

12. MATERNAL, INFANT, AND CHILD HEALTH

Number	Objective
1	Infant mortality
2	Infant mortality from birth defects
3	SIDS mortality
4	Child mortality
5	Fetal death
6	Perinatal mortality
7	Maternal mortality
8	Maternal morbidity
9	Preconception counseling
10	Prenatal care
11	Quality of prenatal care
12	Serious developmental disabilities
13	Childbirth classes
14	Postpartum visits
15	Very low birthweight babies born at Level III hospitals
16	Cesarean delivery
17	Low birthweight
18	Preterm birth
19	Weight gain during pregnancy
20	Infant sleep position
21	Alcohol use during pregnancy
22	Tobacco use during pregnancy
23	Drug use during pregnancy
24	Fetal alcohol syndrome
25	Prenatal exposure to teratogenic prescription medications
26	Neural tube defects
27	Folic acid intake
28	Folate level
29	Breastfeeding
30	Exclusive breastfeeding
31	Newborn screening
32	Sepsis among infants with sickling hemoglobinopathies
33	Newborn hearing screening
34	Training in genetic testing
35	Understanding of inherited sensitivities to disease
36	Genetic testing
37	Primary care services for babies 18 months and younger
38	Screening for vision, hearing, speech, and language impairments
39	Service systems for children with chronic and disabling conditions

Maternal, Infant, and Child Health

Goal

Improve maternal health and pregnancy outcomes and reduce rates of disability in infants, thereby improving the health and well-being of women, infants, children, and families in the United States. The health of a population is reflected in the health of its most vulnerable members. A major focus of many public health efforts, therefore, is improving the health of pregnant women and their infants, including reductions in rates of birth defects, risk factors for infant death, and deaths of infants and their mothers.

Terminology

(A listing of all acronyms used in this publication appears on page 27 of the Introduction.)

The following terms will be used throughout this chapter and in the maternal, infant, and child health objectives.

Birth defects: An abnormality in structure, function, or body metabolism that is present at birth, such as cleft lip or palate, phenylketonuria, or sickle cell disease.

Breastfeeding: Exclusive use of human milk or use of human milk with a supplemental bottle of formula. “Exclusive breastfeeding” refers to the use of only human milk, supplemented by solid food when appropriate, but not supplemented by formula.

Congenital anomaly: See Birth defects.

Developmental disabilities: A broad spectrum of impairments characterized by developmental delay and/or limitation in personal activity, such as mental retardation, cerebral palsy, epilepsy, hearing and other communication disorders, and vision impairment. The more severe developmental disabilities require special interdisciplinary care.

Fetal alcohol syndrome (FAS): A cluster of structural and functional abnormalities found in infants and children as a result of alcohol consumption by the mother during pregnancy and characterized by growth retardation, facial malformations, and central nervous system dysfunction.

Fetal death: The death of a fetus in utero at 20 weeks or more of gestation. The fetal death rate is the number of fetal deaths in a population divided by the total of the live births and fetal deaths in the same population during the same time period.

Genetic disorders: The group of health conditions that result from genes passed to the embryo from the parents.

Infant mortality (IM): Death of an infant less than 1 year old. Neonatal mortality is the death of an infant less than 28 days after birth, while postneonatal mortality is the death of an infant between 28 days and 1 year after birth. The infant mortality rate is the number of deaths of infants less than 1 year old (obtained from death certificates) per 1,000 live births in a population (obtained from birth certificates).

Intrapartum period: Period extending from the onset of labor through the completion of delivery.

1 **Low birthweight (LBW):** Weight at birth of less than 2,500 grams. Very low birthweight (VLBW) means
2 a weight at birth of less than 1,500 grams.

3
4 **Maternal death:** Death of a woman while pregnant or within 42 days of the end of pregnancy, irrespective
5 of the duration or site of the pregnancy, from any cause related to or aggravated by the pregnancy or its
6 management, but not from accidental or incidental causes. The maternal mortality ratio represents the
7 number of maternal deaths for every 100,000 live births.

8
9 **Neonatal period:** The first 28 days of life.

10
11 **Neural tube defects (NTDs):** Birth defects that occur when the embryonic neural tube does not close
12 properly. Two of the most common NTDs are anencephaly (absence of the majority of the brain) and spina
13 bifida (incomplete development of the back and spine).

14
15 **Perinatal mortality:** Perinatal mortality includes fetal deaths after 20 or 28 weeks of gestation and infant
16 deaths within the first 7 days of birth.

17
18 **Postneonatal period:** The period from an infant's 29th day of life until the first birthday.

19
20 **Postpartum period:** The 6-week period immediately following birth.

21
22 **Premature birth:** Birth occurring before 37 weeks of pregnancy.

23
24 **Prenatal care:** Pregnancy-related health care services provided to a woman between conception and
25 delivery. The American College of Obstetricians and Gynecologists recommends at least 13 prenatal visits in
26 a normal 9-month pregnancy: one each month for the first 28 weeks of pregnancy, one every 2 weeks until 36
27 weeks, and then weekly until birth.

28
29 **Sudden infant death syndrome (SIDS):** Sudden unexplained death of an infant from an unknown cause.

30 31 **Overview**

32
33 Improving the health of mothers and infants is a national priority. Infant mortality is an important measure of
34 a nation's health and a worldwide indicator of health status and social well-being. As of 1993, the last year
35 for which data are available, the U.S. infant mortality rate ranked 25th among industrialized nations.¹ In the
36 past decade, critical measures of increased risk of infant death, such as incidence of LBW and VLBW, have
37 actually increased. In addition, the disparity in infant mortality rates between whites and specific ethnic
38 groups (especially African Americans, American Indian/Alaska Natives, Native Hawaiians, and Puerto
39 Ricans) persists; although the overall infant mortality rate has reached record low levels (7.6 per 1,000 live
40 births in 1995), the rate for African Americans remains twice that of white infants.²

41
42 Mortality is not the only measure of the health of infants, however. This chapter addresses a range of
43 indicators of maternal, infant, and child health, including those primarily affecting pregnant and postpartum
44 women (including indicators of maternal morbidity and mortality and preconceptional health) and those that
45 affect infants' health and survival (including birth outcomes; prevention of birth defects; access to preventive
46 care; and fetal, perinatal, and infant mortality). This overview presents a brief introduction to the major areas
47 of maternal, infant, and child health addressed in the objectives for the year 2010.

48
49 In 1995, 29,583 infants died before their first birthday, for an overall rate of 7.6 deaths per 1,000 live births.

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1 This rate has declined steadily over the past 20 years; in 1975, the infant mortality rate was over 15 per
2 1,000.³ In 1995, nearly two-thirds of all infant deaths took place during the neonatal period; the overall
3 neonatal mortality rate in 1995 was 4.9 per 1,000 live births. The remaining one-third of infant deaths took
4 place during the postneonatal period; the Nation's postneonatal mortality rate in 1995 was 2.7 deaths per
5 1,000 live births. Four causes account for more than half of all infant deaths: disorders relating to LBW,
6 birth defects, SIDS, and respiratory distress syndrome. The leading causes of neonatal death in 1995 were
7 disorders related to short gestation and LBW, birth defects, respiratory distress syndrome, and maternal
8 complications of pregnancy. After the first month of life, SIDS is the leading cause of infant mortality,
9 accounting for about one-third of all deaths during this period. The causes of SIDS are not known, but risk
10 factors include maternal smoking and drug use, teenage birth, and infections late in pregnancy. It has been
11 shown that putting infants to sleep on their backs can help to prevent SIDS.⁴ Maternal age is also a risk
12 factor for infant mortality; mortality rates are highest among infants born to teenagers and mothers over age
13 44.

14
15 The death of fetuses before birth is another important indicator of perinatal health. In 1995, 7 fetal deaths
16 were reported for every 1,000 live births and fetal deaths combined; this represents a slight decline from the
17 fetal death rate of 7.6 per 1,000 in 1987. Fetal death is sometimes associated with pregnancies complicated
18 by such risk factors as problems with amniotic fluid levels and maternal blood disorders.⁵ Early,
19 comprehensive, and risk-appropriate care to manage such conditions has contributed to reductions in fetal
20 death rates.

21
22 Important measures in the effort to reduce fetal and infant morbidity and mortality include: reducing rates of
23 preterm birth and LBW; helping women to have healthy pregnancies through the use of timely and
24 appropriate prenatal care; and helping women to avoid tobacco, alcohol, and illicit drugs during pregnancy.
25 Short gestation and LBW are among the leading causes of neonatal mortality, accounting for 20 percent of
26 neonatal deaths. In 1995, a total of 11 percent of births were preterm and 7.3 percent were of LBW.⁶ The
27 LBW rate has risen in recent years from a low of 6.8 percent in 1985. Included in these statistics are infants
28 born at VLBW, or less than 1,500 grams. The rate of VLBW births was 1.4 percent in 1995; among the
29 population as a whole, this rate has remained relatively stable since 1990, but it has risen among African
30 Americans and Puerto Ricans.

31
32 LBW babies are at significantly greater risk of long-term disabilities such as cerebral palsy, autism, mental
33 retardation, vision and hearing impairments, and other developmental disabilities. Despite their low
34 prevalence, expenditures for the care of LBW infants total more than half of the costs incurred for all
35 newborns. In 1988, the cost of a normal healthy delivery averaged \$1,900, while hospital costs for LBW
36 infants averaged \$6,200.⁷ The general category of LBW infants includes both those born too early (preterm
37 infants) and those who are born at full term but who are too small, a condition known as intrauterine growth
38 retardation (IUGR). Risk factors associated with IUGR include maternal LBW, prior LBW birth history, low
39 prepregnancy weight, cigarette smoking, and low pregnancy weight gain. Cigarette smoking is the greatest
40 known risk factor.⁸

41
42 VLBW is usually associated with preterm birth. Relatively little is known about risk factors for preterm
43 birth, but the primary risk factors are prior preterm birth and spontaneous abortion, low prepregnancy weight,
44 and cigarette smoking.⁹ However, these risk factors account for only one-third of all preterm births.
45 Maternal use of illicit drugs may also increase the risk of VLBW. Interventions targeted at prevention and
46 cessation of drug use during pregnancy may be helpful in further reducing the rate of infants born at very low
47 weights.

