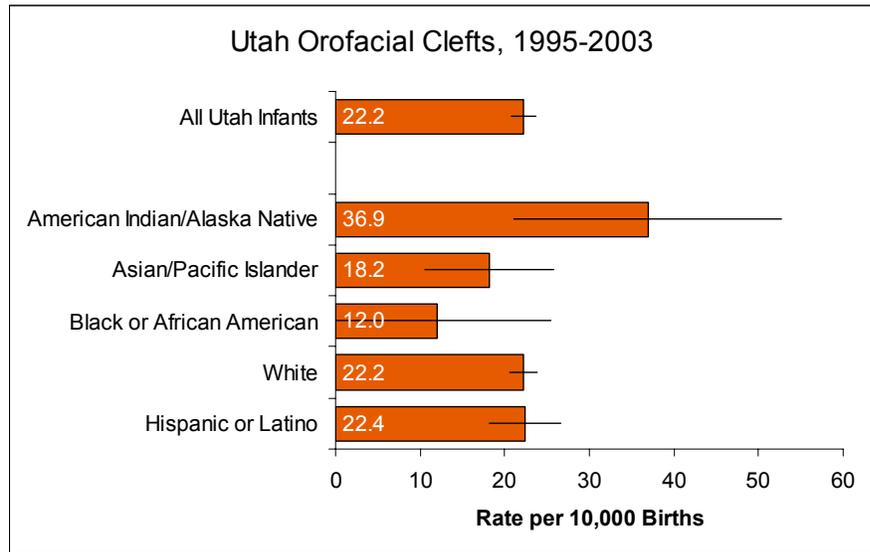


Health Problems of Mothers/Infants

Orofacial Clefts

Why Is It Important?

Orofacial clefts (cleft lip and/or cleft palate) are among the most common birth defects. They can occur alone or in combination with other defects and can significantly affect children's health. Children with orofacial clefts require medical and surgical services to treat the structural malformations. These children, even after surgery, can be at increased risk of illness and disability, particularly with respect to hearing and communication, and may require long-term health and rehabilitation services to improve outcomes and reduce complications.



Although orofacial clefts are common in the U.S., they appear to be even more frequent in Utah, which reports among the highest rates of orofacial clefts in the U.S. and internationally.

How Are We Doing?

The Utah Birth Defect Network (UBDN) began tracking rates of orofacial clefts in Utah in 1995. The rate of orofacial clefts for the period 1995–2003 in Utah was 1 in 450 births (22.2 per 10,000 births). Based on these data, the UBDN estimates that on average, more than 100 affected children are born in Utah every year. Of these children, approximately 65 will have cleft lip with or without cleft palate, and 35 will have cleft palate alone. Rates of orofacial clefts were similar across Utah's racial and ethnic populations. The rate among American Indian/Alaska Native Utahns was seemingly higher, but the estimate was based on few affected children, leading to wide confidence intervals. The number of affected births among Black/African American Utahns was too small for stable rate estimates.

How Can We Improve?

Since 1995, the UBDN has been tracking rates of orofacial clefts, evaluating their origin, and, more recently, researching their causes. Current activities include (1) tracking rates across the state and in different population groups, (2) working with national and international partners in evaluating potential reasons for the high rate in Utah, and (3) supporting the search for further clues on causes. UBDN and University researchers in Utah are also planning to estimate medical costs and assess the quality of life of affected children and families.

Orofacial Clefts, Utah, 1995-2003

Race/Ethnicity	Average Annual #	Total Births	Rate per 10,000 Births (95% CI Range)	Sig.*
All Utah Infants	102	45,807	22.2 (20.8 - 23.7)	n/a
American Indian/Alaska Native	2	632	36.9 (21.1 - 52.7)	
Asian/Pacific Islander	2	1,341	18.2 (10.6 - 25.8)	
Black or African American	<1	279	12.0 (0.0 - 25.5)	
White	84	37,883	22.2 (20.6 - 23.8)	
Hispanic or Latino	12	5,407	22.4 (18.2 - 26.6)	

Source: UDOH, Utah Birth Defect Network

Note: Individuals were classified into only one race/ethnic category. "Total births" include all live births plus fetal deaths.

