

II. MASSACHUSETTS MCH NEEDS ASSESSMENT 2005

IIA: Needs Assessment Process

Methodology and Data Sources

The Massachusetts maternal and child health needs assessment process is continuous. Each year, selected populations and issues are systematically reviewed with direction from the Title V Director and program directors. Particular attention is given to service areas in which MDPH may need to shift funding or service models, or address emerging issues. Annually, the Title V program reviews progress on the MCH national and state measures and priorities.

The Title V Program sits within the Center for Community Health; its Director is the Director of the Center for Community Health and Associate Commissioner of the Department of Public Health. The Center initiates and uses opportunities as they arise to identify issues and needs. External groups and individuals, including insurers, academic institutions, providers, families and professionals, are involved in this process. For example, shortly after the National Survey of Children with Special Health Care Needs (CSHCN) data was posted on the National Center for Health Statistics website and presented to families through the Consortium for CSHCN in October of 2003, Center staff analyzed the survey data and presented findings to insurer quality improvement coordinators.

For both ongoing and the five-year needs assessment, state data are analyzed to identify strengths and weaknesses. Comparisons are made to national indicators, such as the MCHB CSHCN measures and Healthy People objectives. For example, Massachusetts birth data are compared annually to national birth outcome measures published by the National Center for Health Statistics. Similar state and national comparisons are done using the Youth Risk Behavior Survey (YRBS) and Behavioral Risk Surveillance System (BRFSS). Trends are monitored using these and other state, regional and national data.

In addition, data are stratified and analyzed at a number of sub-state geographic levels and for population subgroups. Population stratifiers include race, ethnicity, language, economic status, age, gender, disability or special health needs status, and other characteristics, depending on the data source and question. When available, data are analyzed by city/town, six-state regions and Community Health Network Areas (CHNAs), which are 27 geographically contiguous groupings of Massachusetts communities. Since the provision of local health services are the responsibilities of Massachusetts' 351 cities and towns, rather than the counties, CHNAs assist locally for service and analytic purposes. In Massachusetts, counties are not utilized except for District Attorney Offices and County Houses of Corrections. MDPH is now considering using the new emergency preparedness regions for certain health-related purposes. For the first time in this needs assessment, data were also analyzed for clusters of rural communities previously excluded due to small numbers.

MDPH maintains a user-friendly on-line data analysis tool, the Massachusetts Community Health Information Profile (MassCHIP), which facilitates this process and is helpful for distributing data to stakeholders statewide. Health status indicators and other

data are presented to internal and external stakeholders, consumers, other state agencies, and an array of partners. Additional quantitative data and qualitative perspectives are contributed by these partners.

For this five-year needs assessment the review was more comprehensive, including examination of health status indicators for all of the MCH populations stratified by geographic area and population characteristics. To begin assessing needs, a Needs Assessment Working Group, including senior Bureau of Family and Community Health (BFCH) and Applied Statistics and Evaluation (ASETS) staff (one of whom attended the MCHB training), convened in April of 2004. The group reviewed existing data sources and developed plans for meetings with other groups. The previous five-year needs assessment with updates from 2003 along with numerous reports, such as a comprehensive report on adolescent health published in 2004, were distributed for review and updating.

Massachusetts has substantial needs assessment data available from a variety of sources and perspectives. Data sources used for the needs assessment are included in the Bibliography. Massachusetts used national surveys that provide state-level estimates such as the National Survey of CSHCN and the National Survey of Child Health. The Center for Community Health, Bureau of Health Information, Statistics, Research and Evaluation (CHISRE), other state agencies, health and human services advocates, private organizations, and academic institutions in Massachusetts all conduct needs assessments and evaluations. The MCH needs assessment used these existing resources, which are typically captured in public and private agency reports or websites.

Key quantitative data sources used for the needs assessment included the most recent years available and comparison years as appropriate for: US Census data; Massachusetts Vital Records, including Births, Deaths, Fetal Deaths, and the linked births-death file; Massachusetts BRFSS; Massachusetts Department of Education YRBS; MDPH Youth Health Survey; MDPH Bureau of Communicable Disease surveillance databases; Massachusetts Hospital Discharge and Emergency Room data; MDPH program databases, such as Early Intervention, Essential School Health Services, WIC, and Bureau of Substance Abuse Services. Documents from other state agencies and units within the Center for Community Health, such as the Substance Abuse Strategic Plan and burden documents such as one on healthy weight from the chronic disease units, were used to inform the needs assessment.