48
49 The use of alcohol and tobacco during pregnancy are major risk factors for LBW and other poor infant

1 outcomes. Alcohol is linked to fetal death, LBW, growth abnormalities, mental retardation, and FAS.¹⁰ In
2 addition to the human cost of these conditions, the economic cost of services to substance-exposed infants is
3 great: health expenditures related to FAS are estimated to be from \$75 million to \$9.7 billion each year,¹¹
4 and over \$500 million a year is spent on medical expenses for infants exposed to cocaine in utero. Although
5 the overall rates of alcohol use during pregnancy have declined during recent years, the proportion of
6 pregnant women using alcohol at higher, more hazardous levels has not changed. Smoking during pregnancy
7 is linked to LBW, preterm delivery, SIDS, and respiratory problems in newborns. The overall rates of
8 cigarette smoking during pregnancy have decreased steadily in recent years: in 1995, 86 percent of women
9 abstained from smoking during pregnancy, compared to 83 percent in 1990 and 75 percent in 1985.

10
11 The use of timely, high-quality prenatal care can help to prevent poor birth outcomes, especially by
12 identifying women who are at particularly high risk and by providing counseling to mitigate risks such as the
13 use of alcohol, tobacco, and other drugs. Overall, 81 percent of pregnant women began prenatal care in the
14 first trimester in 1995.¹² This indicator has shown a steady increase since 1990 for all population groups, but
15 racial and ethnic minorities remain less likely than whites to enter care early and to receive adequate care.

16
17 Finally, breastfeeding is an important contributor to overall infant health, as human breast milk presents the
18 most complete form of nutrition for infants.¹³ (The American Academy of Pediatrics recommends that
19 women who test positive for HIV not breastfeed to help prevent transmission of the virus to their infants.¹⁴)
20 Particularly in early infancy, breastfeeding rates have increased in recent years. From 1976 to 1982, the
21 percentage of mothers who began breastfeeding in the hospital reached a high of 61.9 percent, but then
22 gradually declined to 51.5 percent by 1990. Since 1991, however, there has been an increase in breastfeeding
23 among women in nearly all racial and ethnic groups to an overall rate of 59.2 percent in 1996. Breastfeeding
24 rates among women of all races decrease substantially between delivery and 5 to 6 months postpartum; the
25 1996 rates at 5 to 6 months were only 26 percent among white women, 12.1 percent among African
26 American women, and 21.1 percent among Hispanic women.¹⁵

27
28 Another important element of infant health is the prevention of birth defects and developmental disabilities,
29 when possible, and screening and early intervention for children who are born with such conditions to prevent
30 unnecessary disability. A critical example of a category of birth defects that can be prevented is spina bifida
31 and other neural tube defects (NTDs), many cases of which are preventable if women receive adequate doses
32 of folic acid before and during pregnancy. In addition, it is important that all newborns be screened for
33 genetic conditions such as phenylketonuria (PKU), sickle cell anemia, and hypothyroidism. These conditions,
34 although not necessarily preventable, are susceptible to intervention after delivery; for example, nutritional
35 interventions in infancy can prevent mental retardation in children with PKU, penicillin can prevent infection
36 in children with sickle cell disease, and hormone replacement can prevent mental retardation in children with
37 hypothyroidism. Thus, adequate screening of newborns is the first step toward prevention of morbidity,
38 mortality, and disability later in life.

39
40 In addition to infant deaths and health conditions, the effect of pregnancy and childbirth on women is another
41 important indicator of women's health and access to reproductive health care. In 1995, a total of 277
42 maternal deaths were reported.¹⁶ While this number is small, maternal mortality remains significant because
43 a high proportion of these deaths are preventable and because of the impact on families of women's
44 premature death. The overall maternal death ratio in 1995 was 7.1 per 100,000 live births. This ratio has not
45 declined since 1981, nor has the disparity between African American and white women. The maternal
46 mortality ratio among African-American women has consistently been 3 to 4 times that of white women.
47 Ectopic pregnancy is an important cause of pregnancy-related morbidity in the United States and the leading
48 cause of maternal mortality in the first trimester. The risk of ectopic pregnancy increases with age; women of
49 all races aged 35 to 44 are at more than 3 times the risk of ectopic pregnancy than are women aged 15 to 24

1 years. Preeclampsia and eclampsia make up the second leading cause of pregnancy-related death. Other risk
2 factors for maternal mortality are premature rupture of the placenta and placenta previa (a condition in which
3 the placenta covers the opening of the cervix).¹⁷

4
5 Many of the risk factors mentioned here can be mitigated or prevented with good preconception and prenatal
6 care. First, preconception screening and counseling provide an opportunity to identify and mitigate maternal
7 risk factors before pregnancy begins. Prenatal visits also offer an opportunity to provide information about
8 the adverse effects of substance use, including alcohol and smoking during pregnancy. It can also provide a
9 vehicle for referrals to services. Prenatal care is especially important for women who are at increased medical
10 or social risk of poor outcomes. Those least likely to receive adequate prenatal care include pregnant
11 adolescents, African-American women, and low-income women.¹⁸

12
13 Many of these conditions and risk factors disproportionately affect racial and ethnic minorities. The
14 disparities between white and minority groups in infant mortality, maternal mortality, and LBW are wide and
15 in many cases are growing. Specifically:

- 16
17 • The 1995 infant mortality rate among African-American infants was 2.4 times that of white infants.
18 Although infant mortality rates have declined within both racial groups, the proportional discrepancy
19 between African Americans and whites remains largely unchanged.
20
- 21 • The rate of maternal mortality among African Americans is 22.1 per 100,000 live births, more than 5
22 times the white rate of 4.2 per 100,000, and the rate among African Americans has been rising in recent
23 years. African American women are 3 to 4 times more likely to die of pregnancy and its complications.
24 The maternal mortality differential between African Americans and whites is highest for pregnancies that
25 did not end in live birth (ectopic pregnancy, spontaneous and induced abortions, and gestational
26 trophoblastic disease).¹⁹
- 27
28 • Rates of LBW whites have risen from 5.7 percent of births in 1990 to 6.2 percent in 1995. Among
29 African Americans, the LBW rate has declined slightly in the 1990s but remains more than twice as high
30 as that of whites, with a rate of 13 percent reported in 1995. African Americans also are more likely to
31 have other risk factors such as young maternal age, high birth order, less education, and inadequate
32 prenatal care. Puerto Ricans are also especially likely to have LBW infants.
33
- 34 • American Indian/Alaska Natives and African Americans account for a disproportionate share of FAS
35 morbidity. In 1990, the rates of FAS among American Indian/Alaska Natives and African Americans
36 were 5.2 and 1.4 per 1,000 live births, respectively, compared to 0.4 per 1,000 among whites.
37

38 African-American women also are less likely than whites to enter prenatal care early. For both racial groups,
39 the proportion of women entering prenatal care in the first trimester also rises with maternal age until the late
40 thirties, when it begins to decline. For example, in 1995, 55.8 percent of African-American women under the
41 age of 18 began care early, compared to 64.7 percent of white women of the same age; among women aged
42 25 to 39, 76.1 percent of African-American women entered care early compared to 89 percent of white
43 women.²⁰

44
45 Women in racial and ethnic minority groups also are less likely than white women to breastfeed their infants.
46 In the early postpartum period, 37.1 percent of African-American mothers and 59.2 percent of Hispanic
47 mothers breastfed, compared to 63.8 percent of white women. These differences persist at 5 to 6 months
48 postpartum, when 12.1 percent of African-American women, 21.1 percent of Hispanic women, and 26
49 percent of white women breastfed.²¹

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Progress Toward Year 2000 Objectives

Of the 17 maternal and infant health objectives included in Healthy People 2000, progress has been made toward the target in eight objectives (14.1, 14.2, 14.6, 14.8, 14.9, 14.11, 14.13, and 14.15) and we have moved away from the target in four objectives (14.3, 14.4, 14.5, and 14.17). For the remaining objectives, either baselines or updates are not available. A summary of the highlights of our progress toward the objectives is presented below.

- Infant mortality (objective 14.1) declined substantially in 1994 and 1995 and has almost reached the populationwide target of 7 per 1,000 live births. The decline in infant mortality was due to decreases in both neonatal infant mortality (objective 14.1d) and postneonatal mortality (objective 14.1g).
- Fetal mortality (objective 14.2) declined in 1994 and remained level in 1995. However, the rate of fetal death of 7 deaths per 1,000 live births plus fetal deaths still exceeds the target of 5 per thousand.
- Maternal mortality (objective 14.3) has increased since 1987, and the maternal mortality ratio of 7.1 per 100,000 live births remains well above the target of 3.3 per 100,000.
- The rate of fetal alcohol syndrome (objective 14.4) has risen steeply, especially among the African-American population (14.4a). The reported rate overall is now .67 cases per thousand live births (compared to the target of .12 per thousand) and, for African Americans, 5.4 per thousand (with a target of .4 per thousand). However, the increase in FAS rates may be partially explained by improved identification and reporting.
- LBW and VLBW rates (objective 14.5) have increased, with 7.3 percent of babies being born under 2,500 grams and 1.4 percent of babies weighing less than 1,500 grams in 1995. The increase in LBW is largely due to the steady increase in preterm births since 1981. Some of the increase in LBW rates may also be attributable to advances in technology for keeping preterm infants alive; as more preterm infants survive birth, the rate of VLBW increases.
- The ratio of hospitalizations for severe complications of pregnancy (14.7) has dropped dramatically and in 1995 achieved and even surpassed the year 2000 target of 15 per 100 deliveries. However, this is likely to be attributable to the increasing use of ambulatory care for pregnancy complications rather than a decrease in the rate of complications themselves.
- Although the rate of all cesarean sections (objective 14.8) and primary C-sections (14.8a) births continues to decline, at the present rate, they are unlikely to reach the year 2000 targets. In contrast, the repeat C-section rate (14.8b) has been dropping sharply and in 1995 surpassed the year 2000 target. The national year 2000 target for C-sections has already been reached in a number of States as well.²²
- Another objective that has moved in the right direction is the percentage of women who breastfeed their infants during the early postpartum period (Objective 14.9). A slight gain has been made toward this objective among the population as a whole. We have seen more progress among racial and ethnic minorities, with gains of 48 percent and 20 percent for African Americans and Hispanics, respectively. However, little progress has been shown among all women in breastfeeding at 5 to 6 months postpartum.