* The rate for each race/ethnic population has been noted when it was significantly higher (▲) or lower (▼) than the state rate.

Congenital Heart Defects

Why Is It Important?

Congenital heart defects are common birth defects. Children with heart defects can be severely affected and can require complex surgical and medical treatment. Even such treatment sometimes fails to prevent chronic illness and premature death. Children with less severe forms of heart defects can still be affected in their quality of life. As treatment and support continually improves, increasing numbers of affected people live longer and healthier lives. Adolescents and adults that have been

successfully treated now represent a growing group in the population and have specific health care needs.

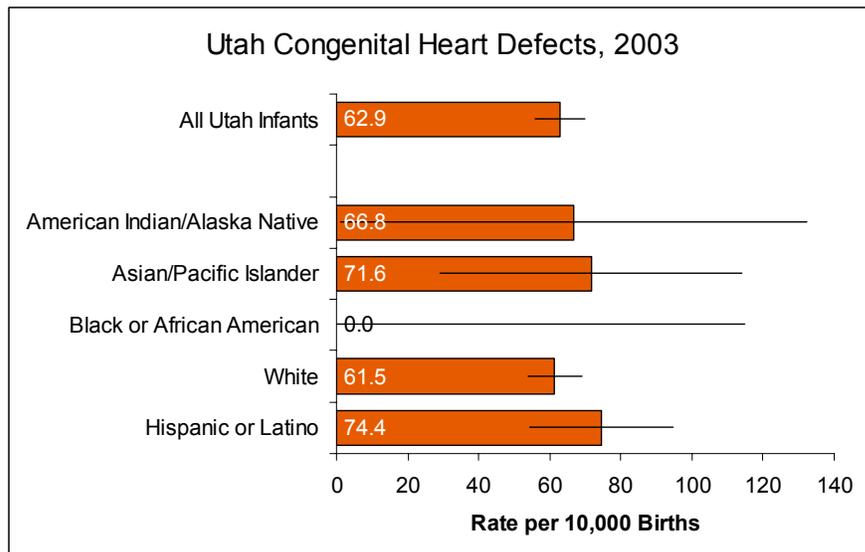
Tracking congenital heart defects among Utahns is crucial in assessing the impact of these common conditions, identifying disparities, evaluating causes, and in effective planning of the care of affected children and adults.

How Are We Doing?

The Utah Birth Defect Network (UBDN) began tracking selected congenital heart defects (conotruncal and left obstructive heart defects) in 1997 and later expanded to include all major heart defects. In 2003 the overall rate of major congenital heart defects was 1 in 159 births (62.9 per 10,000 births). On average, approximately 300 affected babies or more are born every year in Utah. Rates do not appear to vary significantly among racial and ethnic groups in Utah, but the precision of these estimates is limited, and more accumulated data is needed.

How Can We Improve?

More and better data can provide the evidence needed to assess race-specific impact and survival, find causes and preventive factors, and plan for services. Current activities of the UBDN include (1) tracking rates across the state and in different population groups, (2) working with researchers at the University of Utah Health Sciences Center to evaluate the genetics of specific congenital heart defects, and (3) searching for risk factors for congenital heart defects in collaboration with and with funding from the U.S. Centers for Disease Control and Prevention.



Congenital Heart Defects, Utah, 2003

Race/Ethnicity	# Heart Defects	Total Births	Rate per 10,000 Births (95% CI Range)	Sig.*
All Utah Infants	315	50,079	62.9 (56.0 - 69.8)	n/a
American Indian/Alaska Native	4	599	66.8 (1.3 - 132.2)	
Asian/Pacific Islander	11	1,537	71.6 (29.3 - 113.9)	
Black or African American	0	331	0.0 (0.0 - 114.7)	
White	247	40,195	61.5 (53.8 - 69.1)	
Hispanic or Latino	53	7,120	74.4 (54.4 - 94.5)	

Source: UDOH, Utah Birth Defect Network

Note: Individuals were classified into only one race/ethnic category. "Total births" include all live births plus fetal deaths.

* The rate for each race/ethnic population has been noted when it was significantly higher (↑) or lower (↓) than the state rate.