These data provided a very strong foundation for the needs assessment. One difficulty relates to the population data. Intercensal data are not available at the detailed population level, for example by age by race, needed to update certain rates and percentages. For these denominators, Title V uses Census 2000. Because of the wealth of data, readers of this needs assessment are cautioned that indicators may seem to differ somewhat, for example, between the YRBS and Youth Health Survey. Differences in data collection methodologies or specific wordings of questions may be responsible. At times multiple resources are used because they permit different stratifications or provide answers to different questions. The needs assessment presents the most recent, best available data selected from these resources. The needs assessment sections that follow note potential issues with specific indicators, for example, when data from one year may not be comparable to earlier years.

Partnerships and Collaborations

The needs assessment was kicked off at a meeting of program leaders within the Center for Community Health on September 24, 2004, with a presentation of existing data to orient and challenge the group to conduct a more in-depth review of the needs of the MCH populations. The same presentation was given to Statistics and Evaluation staff in the Center, orienting them to their ongoing role of updating indicators and ensuring that appropriate stratifiers were applied to analyses. A review of existing data prior to the meeting had shown that, with some exceptions, key MCH indicators for maternal, infant, child and adolescent health were generally more favorable in Massachusetts compared to the nation. At the same time, disparities were evident in access and outcomes in a number of areas. The kickoff meeting presentation highlighted these disparities by race, ethnicity, geographic area, income, sexual minority status, disability/ special health needs status and other stratifiers. Furthermore, a disparities theme was emphasized throughout the needs assessment.

Information related to state needs, capacity and priorities was collected at meetings and interviews held with various internal and external stakeholders, other state agencies and consumers, including parents of children with special health care needs (CSHCN) and youth. Programs hosted meetings to obtain input about needs, capacity and priorities. Other simultaneous needs assessment activities included additional consumers and external groups. MDPH regional managers solicited input from stakeholders in the geographic areas they cover. Researchers from Massachusetts General Hospital and Boston University conducted analyses and primary data collection that supplemented these efforts. The needs assessment itself identified additional resources to bring in to future needs assessment at the university, hospital, insurer, other state agency, and community levels.

The MCH needs assessment took advantage of several other MDPH efforts simultaneously underway. The Commissioner of Public Health hosted a series of meetings in all regions of the state, called the Public Health in the 21st Century, to collect input from a variety of stakeholders about directions for public health in Massachusetts. Data collected from this series of state-wide meetings has informed the MCH priorities and measures. In addition, the Center was informed by several programs' planned assessments specific to their program populations. For example, the family planning program conducted an in-depth analysis of unplanned pregnancy and family planning needs, including analyses of interpregnancy interval data and consumer and provider focus groups across the state. The Bureau of Substance Abuse and the Title V Director, along with other health and human service agencies and public safety agencies, conducted an assessment and developed a strategic plan to address substance abuse.

A goal of the needs assessment was to disseminate information to constituencies within and outside MDPH about the expanding purposes and populations of the MCH Block Grant, as well as obtain information from them. The role of the Title V Director has broadened to include oversight of bureaus and divisions responsible for substance abuse treatment and prevention, HIV/AIDS treatment and prevention, Office of Multicultural Health, Office of Healthy Communities, and tobacco cessation and prevention activities. The needs assessment presented an opportunity to initiate

additional collaborations between more traditionally MCH-oriented Bureau of Family and Community Health and programs in these areas to benefit MCH populations.

Collaborations are further detailed in section IIC below and the Capacity Assessment of the Four Constructs of a System of Care for CSHCN (Section IIB—2F below).

IIB: 2A. Massachusetts Introduction

The people of Massachusetts enjoy better overall health status and access to health care services than in many other states. These benefits derive in significant part from relatively high levels of income and education, a history of strong support for funding health and social service programs, and strong public health leadership both in state government and in community and advocacy organizations. The Center for Community Health within the Massachusetts Department of Health (MDPH) houses the Title V program. As such, it plays a key role in assuring access to comprehensive, multidisciplinary service networks and systems. It emphasizes public/private partnership and collaboration in building these services. A major focus is on the at-risk and under-served populations of the Commonwealth whose health status and access to care are often compromised.

IIB: 2B. State Overview Demographics

Geography and Demographics

Massachusetts is the sixth smallest state in landmass, measuring just 150 miles in its longest direction; however, it ranks 13th in population.¹ Of Massachusetts' estimated 6,349,097 residents, according to the Census 2000, 26% (1,675,113) were children and youth through 19 years of age and 22% (1,422,476) were women ages 15 to 44.² For 2004, the Census Bureau estimates the Massachusetts population at 6,416,505.³ Massachusetts is a relatively dense and urbanized state. The Census 2000 recorded nine percent of Massachusetts' residents living on the eastern seaboard in Boston (pop. 589,141),⁴ the state capital and largest city. Nearly 44% (43.7%) were living within the combined area of metropolitan Boston, Cambridge, and Quincy.⁵ After Boston, the next two largest cities are Worcester in central Massachusetts (pop. 172,648)⁶ and Springfield in the west (pop. 152,082).⁷

There are also numerous smaller cities in Massachusetts, many of which are historically based in the mill industries, as well as island populations. In eastern Massachusetts, there are 1,500 miles of coastline on the Atlantic Ocean. Two islands, Nantucket and Martha's Vineyard, are located 16 and 5 miles off the Cape Cod shore. With a combined year-round population of approximately 24,500⁸ and a summer population that swells to three times that number, these rural island communities face particular challenges in meeting their health care needs.