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- 1 • We have seen mixed outcomes for objective 14.10, abstinence from alcohol, tobacco and drug use during
2 pregnancy. The rate of abstinence from tobacco has increased to 86 percent, while rates of abstinence
3 from alcohol, cocaine, and marijuana have remained nearly unchanged.
4
5 • Progress is also being made in the receipt of early prenatal care (objective 14.11), with 81 percent of
6 women entering care in the first trimester in 1995.
7

Draft 2010 Objectives

Infant and Child Mortality

- 1. (Former 14.1) Reduce the infant mortality rate to no more than 5 per 1,000 live births.** (Baseline: 7.6 per 1,000 live births in 1995)

	1995	2010 Target
1a. Neonatal mortality	4.9	3.3
1b. Postneonatal mortality	2.6	1.7

Select Populations	Infant Mortality	1995	
		Neonatal	Postneonatal
African American	14.6	9.6	5.0
American Indian/Alaska Native	9.0	3.9	5.1
Asian/Pacific Islander	5.3	3.4	1.9
Asian Indian*	5.3	3.7	1.6
Chinese	3.8	2.3	1.5
Filipino	5.6	3.4	2.2
Guamanian*	*	*	*
Hawaiian	6.6	4.0	**
Japanese	5.3	3.3	**
Korean*	3.5	2.3	1.2
Samoan*	12.2	7.7	4.5
Vietnamese*	5.8	4.3	1.6
Other Asian or Pacific Islander*	5.9	3.7	2.2
Hispanic	6.3	4.1	2.1
Central and South American	5.5	3.7	1.9
Cuban	5.3	3.6	1.7
Mexican American	6.0	3.9	2.1
Puerto Rican	8.9	6.1	2.8
Other Hispanic	7.4	4.8	2.6
White	6.3	4.1	2.2
Mother under age 15	17.1	11.1	6.0
Mother aged 15-19	10.6	6.4	4.3
Mother aged 20-24	8.4	5.1	3.3
Mother aged 25-29	6.5	4.3	2.1
Mother aged 30-34	6.2	4.4	1.8
Mother aged 35 and over	7.5	5.3	2.2
Birthweight 2,500g and over	3.1	1.2	1.9
Birthweight 1,500-2,499g	18.2	10.2	8.0
Birthweight less than 1,500g	268.4	236.9	31.5

* Based on data from seven States: California, Hawaii, Illinois, New Jersey, New York, Texas, and Washington.

** Numbers are too small to calculate a meaningful rate.

Target Setting Method: Better than the best.

1 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.²³

- 2
3 **2. Reduce the infant mortality rate from all birth defects to 1.2 per 1,000 live births.** (Baseline: 1.7
4 deaths per 1,000 live births in 1995)

5
6 **Cause-Specific Subobjectives:**

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8

	1995	2010 Target
9 2a. Heart defects	0.59	0.41
10 2b. Neural tube defects	0.11	0.08

11
12

13

Select Populations	1995
African American	2.0
American Indian/Alaska Native	2.0
Asian/Pacific Islander	1.2
Hispanic	1.2
White	1.6

14

15 **Target Setting Method:** 30 percent improvement.

16 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.

- 17
18 **3. Reduce the sudden infant death syndrome (SIDS) mortality rate to 0.3 per 1,000 live births.**
19 (Baseline: 0.8 per 1,000 live births in 1995)

20
21 **Target Setting Method:** 60 percent improvement.

22
23 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.

- 24
25 **4. Reduce the rate of child mortality to 30 per 100,000 children aged 1-4 and 17 per 100,000 children**
26 **aged 5-14.** (Baseline: 40.4 per 100,000 children aged 1-4 and 22.1 per 100,000 children aged 5-14 in
27 1995)

28
29 **Target Setting Method:** 25 percent improvement.

30
31 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.

32
33 Infant mortality is a critical indicator of the health of a population, as it reflects the overall state of maternal
34 health as well as the quality and accessibility of primary health care available to pregnant women and infants.

35 Despite steady declines in the 1980s and 1990s, the rate of infant mortality in the U.S. remains among the
36 highest in the industrialized world.²⁴ Moreover, the rate of decline in infant mortality has slowed since the
37 1970s, when major advances in neonatal care contributed to steep reductions in the neonatal mortality rate;
38 during the 1980s, the rate of decline slowed. In the early 1990s, the introduction of synthetic surfactant
39 contributed to declines in neonatal mortality rates through decreased incidence of intraventricular hemorrhage
40 and decreased severity of respiratory disease in preterm, very small infants.^{25,26}

41
42 The leading causes of neonatal mortality include congenital anomalies, disorders related to short gestation
43 and LBW, and pregnancy complications. Of these, the most likely to be preventable are those related to

1 preterm birth and LBW, which represent approximately 20 percent of neonatal deaths.
2

3 Postneonatal mortality reflects risks experienced in infancy, including SIDS, congenital anomalies, injuries,
4 and homicide. Congenital anomalies, many of which are unlikely to be preventable, account for
5 approximately 17 percent of postneonatal deaths; the remainder are likely to stem from preventable causes.
6 SIDS is the leading cause of postneonatal mortality among all racial and ethnic groups, representing nearly
7 one-third of all cases of postneonatal mortality. Moreover, the rate of SIDS among African Americans is 1.6
8 per thousand live births, twice that of whites. Therefore, a reduction in the rate of death from SIDS,
9 particularly among African Americans, can contribute greatly to reducing the overall infant mortality rate and
10 particularly to closing the racial gap in postneonatal mortality. The target of .3 per thousand live births
11 represents a 60 percent decline in the rate of SIDS, a rate that should be achievable with continued education.
12
13

14 Rates of mortality from birth defects can be reduced either by preventing the occurrence of the defect itself or
15 by providing the necessary care to prevent death. In the case of neural tube defects, the anomalies themselves
16 can be prevented; this will be addressed further in objectives 23-25. Mortality from heart problems and other
17 birth defects can be prevented with access to appropriate medical care.
18

19 A particular issue in the reduction of infant mortality is the reduction of discrepancies among subpopulations,
20 particularly as defined by race and ethnicity, maternal age, and infant birthweight. The gap between whites
21 and African Americans in infant mortality is large and has not diminished in recent years. In addition, several
22 other racial and ethnic groups experience high infant mortality rates; the rate among Samoans is twice as high
23 as that of whites, and Puerto Ricans have infant mortality rates that are substantially higher than other
24 Hispanic groups. A major public health objective, therefore, is to close the gap among racial and ethnic
25 groups in infant mortality. Large gaps also exist in infant mortality rates across maternal age groups. The
26 rate of infant mortality decreases with increasing maternal age until the late thirties, with the highest rates
27 found among the youngest and oldest mothers. Specifically, infants born to young adolescents (those under
28 age 15) are more than twice as likely to die in infancy as those born to women in their twenties or thirties.
29

30 The deaths of children after infancy also present a public health concern and an opportunity for prevention.
31 In 1995, 14,989 children aged 1-14 died, representing a mortality rate of 62.5 per 100,000 children in that
32 age group. The death rate among children has declined substantially over the past decades; in recent years,
33 however, these declines have slowed. Since 1994, death rates for children aged 1-4 have declined only 5
34 percent, while those for children aged 5-14 have been stable.
35

36 The leading cause of death for children of all ages is injury, which accounts for 36 percent of deaths of
37 preschool children and 41 percent of deaths among children of school age. Among children aged 1-4, the
38 leading injury-related causes of death are motor vehicle crashes, drowning, and fires and burns; among those
39 aged 5-14, the leading causes include motor vehicle crashes and firearms (including homicides, suicides, and
40 accidents). These deaths are, for the most part, preventable. Other leading causes of death among children
41 that are less likely to be preventable include congenital anomalies (representing 4.4 deaths per 100,000
42 children aged 1-4 and 1.2 deaths per 100,000 children aged 5-14), malignant neoplasms (representing 3.1
43 deaths per 100,000 children aged 1-4 and 2.7 deaths per 100,000 children aged 5-14), and heart disease
44 (representing 3.1 deaths per 100,000 children aged 1-4 and 0.8 deaths per 100,000 children aged 5-14).
45

1 **Perinatal and Fetal Mortality**
2

3 **5. (Former 14.2) Reduce the fetal death rate (death of fetus at 20 or more weeks of gestation) to no**
4 **more than 5 per 1,000 live births plus fetal deaths.** (Baseline: 7 per 1,000 live births plus fetal deaths
5 in 1995)
6

7 **Target Setting Method:** Retain year 2000 target.
8

9 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.
10

11 **6. Reduce the perinatal mortality rate per 1,000 live births plus fetal deaths as follows:**
12

	1995	2010 Target
Deaths of infants from 28 weeks' gestation to 7 days after birth	7.6	5.3
Deaths of infants from 20 weeks' gestation to 7 days after birth	11.0	7.7

13
14 **Target Setting Method:** 30 percent improvement.
15

16 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.
17

18 The health of infants depends in large part on their health in utero; a fetus with severe anomalies or growth
19 problems may not be born alive. Because only live births are counted in infant mortality rates, perinatal and
20 fetal mortality rates provide a more complete picture of perinatal health than does infant mortality rate alone.
21

22 Fetal death is associated with maternal complications of pregnancy, such as problems with amniotic fluid
23 levels and blood disorders. According to analyses of the Standard Report of Fetal Death, rates of fetal
24 mortality are 35 percent greater than average in women who use tobacco during pregnancy and 77 percent
25 higher in women who use alcohol. Fetal mortality rates are also high when congenital anomalies, such as
26 anencephalus, renal agenesis, and hydrocephalus, are present.²⁷ The baseline fetal death rate of 7 per
27 thousand represents only a 6.7 percent reduction since 1990, an average rate of decline of only 1.3 percent per
28 year. The fetal death rate among African Americans was 12.7 per thousand in 1995, 1.8 times that of the
29 population as a whole. Moreover, this gap has widened since 1990; the rate among African Americans
30 declined by only 4.5 percent over this period, a decline of less than 1 percent per year. Targeting prenatal risk
31 screening and intervention to high-risk groups, particularly African-American women, is critical to reducing
32 this gap.
33

34 The perinatal mortality rate includes both deaths of live-born infants through the first 7 days of life and fetal
35 deaths after 28 or 20 weeks of gestation. Because this rate includes both deaths of live-born infants and fetal
36 deaths, it is a useful overall measure of perinatal health and the quality of health care provided to pregnant
37 women and newborns. The rate of perinatal mortality (including only deaths after 28 weeks' gestation) has
38 declined by 40 percent since 1980; however, the gap between African Americans and whites has increased,
39 with the rate among African Americans now more than twice that of whites.
40

41 The objective for reducing the perinatal mortality rate is presented using two definitions of perinatal
42 mortality. The first, beginning at 28 weeks' gestation, represents the standard definition promoted by the
43 World Health Organization and is therefore useful for international comparisons. In the United States,
44 however, a substantial number of fetal deaths are likely to occur between 20 and 28 weeks' gestation;
45 moreover, the proportion of fetal deaths that falls into this time period has tended to increase as accuracy and
46 completeness of fetal death reporting improve. In the State of New York, for example, where fetal death

1 reporting is particularly thorough, 56 percent of fetal deaths after 20 weeks occurred in the 20- to 27-week
2 interval. It is therefore important that these deaths be included in an overall perinatal mortality rate.

3
4 **Maternal Morbidity and Mortality**

5
6 **7. (Former 14.3) Reduce the maternal mortality ratio to no more than 3.3 per 100,000 live**
7 **births.** (Baseline: 7.1 maternal deaths per 100,000 in 1995)

8

Select Populations	1995
African American	22.1
American Indian/Alaska Native	*
Asian/Pacific Islander	*
Hispanic	6.3
White	4.2

9
10 * Numbers are too small to calculate a meaningful rate.

11
12 **Target Setting Method:** Retain year 2000 target.

13
14 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.

15
16 **8. Reduce the rate of maternal morbidity. Specifically:**

17
18 **8a. (Former 14.7) Reduce to less than 20 percent the proportion of pregnant women who**
19 **experience maternal complications during labor and delivery.** (Baseline: 25.6 percent in 1994)

20
21 **Target Setting Method:** 20 percent improvement.

22
23 **Data Source:** National Hospital Discharge Survey, CDC, NCHS.

24
25 **8b. (Developmental) Reduce the rate of severe pregnancy-induced hypertension and eclampsia.**

26
27 **8c. (Developmental) Reduce the number of ectopic pregnancies.**

28
29 **8d. (Developmental) Reduce severe antenatal complications of pregnancy.**

30
31 **8e. (Developmental) Reduce postpartum complications of pregnancy, including postpartum**
32 **depression.**

33
34 Maternal mortality in the United States is rare; in 1995, 277 maternal deaths were reported, the major causes
35 of which were pregnancy-induced hypertension, ectopic pregnancy, and other complications of pregnancy and
36 childbirth. However, the overall maternal mortality ratio has increased from the Healthy People 2000
37 baseline of 6.6 per 100,000 live births in 1987 and has decreased only 13 percent since 1990, well below the
38 Healthy People 2000 goal of a 50 percent decrease. Moreover, the gap between African Americans and
39 whites remains, with the maternal mortality ratio among African Americans 5 times that of whites in 1995;
40 the ratios among African Americans have been at least 3 to 4 times higher than those of whites since 1940.
41 The ratio among African Americans has remained nearly stable since 1990, showing a decrease of only 1.3
42 percent.

1 Pregnancy and delivery can also lead to serious physical and mental health problems for women. In the past,
2 maternal morbidity was monitored through objectives relating to the ratio of hospitalizations for pregnancy
3 complications to the total number of deliveries. This has become a less useful measure, however, as rates of
4 hospitalization in general have declined due to the increasing use of managed care and its emphasis on
5 outpatient treatment. Therefore, attention should be focused on the major causes of maternal morbidity,
6 particularly those, such as ectopic pregnancy, that are most likely to be associated with maternal mortality.
7 The outcomes of interest should include not only prenatal morbidity and complications during labor and
8 delivery, but also postpartum complications. Postpartum depression, for example, is disabling for a new
9 mother and can compromise her ability to care for her infant.

10
11 *Preconception, Prenatal, and Postpartum Care*

12
13 **9. (Developmental) Increase the proportion of providers of primary care to women of reproductive**
14 **age who routinely provide preconception counseling concerning:**

- 15
16 • **Risks to all pregnancies, such as the risk to the developing fetus associated with use of**
17 **medications, tobacco, and alcohol, inadequate consumption of folic acid, maternal infection**
18 **(such as HIV, rubella, and toxoplasmosis), and occupational exposures (such as lead);**
19
20 • **Risks associated with maternal health conditions, such as diabetes (type I), phenylketonuria**
21 **(PKU), epilepsy, chronic hypertension, Rh negative blood type; and**
22
23 • **Risks associated with a history of previous affected pregnancies, such as a birth defect with an**
24 **increased recurrence risk (e.g., neural tube defect, oral-facial clefts, and fetal alcohol**
25 **syndrome) or a genetic condition for which carrier testing is available (e.g., cystic fibrosis,**
26 **sickle cell disease, and fragile X syndrome).**

27
28 **Potential Data Source:** Primary Care Providers Survey, ODPHP, could be modified.
29

1 **10. (Former 14.11) Increase to at least 90 percent the proportion of all pregnant women who begin**
2 **prenatal care in the first trimester of pregnancy.** (Baseline: 81.3 percent of live births in 1995)
3

Select Populations	1995
African American	70.4%
American Indian/Alaska Native	66.7%
Asian/Pacific Islander	79.9%
Chinese	85.7%
Filipino	80.9%
Hawaiian	75.9%
Japanese	89.7%
Other Asian	77.0%
Hispanic	70.8%
Central and South American	73.2%
Cuban	69.2%
Mexican American	69.1%
Puerto Rican	74.0%
Other Hispanic	74.3%
White	83.6%
Mother under 15 years	46.3%
Mother 15-19 years	64.5%
Mother 20-24 years	74.1%
Mother 25-29 years	83.5%
Mother 30-34 years	86.3%
Mother 35 years and over	84.5%

4
5 **Target Setting Method:** Retain year 2000 target.

6
7 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.
8

1 **11. Increase to at least 90 percent the proportion of all live-born infants whose mothers receive**
2 **prenatal care that is adequate or more than adequate according to the Adequacy of Prenatal Care**
3 **Utilization Index.** (Baseline: 73 percent of live births in 1995)
4

Select Populations	1995
African American	64.4%
American Indian/Alaska Native	57.3%
Asian/Pacific Islander	71.0%
Asian Indian	72.0%
Chinese	75.1%
Filipino	73.1%
Guamanian	63.8%
Hawaiian	74.4%
Japanese	79.4%
Korean	68.4%
Samoan	55.3%
Vietnamese	72.3%
Other Asian	67.3%
Hispanic	62.3%
Central and South American	62.4%
Cuban	82.2%
Mexican American	61.1%
Puerto Rican	64.9%
Other Hispanic	64.6%
White	74.6%
Mother under 15 years	47.3%
Mother 15-19 years	61.7%
Mother 20-24 years	68.4%
Mother 25-29 years	75.3%
Mother 30-34 years	77.9%
Mother 35 years and over	78.0%

5
6 **Target Setting Method:** 20 percent improvement.

7
8 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.
9

1 **12. Reduce the prevalence of serious developmental disabilities arising from events in the prenatal**
 2 **and infant periods.**
 3

	1991–93 Rate per 10,000	2010 Target
Mental retardation		
Mild (IQ 50-70)	72.4	68.7
Moderate, severe, profound (IQ<50)	39.1	37.1
Cerebral palsy	28.7	27.3
Blindness and moderate to		
severe low vision, bilateral	10.5	10.0
Moderate to profound hearing loss, bilateral	12.2	11.6
Hearing loss: moderate, unilateral	Not available	

4
 5 **Note:** The prevalence of the specific developmental disabilities will be monitored among school-aged
 6 children, since the majority of developmental disabilities are caused by events in the prenatal and infant
 7 periods that may not be recognized until the child approaches school age or is educationally challenged in
 8 school. Surveillance systems developed to monitor the implementation of early hearing detection and
 9 intervention programs will be adapted to measure the prevalence of hearing loss, both bilateral (moderate
 10 to profound) and unilateral (moderate).
 11

12 **Target Setting Method:** 5 percent improvement.
 13

14 **Data Source:** Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP),
 15 CDC.
 16

17 **13. (Developmental) Increase the proportion of pregnant women who attend a formal series of**
 18 **prepared childbirth classes.**
 19

20 **Potential Data Sources:** The National Pregnancy and Health Survey, National Survey of Family
 21 Growth (NSFG), or National Health Interview Survey (NHIS), CDC, NCHS, could be modified.
 22

23 **14. (Developmental) Increase the proportion of women who receive a postpartum visit 4 to 6 weeks**
 24 **after delivery.**
 25

26 Continuous care for prospective mothers, from before they get pregnant through the postpartum period, is
 27 important both to their own health and that of their infants. Preconception screening, counseling, and
 28 anticipatory guidance are important initial steps in this continuum of care.²⁸ A preconception visit should
 29 include a detailed medical and psychosocial history, in order to identify potential risk factors; a physical
 30 examination and series of laboratory tests, to identify potential medical problems; and a health promotion
 31 session, potentially including substance abuse counseling, nutrition supplementation, and home visits, to
 32 reduce risks and provide information about pregnancy and parenting. A preconception visit is a critical
 33 opportunity to screen women for risk factors before pregnancy begins and to counsel them on behaviors and
 34 exposures that can threaten the health of a fetus early in its development. Therefore, it is important that
 35 counseling be provided at this preconception visit to mitigate a range of prenatal risks, including behavioral
 36 risks (those associated with smoking and alcohol, for example), medical and genetic risks, and occupational
 37 and environmental exposures.
 38

39 Even before a pregnancy is planned, the primary care provider can play an essential role in shaping women's
 40 health behaviors and identifying medical conditions that will require specialized management during

1 pregnancy. Studies have documented the importance of counseling by health professionals in increasing
2 patient compliance with recommended patient behaviors. Since more than half of all pregnancies are
3 unplanned, and many healthy maternal behaviors must be in place before pregnancy is recognized, routine
4 preconceptional counseling of women of reproductive age in primary care settings should improve health by
5 increasing the prevalence of recommended maternal behaviors.

6
7 Unfortunately, not all primary care providers are fully aware of the importance of preconception care and are
8 thus unable to promote such a visit to their patients who may become pregnant. Promotion of the
9 preconception visit among providers is an important first step to educating women about the importance of
10 assessing their risks and improving their health before pregnancy begins. Evidence-based guidelines have
11 been developed to improve infant outcomes from pregnancies of mothers with underlying health conditions
12 such as type I diabetes and epilepsy. If communitywide benefits are to be realized from the use of these
13 protocols, preconceptional counseling is necessary for health professionals to identify women at risk and
14 make necessary recommendations.