Rural areas predominate in the western section of the state, where the Berkshire Mountains separate many small towns with limited health services. Franklin County in the northwest has just 102 people per square mile.⁹ About 18.5% of Massachusetts' residents live in 193 communities in the west and other parts of the state that meet one of the several federal definitions of rural.¹⁰ These communities cover about 65% of the state's landmass.¹¹ Farming is still a significant industry in rural areas. To facilitate understanding of rural communities, MDPH and the Massachusetts Rural Health Advisory Council have designated two levels of rural communities based on the number of federal criteria for *rural* a community meets (see Figure 2B.1 for a map attached at the end of this needs assessment). For finer analyses, geographically and historically related rural communities have been grouped into areas that have been termed *rural clusters*.

The entire state is incorporated (there are no frontier areas) into 351 cities and towns, which are the functioning units for most local services, including public health, below the state level. There are no county health systems. However, the Commonwealth's cities and towns have been grouped into 27 *Community Health Network Areas (CHNAs)*. (For a map, see Figure 2B.2 attached at the end of this needs assessment) In each CHNA, health and human service providers come together with residents to engage in systematic community planning, building on existing coalitions and cooperative efforts. For emergency preparedness, the state has been clustered into 10 different geographic areas. The Executive Office of Health and Human Services (EOHHS) utilizes six regional clusters, which the Department of Public Health recognizes. Other EOHHS Departments use variants of these regional clusters.

Immigration, Puerto Rican Migration, and Race/Ethnicity Trends

Racial and ethnic minorities made up more than 12% of the state's population in 1990 (black non-Hispanics at 5%, Hispanics at 4.8%, and Asians at 2.4%). However, a decade later in 2000, minorities made up more than 16% (blacks at 5.4%, Hispanics at 6.8%, Asians at 3.8%, and two or more races at 2.3%). By 2010, Massachusetts' population is projected to be 6,690,740 with minority populations continuing to account for population growth. Hispanics are projected to increase by more than 38% and blacks by 32%. In several Massachusetts communities including Boston, minority groups constitute the majority of the population.

The state's overall population grew slowly in the 1990s, up 5.5% from 1990 to 2000, that modest increase due only to immigration.¹² In 2000, Massachusetts ranked 8th in the U.S. in its population of immigrants -- many of whom arrived within the last decade. A 2005 report concerning Puerto Ricans and immigrants found that one in seven (907,000) residents of Massachusetts was born in the U.S. territory of Puerto Rico or a foreign country.¹³ In 2004, these residents made up 17% of the labor force.¹⁴ Immigration will continue to play the main role in Massachusetts' labor force growth for the foreseeable future. In 1980, the labor market was composed of 9.4% foreign-born residents; in 2004, 14.3% of Massachusetts' workers came from other countries.¹⁵ Immigrants play a vital role in Massachusetts' development.

Estimates of immigrants and refugees may vary due to the inherent difficulty in counting changing populations whose language is not English and who experience cultural isolation. The following countries provided the largest percentages of Massachusetts' newest citizens: Portugal, China/HK/Taiwan, Dominican Republic, former USSR, Haiti, Vietnam, Italy, India, El Salvador and Brazil. Since the Census 2000, the hospitality industry has recruited a large number of Brazilians to work in hotels and restaurants throughout the state. Almost one in five immigrants entering the state from 2000 to 2003 was Brazilian.

Based on the 2000 Census, approximately 6% of Massachusetts non-Hispanic white residents were foreign-born. Immigration from Europe (overall, with exceptions noted above) and Canada has decreased over recent decades. Puerto Rican in-migration to Massachusetts has also decreased. Nearly half of all recent immigrants are from Latin America and the Caribbean; almost one-quarter from various countries in Asia.¹⁶ In addition, smaller numbers of populations increasingly come from varying linguistic groups in countries of Africa. Decreases in births among women born in the US

simultaneous with increasing births among foreign-born women also contribute to changing demographics in the state. (See Section 2C below for birth data.)

Nationally, the influx of Spanish speakers has outpaced the immigration of other groups. Massachusetts differs in that its foreign-born population is diverse across multiple race and linguistic groups and within racial categories. Understanding this phenomenon helps us examine health disparities among broad race groups—white non-Hispanic, black non-Hispanic, Hispanic, Asian, and American Indian--and is crucial for understanding differences in disease risk, health outcomes, and inequities in the delivery of medical care. It is also important to look *within* each broad racial group, since in some instances there are greater differences in outcomes and risk among detailed ethnicity groups within one race category than between race categories. The following sections provide a brief overview of the various population groups.