15
16 Prenatal care includes three major components: risk assessment, treatment for medical conditions or risk
17 reduction, and education. Each of these components can contribute to reductions in perinatal morbidity and
18 mortality by identifying and mitigating potential risks and helping women to address the behavioral factors,
19 such as smoking and alcohol use, that contribute to poor outcomes. Prenatal care is more likely to be
20 effective if women begin receiving care early in pregnancy. Since 1990, the percentage of infants whose
21 mothers entered prenatal care in the first trimester increased 7 percent, from 75.8 percent to 81.3 percent.
22 Among African Americans, this percentage grew 16 percent and among Hispanics, 19 percent. Thus,
23 increases in early entry into prenatal care have been concentrated in those populations whose perinatal
24 morbidity and mortality rates are highest and who are most likely to have low incomes. It is likely that these
25 increases are due at least in part to increased access to Medicaid coverage for pregnancy-related services and
26 improved outreach by Medicaid programs.²⁹ In addition, the likelihood of early entry into prenatal care rises
27 with age. The risk of poor birth outcomes is greatest among the youngest mothers. Clearly, therefore,
28 continued work is needed to educate women, particularly young women, about the need for to begin prenatal
29 care early in pregnancy.

30
31 Prenatal care should not only begin early in pregnancy; it should continue throughout pregnancy, according to
32 accepted standards of periodicity. For example, the American College of Obstetricians and Gynecologists
33 recommends that women receive at least 13 prenatal visits during a full-term pregnancy.³⁰ Therefore, to
34 assess the adequacy of the care that pregnant women receive, it is important to monitor not only the month of
35 initiation of prenatal care but also the adequacy of the care they receive throughout pregnancy. The
36 Adequacy of Prenatal Care Utilization Index (APNCU) includes indices of two dimensions of care: the
37 adequacy of initiation of care and the adequacy of the utilization of prenatal services once care has begun (by
38 comparing actual utilization to the recommended number of visits based on the month of initiation of care and
39 the length of the pregnancy).³¹ These two dimensions are combined to characterize each woman's prenatal
40 care utilization history as inadequate, intermediate, adequate, or adequate plus. The baseline rates presented
41 above include all women who received either adequate or adequate-plus care.

42
43 Overall, nearly three-quarters of women receive adequate prenatal care. This proportion varies across racial
44 and ethnic groups, and certain groups, such as American Indian/Alaska Natives and Samoans, are particularly
45 likely to receive less-than-adequate prenatal care. The likelihood of receipt of adequate prenatal care rises
46 with maternal age, with fewer than half of pregnant women under age 15 receiving adequate care. This
47 emphasizes the necessity of prevention of unwanted pregnancy in adolescents and of educating pregnant
48 women about the need for early, continuous prenatal care.

1 Part of this care should address the prevention of developmental disabilities (mental retardation, cerebral
2 palsy, hearing and vision impairment), the most common group of disorders that cause lifelong disability.³²
3 Although many developmental disabilities may not be recognized until the child is challenged in school, the
4 majority of developmental disabilities are caused by events occurring in the prenatal and infant periods.^{33,34}
5 Thus, interventions to decrease the prevalence of the underlying disabling conditions must be targeted to
6 prevent known causes before they occur.

7
8 As part of comprehensive prenatal care, a formal series of prepared childbirth classes conducted by a certified
9 childbirth educator is recommended for all women by the Expert Panel on the Content of Prenatal Care.³⁵
10 These classes can help to reduce women's pain³⁶ and anxiety³⁷ as they approach childbirth, making delivery a
11 more pleasant experience and preparing women for what they will face as they give birth. A full series of
12 sessions is recommended for women who have never attended, and a refresher series of one or two classes is
13 recommended for parous women who have attended during a previous pregnancy. At a minimum, the
14 childbirth classes should include information regarding the physiology of labor and birth, exercises and self-
15 help techniques for labor, the role of support persons, family roles and adjustments, and preferences for care
16 during labor and birth. The classes should also include an opportunity for the mother and her partner to have
17 questions answered about providers, prenatal care and other relevant issues, as well as provide information
18 regarding birth settings and cesarean childbirth. Attendance is recommended during the third trimester of
19 pregnancy, so that information learned will be used relatively soon after it is presented. Classes should begin
20 at the 31st or 32nd week and be completed no later than 38 weeks; the refresher class can be completed at any
21 time between 36 and 38 weeks.

22
23 Finally, care of a new mother after delivery is important to ensure that she is in good physical health and is
24 prepared to care for her infant. The American College of Obstetricians and Gynecologists' *Guidelines for*
25 *Perinatal Care* recommends that women receive a comprehensive postpartum assessment and examination
26 approximately 4 to 6 weeks after delivery (or sooner after a cesarean or complicated delivery).³⁸ During this
27 visit, the woman should receive a physical examination; counseling about breastfeeding and family planning;
28 an assessment for mental or emotional problems; and, where appropriate, preconception counseling regarding
29 planning for future pregnancies. The postpartum period is a critical opportunity to assess the physical and
30 psychosocial health of both the mother and her newborn and to provide the counseling and support needed to
31 identify and address nascent problems within the family.

32 *Obstetrical Care*

33 **15. (Developmental/Former 14.14) Increase the proportion of very low birthweight infants born at** 34 **Level III hospitals (facilities for high-risk deliveries and neonates).**

35 **Potential Data Source:** Maternal and Child Health (MCH) Block Grant, MCHB, HRSA.

36 **16. (Former 14.8) Reduce the cesarean delivery rate to no more than 15 per 100 deliveries.** (Baseline: 37 20.8 per 100 deliveries in 1995)

	1995	2010 Target
16a. Primary (first time) cesarean delivery	14.7	12
16b. Repeat cesarean deliveries*	72.5	65

38
39
40
41
42
43
44 *Among women who had a previous cesarean delivery.

45 **Target Setting Method:** Retain year 2000 target.

1 **Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.

2 The method and location of delivery can affect the health of mothers as well as the likelihood of survival of
3 VLBW infants. During the 1980s, rates of cesarean deliveries rose steadily, with a peak rate of 24.4 percent
4 of deliveries reported in 1987. Since that time, the rate has been slowly decreasing, with the majority of the
5 decline attributable to reduction in the rates of repeat cesareans. In 1987, 91.2 percent of deliveries by
6 women who had had a previous cesarean were conducted surgically; by 1995, this rate had declined 29
7 percent, to 64.5 percent. The rate of first-time cesareans declined by 11 percent, from 17.4 percent of
8 deliveries to 15.5 percent. These reductions are likely to be attributable to better education of physicians on
9 the positive prospects for vaginal delivery after cesarean and to other strategies implemented by hospitals to
10 reduce C-section rates, such as stringent requirements for second opinions.^{40,41} In addition, increasing
11 concern about cost containment within the health care system may be an important factor. In addition to
12 increased cost and longer hospital stays, the risk of maternal morbidity and mortality and of perinatal
13 morbidity are greater when infants are delivered surgically. Thus, it is important that further declines in the
14 rate of cesarean delivery be encouraged.

15
16 Much research has demonstrated the benefits of delivering high-risk infants in settings that have the
17 technological capacity to care for them. Specifically, research has shown that VLBW infants have lower
18 mortality rates when they are delivered at Level III hospitals.⁴²⁻⁴⁴ To ensure that high-risk pregnant women
19 have access to appropriate levels of obstetric care, many States have implemented perinatal regionalization
20 strategies and protocols for the transfer of high-risk women to Level III facilities. However, there is some
21 evidence that these systems may be eroding as health care networks and financing systems change.^{45,46} To
22 monitor the continuing effectiveness of these systems and the appropriateness of the level of care delivered to
23 high-risk pregnant women and infants, it is important to monitor the proportion of VLBW infants who are
24 delivered in the Level III obstetric hospitals that are best equipped to provide appropriate neonatal care.

25

1 **Risk Factor Objectives**
2

3 **17. (Former 14.5) Reduce low birthweight (LBW) to an incidence of no more than 5 percent of live**
4 **births and very low birthweight (VLBW) to no more than 1 percent of live births.** (Baseline: 7.3
5 and 1.4 percent, respectively, in 1995)
6

Select Populations	1995	
	LBW	VLBW
African American	13.1%	3.0%
American Indian/Alaska Native	5.6%	1.1%
Asian/Pacific Islander	6.9%	0.9%
Asian Indian	8.9%	1.0%
Chinese	5.3%	0.7%
Filipino	7.6%	1.1%
Guamanian	5.6%	*
Hawaiian	6.8%	0.9%
Japanese	7.3%	0.8%
Korean	4.8%	0.7%
Samoan	4.3%	*
Vietnamese	6.4%	0.8%
Other Asian or Pacific/Islander	7.1%	0.9%
Hispanic	6.3%	1.1%
Central and South American	6.2%	1.1%
Cuban	6.5%	1.2%
Mexican American	5.6%	1.0%
Puerto Rican	9.4%	1.8%
Other Hispanic	7.6%	1.3%
White	6.2%	1.0%
Mother under 15 years	13.5%	3.2%
Mother 15-19 years	9.3%	1.7%
Mother 20-24 years	7.3%	1.3%
Mother 25-29 years	6.4%	1.2%
Mother 30-34 years	6.7%	1.2%
Mother 35 years and over	8.3%	1.6%

7
8 * Numbers are too small to calculate a meaningful rate.
9

10 **Target Setting Method:** Retain year 2000 target.

11
12 **Baseline Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.
13

1 **18. Reduce the incidence of preterm birth to 7.6 per 1,000 live births.** (Baseline: 9.1 percent of live
 2 births born at 32 through 36 weeks of gestation, and 1.9 percent of live births born at less than 32 weeks
 3 of gestation in 1996)
 4

Select Populations	<32 Weeks		32–36 Weeks	
	1996	2010 Target	1996	2010 Target
African American	4.1%	1.3%	13.3%	6.3%
American Indian/Alaska Native	2.0%	1.3%	9.9%	6.3%
Asian/Pacific Islander	1.3%	1.3%	8.4%	6.3%
Hispanic	1.7%	1.3%	9.2%	6.3%
White	1.5%	1.3%	8.3%	6.3%

5
 6 **Target Setting Method:** 30 percent improvement.

7
 8 **Baseline Data Source:** National Vital Statistics System (NVSS), CDC, NCHS.
 9

10 **19. (Developmental) Increase the proportion of mothers who achieve a weight gain consistent with**
 11 **the Institute of Medicine guidelines during their pregnancies.**

12
 13 **20. Increase to 90 percent the percentage of infants who are put to sleep on their backs.** (Baseline: 76
 14 percent in 1996)
 15

16 **Target Setting Method:** 20 percent improvement (excluding healthy preterm infants, who have been
 17 shown to be more vulnerable to respiratory problems when put to sleep on their backs.⁴⁷)
 18

19 **Data Source:** NIH, NICHD.
 20

21 Several risk factors are specifically related to poor birth outcomes, including infant mortality; these include
 22 LBW and preterm delivery, which are linked to neonatal mortality, and infant sleep position, which is related
 23 to postneonatal SIDS. Maternal weight gain during pregnancy is itself an important factor in ensuring that
 24 infants are born at adequate weight.
 25

26 LBW is the risk factor most closely associated with neonatal mortality; thus, improvements in infant
 27 birthweight can contribute substantially to reductions in the infant mortality rate. Some researchers have
 28 proposed that further improvement in the survival of VLBW infants is nearly impossible, and reduction in the
 29 underlying rate of VLBW births is the only avenue toward reduction of neonatal mortality rates.⁴⁸ Another
 30 important issue, however, is the long-term effects of LBW on affected infants who survive their first year, a
 31 concern that has grown as improvements in neonatal medicine have improved the rates of survival of LBW
 32 and VLBW infants. Surviving LBW infants are significantly more likely to experience long-term
 33 developmental and neurologic disabilities than are infants of normal birthweight.^{49,50} However, efforts to
 34 prevent LBW in infants have largely been unsuccessful, and rates of LBW in the population as a whole have
 35 risen 1 percent over the past decade.⁵¹
 36

37 LBW is associated with the use of tobacco, alcohol, and illicit drugs during pregnancy, with smoking
 38 estimated to account for 20 to 30 percent of all LBW births in the U.S. The effect of smoking on LBW rates
 39 appears to be attributable to intrauterine growth retardation rather than on preterm delivery.⁵² VLBW, in
 40 contrast, is primarily associated with preterm birth, which may itself be associated with the use of illicit drugs
 41 during pregnancy.
 42

1 Rates of LBW and VLBW among African-American infants are twice as high as those of whites. Certain
2 other ethnic groups, such as Puerto Ricans and Asian Indians, have rates of LBW that are substantially higher
3 than average. In addition, young mothers, particularly those under age 15, are much more likely than older
4 women to have LBW infants.

5
6 Approximately two-thirds of cases of LBW and 98 percent of cases of VLBW are attributable to preterm
7 delivery. In addition, preterm births are the leading cause of those neonatal deaths that are not caused by
8 congenital anomalies. Survival rates of infants have been shown to increase as gestational age advances, even
9 among very preterm infants.^{53,54} Therefore, reduction in preterm delivery holds the greatest promise for
10 overall reduction in infant morbidity and mortality. However, the specific causes of preterm delivery are
11 unclear.^{55,56} Preterm birth is associated with a number of modifiable risk factors, including the use of
12 alcohol, tobacco, or other drugs during pregnancy,^{57,58} and low prepregnancy weight or low weight gain
13 during pregnancy.^{59,60}

14
15 Rates of preterm delivery in the U.S. have increased over the past three decades.^{61,62} The gap between
16 African-American and white infants has persisted as well, for reasons that are largely unexplained⁶³ and have
17 been shown to be independent of other known risk factors.^{64,65} Risk factors that African-American women
18 may disproportionately experience include short interpregnancy intervals⁶⁶ and exposure to psychosocial
19 stress.^{67,68}

20
21 Current evidence indicates that gestational weight gain, particularly during the second and third trimesters, is
22 an important determinant of fetal growth, and inadequate weight gain during pregnancy is associated with an
23 increased risk of intrauterine growth retardation, LBW, and infant mortality.⁶⁹⁻⁷¹ Importantly, maternal
24 weight gain is susceptible to intervention, and thus represents an avenue for prevention of poor birth
25 outcomes. The Institute of Medicine's 1990 guidelines for weight gain in pregnancy recommend a graduated
26 level of weight gain based on a woman's prepregnancy body mass index (that is, the ratio of her weight to her
27 height). Under these guidelines, a woman with normal BMI should gain 25 to 35 pounds during pregnancy;
28 those with below-normal BMI should gain 28 to 40 pounds; and overweight women should gain 15 to 25
29 pounds.

30
31 In 1988, the last year for which national data are available, approximately three-quarters of married women
32 who delivered at full term gained the recommended weight during pregnancy. Two groups of women who
33 continue to gain less than the recommended level of weight during pregnancy, teenagers and African-
34 American women, are also at particularly high risk for having LBW infants and other adverse pregnancy
35 outcomes.

36
37 Much research has shown that nonprone sleeping position (that is, sleeping on the side or back rather than the
38 stomach) greatly decreases the risk of SIDS among infants.^{72,73} The American Academy of Pediatrics has
39 therefore recommended that healthy full-term infants be put down to sleep on their sides or backs, and the
40 National Institute for Child Health and Human Development and the Maternal and Child Health Bureau
41 instituted the "Back to Sleep" campaign in 1994 to educate parents and physicians about this
42 recommendation.

1 **Prenatal Substance Exposure**

2
3 **21. (Former 14.10) Increase abstinence from alcohol use by pregnant women.**

	1994–95	2010 Target
4		
5		
6 21a. Any use in the past month	78.7%	95%
7 21b. Binge drinking in the past month	97.1%	99%

8
9 **Target Setting Method:** Retain year 2000 target for any past-month use.

10
11 **Data Source:** National Household Survey on Drug Abuse (NHSDA), SAMHSA.

12
13 **22. (Former 14.10) Increase abstinence from tobacco use by pregnant women to 95 percent.**
14 (Baseline: 78.5 percent of pregnant women report *not* using tobacco in the past month in 1994-95)

15
16 **Target Setting Method:** 20 percent improvement.

17
18 **Data Source:** National Household Survey on Drug Abuse (NHSDA), SAMHSA.

19
20 **23. (Former 14.10) Eliminate use of illicit drugs by pregnant women.** (Baseline: 97.7 percent of
21 pregnant women report *not* using illicit drugs in the past month in 1994-95)

22
23 **Target Setting Method:** Retain year 2000 target.

24
25 **Data Source:** National Household Survey on Drug Abuse (NHSDA), SAMHSA.

26
27 **24. (Developmental/Former 14.4) Reduce the incidence of fetal alcohol syndrome (FAS).**

28
29 **25. (Developmental) Reduce the incidence of birth defects caused by prenatal maternal exposure to**
30 **prescription medications with known teratogenic effect, such as Accutane and thalidomide.**

31
32 **Potential Data Sources:** Centers for Birth Defect Research and Prevention case registries; surveillance
33 systems maintained by the pharmaceutical manufacturers.

34
35 The effects of licit and illicit drugs, including alcohol, tobacco, cocaine, marijuana, and some prescription
36 medications, on the developing fetus are well documented. As was discussed above, tobacco is associated
37 with LBW, spontaneous abortion, and SIDS.⁷⁴ Heavy alcohol use is associated with fetal alcohol syndrome⁷⁵
38 and even moderate alcohol use has demonstrated effects on preterm delivery.⁷⁶ The use of cocaine during
39 pregnancy is associated with premature birth, impaired fetal growth, and neonatal seizures.⁷⁷⁻⁸⁰ In addition,
40 women who use cocaine are at especially high risk of infectious diseases, including hepatitis B and HIV.
41 Exposure to marijuana in utero may be associated with LBW, preterm birth, and neurobehavioral functioning;
42 however, it is difficult to isolate the effects of marijuana use on newborns, as users of the drug often use
43 alcohol and tobacco as well.⁸¹

44
45 Rates of abstinence from harmful substances during pregnancy appear to be rising. Between 1985 and 1995,
46 the percentage of pregnant women who abstained from the use of tobacco during pregnancy rose 15 percent,
47 from 75 percent to 86 percent. Use of illicit drugs, such as cocaine and marijuana, is quite rare, with 99
48 percent and 97 percent of pregnant women reporting abstaining from these drugs, respectively.

1 The use of alcohol during pregnancy, despite the established health risk, contradicts this trend. Alcohol use
2 during pregnancy appears to be widespread: in 1993, 81 percent of pregnant women abstained from alcohol
3 use, an increase of only 2.5 percent from the 1988 baseline. Rates of frequent drinking (at least seven drinks
4 per week or at least five drinks on any occasion in the past month) among pregnant women are increasing
5 substantially, from 0.8 percent in 1991 to 3.5 percent in 1995. Unintentional alcohol exposure is particularly
6 likely to occur early in pregnancy, before a woman knows she is pregnant.

7
8 Fetal alcohol syndrome is one of the leading preventable causes of mental retardation and a leading cause of
9 birth defects, including growth deficiency and microcephaly. Affected children are also likely to show
10 infantile irritability, poor coordination, hypotonia, and attention deficit/hyperactivity disorder.^{82,83} The
11 diagnosis of FAS is based on three criteria: prenatal and/or postnatal growth retardation, central nervous
12 system impairment, and characteristic facial malformations. However, abnormalities of other organs and
13 systems have been noted in combination with these characteristics.⁸⁴ Estimates of the prevalence of FAS vary
14 from 0.2 to 1.0 per 1,000 live births. In addition to FAS, studies have documented more subtle growth and
15 neurodevelopmental deficits among children whose mothers drank during pregnancy. Alcohol-Related Birth
16 Defects (ARBD) and Alcohol-Related Neurodevelopmental Disorders (ARND) are thought to be 3 to 4 times
17 as prevalent as diagnosed cases of FAS. Because of these lifelong effects, and because a safe level of alcohol
18 consumption during pregnancy has not been identified, the American Academy of Pediatrics and the
19 American College of Obstetricians and Gynecologists recommend that women who are pregnant or are
20 planning a pregnancy abstain from the use of alcohol.^{85,86}

21
22 Despite broad agreement on the importance of FAS, consistent diagnosis of the syndrome at birth has been
23 difficult to achieve. Thus, it is a challenge to accurately estimate the number or proportion of infants that are
24 affected by FAS. This challenge stems from a number of causes: the difficulty of evaluating an infant's
25 central nervous system, lack of training among clinicians, inconsistent diagnostic criteria, and clinicians'
26 tendency to avoid associating their patients with the stigma of alcohol problems.⁸⁷

27
28 At times, medications known to be strong teratogens (such as Accutane and thalidomide) are deemed to have
29 sufficient unique benefits that warrant their distribution by prescription. In the cases of Accutane and
30 thalidomide, manufacturers have instituted rigorous constraints to prevent exposure in pregnant women.
31 With the increasing availability of teratogenic medications comes the public health responsibility to ensure
32 that the measures to prevent exposure in pregnant women are effective.⁸⁸

33 34 *Neural Tube Defects*

35
36 **26. (Former 14.17) Reduce the incidence of spina bifida and other neural tube defects to 3 per 10,000**
37 **live births.** (Baseline: 7 per 10,000 in 1993)

38
39 **Target Setting Method:** Retain year 2000 target.

40
41 **Data Source:** National Birth Defects Prevention Network (NBDPN), CDC, NCEH.

42
43 **27. Increase to at least 80 percent the proportion of women of childbearing age who take a vitamin**
44 **with the recommended 0.4 mg of folic acid daily.** (Baseline: 30 percent in 1997)

45
46 **Target Setting Method:** 160 percent improvement.

47
48 **Data Source:** March of Dimes/Gallup Survey.

49

1 **28. (Developmental) Increase the mean red blood cell (RBC) folate level among women aged 18-44.**

2
3 **Potential Data Source:** National Health and Nutrition Examination Survey (NHANES), CDC, NCHS.

4
5 Neural tube defects, including spina bifida, occur when the fetal neural tube fails to close fully, interrupting
6 development of the central nervous system. Approximately 50 percent of cases of neural tube defects may be
7 prevented with adequate levels of folic acid from the time of conception throughout pregnancy.⁸⁹ Therefore,
8 the U.S. Public Health Service has recommended that all women of childbearing age consume at least 400
9 micrograms of folic acid daily. Enriched grains (including flour, bread, and pasta) are fortified with folic
10 acid. However, the amount of folic acid that a woman is likely to receive through her diet, even with this
11 fortification, is unlikely to meet this Public Health Service recommendation. Thus, these objectives
12 emphasize the need for women of childbearing age to take vitamins that contain folic acid.
13

Breastfeeding

29. (Former 14.9) Increase to at least 75 percent the proportion of mothers who breastfeed their babies in the early postpartum period; to at least 50 percent the proportion who breastfeed until their babies are 6 months old; and to at least 25 percent the proportion who breastfeed until their infants are 1 year old. (Baseline: 60 percent during early postpartum period and 22 percent at 6 months in 1996; 8.6 percent of singleton infants breastfed at 1 year in 1990-93)

Select Populations	1996 (unless noted)
Mothers breastfeeding their babies during early postpartum period	
African American	37%
American Indian/Alaska Native	52%
Asian/Pacific Islander	Not available
Hispanic	61%
White	64%
In hospital	
Grade school	47%
High school	49%
Non-college	48%
College	74%
Mothers breastfeeding their babies at 6 months	
African American	11%
American Indian/Alaska Native	24%
Asian/Pacific Islander	Not available
Hispanic	20%
White	24%
Grade School	18%
High School	15%
Non-college	15%
College	31%
Singleton infants breastfed at 1 year	
African American mother	2.3% (1990-93)
American Indian/Alaska Native mother	Not available
Asian/Pacific Islander mother	Not available
Hispanic mother	6.9% (1990-93)
White mother	10.2% (1990-93)
0-149% of poverty threshold	7.2% (1990-93)
150-299% of poverty threshold	10.1% (1990-93)
≥300% of poverty threshold	9.6% (1990-93)

Note: The definition used for breastfeeding in this objective includes exclusive use of human milk or the use of human milk with a supplemental bottle of formula.

Target Setting Method: Retain year 2000 target.

Data Source: Mothers' Survey, Ross Products Division, Abbott Laboratories, Inc.

30. (Developmental) Increase the proportion of women whose infants are breastfed exclusively.

1 **Potential Data Source:** Mothers' Survey, Ross Products Division, Abbott Laboratories, Inc.

2
3 Breast milk is widely acknowledged to be the most complete form of nutrition for infants, with a range of
4 benefits for infants' health, growth, immunity, and development. The benefits of breastfeeding include
5 decreased incidence or severity of diarrhea,⁹⁰⁻⁹⁴ respiratory infections,^{95,96} and ear infections,⁹⁷⁻⁹⁹ among
6 others, and reduced cost to the family.^{100,101} In addition, breastfeeding has been shown to improve maternal
7 health, with demonstrated effects, including reduction in postpartum bleeding,¹⁰² earlier return to
8 prepregnancy weight,¹⁰³ reduced risk of premenopausal breast cancer,¹⁰⁴ and reduced risk of osteoporosis,¹⁰⁵
9 continuing long after the postpartum period. In general, the American Academy of Pediatrics considers
10 breastfeeding to be "the ideal method of feeding and nurturing infants."¹⁰⁶

11
12 Universal breastfeeding is not recommended in the United States, as women who use illegal drugs, who have
13 active, untreated tuberculosis, or who test positive for HIV, as well as those who use certain prescribed drugs,
14 should not breastfeed.¹⁰⁷⁻¹⁰⁹ In general, however, increasing the rate of breastfeeding, particularly among the
15 low-income and minority populations who are less likely to begin breastfeeding in the hospital or to sustain it
16 throughout the infant's first year, is an important public health goal.

17
18 Rates of breastfeeding are highest among college-educated women, those age 35 and older, and those with
19 family incomes of at least \$25,000. The lowest rates of breastfeeding are found among those whose infants
20 are at highest risk of poor health and development: those with low incomes, those under age 21, and those
21 with low educational levels. However, many of these groups have shown the greatest increase in
22 breastfeeding rates since 1989. Rates of breastfeeding among African-American women during the
23 postpartum period increased 61 percent, and rates of African-American women breastfeeding at 6 months
24 grew 75 percent between 1989 and 1995. Breastfeeding rates among women age 20 and below at both
25 periods also increased substantially, as did those for low-income women and those with a grade-school
26 education.¹¹⁰ While these improvements are encouraging, education of new mothers and their partners; social
27 support, including support from employers; and greater media portrayal of breastfeeding as the normal
28 method of infant feeding are needed to increase breastfeeding rates among those at highest risk.

29
30 ***Newborn Screening***

31
32 **31. (Developmental/Former 14.15) Ensure that all newborns are screened by State-sponsored**
33 **programs to detect phenylketonuria (PKU), congenital hypothyroidism, galactosemia, and**
34 **hemoglobinopathies.**

35
36 **31a. Screened at birth.**

37
38 **31b. Followup diagnostic testing for screening positives.**

39
40 **31c. Access to interventions for infants with diagnosed disorders.**

41
42 **Potential Data Source:** Title V Performance Measures, HRSA, MCHB.

43
44 **32. (Developmental) Reduce the incidence of life-threatening sepsis among infants with sickling**
45 **hemoglobinopathies.**

46
47 **Potential Data Source:** National Hospital Discharge Survey (NHDS), CDC, NCHS.

48

1 **33. (Developmental) Increase to 100 percent the proportion of newborns who are screened for**
2 **hearing loss by 1 month of age, have diagnostic followup by 3 months and are enrolled in**
3 **appropriate intervention services by 6 months.**

4
5 **33a. Hearing screening by 1 month.**

6
7 **33b. Followup diagnostic completed by 3 months.**

8
9 **33c. Enrolled in appropriate services by 6 months.**

10
11 **Potential Data Source:** Title V Performance Measures, HRSA, MCHB.

12
13 Virtually all States screen infants for genetic and metabolic disorders and treat or refer for treatment those
14 with a confirmed diagnosis. However, some disorders are more uniformly screened for than others, and
15 followup testing and early initiation of preventive treatment is uneven. For example, screening for PKU and
16 congenital hypothyroidism is virtually universal, although reporting is not. Screening and followup for
17 galactosemia, sickle cell disease, and other hemoglobinopathies have been less consistent. Significant
18 mortality and morbidity are associated with sickle cell because of increased susceptibility to severe bacterial
19 infections; meningitis, pneumonia, and septicemia are major causes of death among children with the
20 disorder.¹¹¹ The inherited disorder of galactosemia leads to an increased risk of death from overwhelming
21 infection in early infancy, failure to thrive, vomiting, liver disease, and mental retardation in untreated
22 survivors.¹¹² Therefore, it is vital that screening be universally available, that diagnostic testing be provided
23 for those newborns who screen positive, and that followup treatment be offered to children with diagnosed
24 disorders.^{113,114}

25
26 Early identification of congenital conditions is necessary to prevent complications of these conditions. For
27 example, life-threatening episodes of sepsis from pneumococcus and other organisms are well-recognized
28 complications of sickle cell disease in children. The effectiveness of early treatment was shown by the results
29 of a U.S. randomized trial published in 1986 that showed the efficacy of daily oral penicillin prophylaxis in
30 preventing infection among young children with sickle cell disease.¹¹⁵ The results of prophylactic penicillin
31 trials in the U.S. and Jamaica led to scientific consensus about the need for screening and subsequently
32 widespread adoption of newborn hemoglobinopathy screening programs, and survival of young children with
33 sickle cell disease has improved in the past three decades.^{116,117} Sepsis rates were shown to be clearly
34 improved by prophylactic therapy in the U.S. penicillin trial, but concerns about actual use of penicillin in
35 large populations and penicillin-resistant organisms necessitate continued monitoring of sepsis rates in large
36 populations.

37
38 The future of a child born with a significant hearing loss depends to a very large degree on early identification
39 (i.e., audiological diagnosis before 6 months of age) followed by immediate and appropriate intervention. If
40 children with hearing loss are not identified early, it is difficult, if not impossible, for many of them to acquire
41 the fundamental language, social, and cognitive skills that provide the foundation for later schooling and
42 success in society. When early identification and intervention occurs, children with hearing loss make
43 dramatic progress, are more successful in school, and become more productive members of society. The
44 earlier intervention and habilitation begins, the more dramatic the benefits.

45
46 Unfortunately, the average age at which children with significant hearing loss (i.e., moderate to profound
47 bilateral hearing loss) are identified in the United States is somewhere between 24 and 30 months of age. This
48 contrasts sharply with other countries such as Israel and Great Britain where the average age of identification
49 is 7 months of age. Factors that contribute to failure to identify children earlier in the United States include

1 lack of parental awareness of the indicators of hearing loss in very young children, the “wait-and-see” attitude
2 exhibited by many physicians when parents express concern about possible hearing loss, and the fact that
3 only a handful of States have implemented screening programs for high-risk children. Existing knowledge
4 and technology provide the tools to address these obstacles and thereby reduce the average age at which
5 children with hearing loss are identified. Establishment of universal newborn hearing screening prior to
6 hospital discharge was endorsed at a NIH Consensus Conference convened in 1993 to weigh the merits of
7 early identification and intervention of hearing loss.

8
9 ***Genetic Testing***

10
11 **34. (Developmental) Increase the proportion of primary care providers who have specific training in
12 the use and interpretation of genetic testing methods.**

13
14 **Potential Data Sources:** Association of American Medical Colleges (AAMC) database on courses
15 offered at all U.S. medical schools; Primary Care Providers Survey, ODPHP.

16
17 **35. (Developmental) Increase the level of public knowledge about how inherited sensitivities can lead
18 to the early onset of disease and create opportunities for health promotion and disease prevention
19 in order to:**

- 20
21 • **Enhance individual decisionmaking and public participation in ethical and social policy
22 deliberations related to genetic technologies; and**
23
24 • **Reduce the risk of adverse consequences of genetic testing in personal and public health.**

25
26 **Potential Data Source:** Gallup Poll and Dana Foundation public surveys.

27
28 **36. (Developmental) Before genetic testing for a particular condition becomes widely available,
29 increase the proportion of States that have in place mechanisms to ensure the following:**

30
31 **36a. Ongoing oversight of screening activities by informed representatives from the health
32 professions and the public, to monitor the validity and utility of the testing.**

33
34 **36b. Laboratory quality control of genetic testing.**

35
36 **36c. Assurance that no test results will be used to limit access to health insurance or employment.**

37
38 **36d. Assurance that informed consent will be required and genetic counseling available.**

39
40 **Potential Data Source:** Maternal and Child Health Block Grant Performance Measures, HRSA,
41 MCHB.

42
43 Over the past 20 years, the ability to diagnose genetic disease has been developing rapidly.¹¹⁸ Our knowledge
44 will advance even more dramatically as the Human Genome Project increases our capacity to identify the
45 genetic basis for diseases. Not only have direct tests for mutations been developed, but, in time, tests for
46 genetic predispositions to multifactorial disorders, as well as techniques to simultaneously test for hundreds
47 of different disease-causing mutations, will be available.¹¹⁹ As the availability of genetic tests increases and
48 testing becomes more commonplace, it is likely that genetic testing will be ordered and interpreted by primary
49 care providers, including pediatricians, obstetrician-gynecologists, internists, family physicians, and nurse

1 practitioners.¹²⁰ These health care providers increasingly will be called upon to apply genetic information to
2 individual patients and help those patients make decisions about testing and treatment. To ensure that genetic
3 tests are administered in an appropriate manner, genetic counseling and education will need to be considered
4 essential components of the standard of care for primary care providers.¹²¹

5
6 Providers must be trained to perform educational and counseling functions appropriately and to know when to
7 refer patients to specialized genetics personnel. Training will need to encompass basic genetics principles,
8 sensitivities of genetics education, ethical, legal, and social issues surrounding genetic diagnosis, testing, and
9 screening, and “evidence-based” and “authoritative opinion” guidelines for medical management of the
10 various genetic conditions. Although some progress has been made in increasing primary care providers’
11 knowledge of genetics and genetic testing, many of these providers are unprepared for the increasing need for
12 genetic testing, education, and counseling projected for the future.¹²² To meet this need, training will need to
13 be increasingly incorporated into medical school, nursing school, and postgraduate and continuing medical
14 and nursing curricula. It is expected, too, that medical and scientific organizations such as the American
15 Academy of Pediatrics (AAP), American College of Medical Genetics (ACMG), and American College of
16 Obstetricians and Gynecologists (ACOG) will issue standards and guidelines for practice that provide further
17 educational opportunities and potentially influence the primary care provider’s decisions.

18
19 The growing ability to map the human genome will lead to the identification of disease-causing genes and to
20 the development of tests to detect some of the mutations that are responsible for susceptibility to many
21 common disorders. The genetic tests may benefit those at risk for developing genetic disorders by permitting
22 early treatment. Safety and effectiveness must be established before these tests are routinely used within
23 State newborn screening programs. It is also important that the users of these new technologies be assured
24 that the results of these tests will not be misused or used for discriminatory purposes.¹²³ Examination of the
25 ethical, legal, and social implications of genetic testing has prompted the recommendations for more
26 education in genetics for health providers and the general public and public oversight of genetics-related
27 practices to assure the public health.^{124,125}

28
29 *Service System*

30
31 **37. (Developmental/Former 14.16) Increase the proportion of babies aged 18 months and younger**
32 **who receive recommended primary care services at the appropriate intervals.**

33
34 **38. (Developmental) Increase the proportion of primary care providers who routinely refer or screen**
35 **infants and children for impairments of vision, hearing, speech, and language, and who assess**
36 **other developmental milestones as part of well-child care.**

37
38 **Potential Data Source:** Primary Care Providers Survey, ODPHP.

39
40 **39. (Developmental/Former 17.20) Increase the number of States and territories that have service**
41 **systems for children with or at risk for chronic and disabling conditions, as required by Public**
42 **Law 101-239.**

43
44 **Potential Data Sources:** Maternal and Child Health Bureau, HRSA, Reporting System; Family
45 Satisfaction Survey, Family Voices.

46
47 It is essential that appropriate primary care continue throughout a child’s first months. The American
48 Academy of Pediatrics recommends that babies have 10 primary care visits in their first 18 months of life: an
49 evaluation at birth, at 2 to 4 days, by 1 month, and at age 2 months, 4 months, 6 months, 9 months, 12

1 months, 15 months, and 18 months. Each of these visits includes a recommended set of measurements,
2 screens, developmental and behavioral assessments, immunizations, and anticipatory guidance.¹²⁶ A similar
3 schedule of visits for infants and young children has been developed by the Maternal and Child Health
4 Bureau in its “Bright Futures” guidelines.¹²⁷

5
6 These visits are important to ensure infants’ health and development, to identify potential problems early in
7 life, to educate parents about child health and safety, and to provide immunizations. Population-based data
8 are not currently available to assess the proportion of babies who receive the full schedule of visits. The
9 development of such a data source, either through national sample surveys or through the analysis of
10 administrative databases, is important to the assurance of infants’ access to comprehensive, age-appropriate
11 primary care.

12
13 An important role of these visits is screening for developmental delays, sensory impairments, and other
14 disorders that may not be obvious to a child’s parents. Twelve percent of all children have mental
15 retardation, speech-language and hearing impairments, emotional/conduct disturbances, and other causes of
16 developmental delay that can interfere significantly with academic success and life functioning.¹²⁸ Early
17 identification of children with special learning needs and appropriate intervention has been shown to improve
18 family functioning, child behavior, and/or adult outcome, including socioeconomic status.¹²⁹

19
20 Children with or at risk of chronic and disabling conditions, often referred to as children with special health
21 care needs, include children with psychosocial as well as physical problems. This population encompasses
22 children with a wide variety of actual or potential disabling conditions, including children with or at risk for
23 cerebral palsy, mental retardation, sensory deprivation, developmental disabilities, spina bifida, hemophilia,
24 other genetic disorders, and health-related educational and behavioral problems. Service systems for such
25 children are organized networks of comprehensive, community-based, coordinated, and family-centered
26 services.

27
28 The establishment of systems of services that reflect the principles of comprehensive, community-based,
29 coordinated, family-centered care are essential for effectively facilitating activities to: (1) avoid the initial
30 occurrence of chronic and disabling conditions among children, (2) reverse or slow the process of chronic and
31 disabling conditions among children, and (3) minimize the complications and impact of chronic and disabling
32 conditions among children. The establishment of these service systems is also essential to strengthening the
33 ability of families to care for and cope with children with actual or potential chronic and disabling conditions
34 and enables children with more serious conditions to be placed in home and community-based living
35 arrangements rather than in institutional living arrangements.

36
37 Children with potential or actual chronic and disabling conditions and their families often require a range of
38 different types of services. Health activities and services, for example, are one necessary component and
39 should include: (1) health education and health promotion activities for children and their families, (2)
40 preventive and primary care that includes routine screening for impairments of vision, hearing, speech and
41 language and assessment of physical and psychosocial milestones, (3) specialized diagnostic and therapeutic
42 services, and (4) habilitation and rehabilitation services. Early intervention services are another necessary
43 component as are educational, vocational, and mental health services for children and support for their
44 families. Service systems should provide coordination to overcome gaps in and duplication of services.

45
46 Finally, service systems should be family-centered in order to support and assist families in their natural and
47 pivotal role as primary caretakers by involving families and professionals as partners in the care of children.
48 Family-centered services recognize the importance of the family in the child’s life and the fact that the family
49 is constant in the child’s life, whereas those providing health and other services are transitory.

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Related Objectives From Other Focus Areas

Nutrition

- 4 Growth retardation
- 12 Anemia in pregnant women

Tobacco Use

- 2 Cigarette smoking during pregnancy
- 7 Smoking cessation during pregnancy
- 8 Smoking cessation by new mothers

Environmental Health

- 11 Blood lead levels
- 17 Testing for lead-based paint

Injury/Violence Prevention

- 6 Child death review systems
- 34 Maltreatment of children

Oral Health

- 12 Screening/counseling for 2-year-olds

Access to Quality Health Services

- A.1 Uninsured children and adults
- A.2 Insurance coverage
- A.3 Routine screening about lifestyle risk factors
- A.4 Reporting on service delivery
- A.5 Training to address health disparities
- B.1 Source of ongoing primary care
- B.2 Failure to obtain all needed health care
- B.3 Lack of primary care visits
- B.4 Access to primary care providers in underserved areas
- B.5 Racial/ethnic minority representation in the health professions
- B.6 Preventable hospitalization rates for chronic illness
- C.1 Access to emergency medical services
- C.2 Insurance coverage
- C.3 Toll-free Poison Control Center number
- C.4 Time-dependent care for cardiac symptoms
- C.5 Special needs of children
- C.6 Followup mental health services

Family Planning

- 1 Planned pregnancy
- 2 Repeat unintended births
- 7 Adolescent pregnancy

Diabetes

- 7 Perinatal mortality in infants of mothers with diabetes

1 8 Congenital malformations in infants of mothers with diabetes

2
3 **Disability and Secondary Conditions**

4 9 Inclusion of children with disabilities in regular education programs

5
6 **HIV**

7 12 Perinatally acquired HIV infection

8
9 **Immunization and Infectious Diseases**

10 4 Hepatitis B in infants

11 21 Immunization of children 19-35 months

12 22 States with 90 percent immunization coverage

13 23 Immunization coverage for children in day care, kindergarten, and first grade

14 30 2-year-olds receiving vaccinations as part of primary care

15
16 **Mental Health and Mental Disorders**

17 13 Primary care provider assessment of mental health of children

18 16 Children's access to mental health services

19 18 Children with mental health insurance

20
21 **Sexually Transmitted Diseases**

22 8 Congenital syphilis

23 9 Neonatal STDs

24 18 Screening of pregnant women

25
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