Note that Census 2000 allowed individuals to identify more than one race category when responding. In order to account for this change, MDPH created the MDPH Population Estimate for 2000 that accounted for individuals who checked “some other race alone,” “some other race in combination with other races,” and those who indicated more than one race. The figures below are based on this method, and they may differ somewhat from others in this document.

Asian: Since the 1990 census, the Asian population has grown by 74% and now comprises approximately 4% of the total population. Asians are 26% of the foreign-born population, and 72% of Asians are foreign-born.¹⁷ Although the largest ethnic Asian group is Chinese (35% of the Asian population), 11 other groups have been identified (in order by %): Asian Indian, Vietnamese, Cambodian, Korean, Japanese, Filipino, Laotian, Thai, Pacific Islanders, Pakistani and “Other Asian”. Each ethnicity has different customs, health beliefs and language, and differs markedly in socioeconomic indicators. Boston, Lowell, Cambridge, Quincy, Worcester and Brookline are cities with the largest Asian populations.

Black: According to this estimate, blacks are 6.2% of the Massachusetts population. About 24% of blacks were foreign-born,¹⁸ with 66% from the Caribbean and 26% from Africa.¹⁹ The birth certificate enables mothers to identify both their race and ethnicity. These include: African American, Haitian, Jamaican, Cape Verdean, Nigerian, Barbadian, Other African, Other West Indian/Caribbean. In addition, the foreign-born population has significant representation from: Western, Eastern and South Africa, Trinidad and Tobago. These ethnic groups have different languages and customs. Although some countries might have English as one of the official languages, most residents maintain tribal traditions and languages, thus making it difficult to categorize them with common attributes. An increasing number of individuals are entering as refugees or fleeing the conflicts in Africa. Blacks can be found in communities throughout the state with larger concentrations in: Boston, Springfield, Brockton, Worcester, Cambridge, Randolph, Lynn, Lawrence, and Milton.

Hispanic: Hispanics were the largest minority group identified in Census 2000 and the second fastest growing population group in Massachusetts. Of Hispanics, 31% are foreign-born and 23% born in Puerto Rico.²⁰ Nearly half of all immigrants and Puerto Ricans who arrived in Massachusetts between 2000 and 2004 were from Latin America and the Caribbean. The Hispanic population grew by 49% between 1990 and 2000. Although their numbers are falling, Puerto Ricans still comprise the largest group

(approximately 47% of all Hispanics) in Massachusetts. In most other US states, unlike Massachusetts, Mexicans are the largest group in the Hispanic population. As with other broadly defined groups, Hispanics are often assumed to be homogenous in language and customs. This is not the case with Hispanics in Massachusetts. Immigrants from Nicaragua are from a country composed of various populations who speak different languages. On Nicaragua's eastern coast, English-speaking blacks reside; in the center and Pacific coasts, Spanish speakers who are indigenous and whites reside. In Massachusetts, other ethnic populations include: Other Hispanics, Dominicans, Mexicans, Other Central American, Salvadorans, Other South American, Colombians, and Cubans. Boston had the biggest Hispanic population, but Lawrence had the largest concentration (60% of its residents). In addition, 14 communities have Hispanic populations totaling more than 10% of the population: Chelsea (48%), Holyoke (41%), Springfield (27%), Southbridge (20%), Lynn (18%), Worcester (15%), Fitchburg (15%), Boston (14%), Lowell (14%), Salem (11%), Leominster (11%), Framingham (11%), and New Bedford (11%).²¹

Unauthorized Immigrants: The Census Bureau estimates 87,000 unauthorized immigrants in Massachusetts as of January 2000.²² A 2005 study estimates the number of "unauthorized migrants"²³ (encompassing individuals often termed "undocumented") in Massachusetts to be between 200,000 to 250,000.²⁴ The unauthorized population has been increasing since the last half of the 1990s and in Massachusetts is estimated to be between 20% and 29% of the foreign-born population.²⁵

Linguistic minorities: The recent shift in immigration, away from European and other English-speaking countries, to those where English is not the primary language, presents challenges for Massachusetts. An increasing number of new immigrants do not speak English at all, or do not speak English well.²⁶ The 2000 Census recorded almost one in five Massachusetts residents (18.7% in MA compared to 17% in US) 5 years and older who spoke a language other than English at home. Of those, 22% spoke English "not well" or "not at all." This is a significant increase from the 1990 census when only 1 in 10 (12.4%) residents fell in that category.

It is estimated that more than 150 languages are spoken in Massachusetts. Spanish-speakers accounted for 30% of those who speak a language other than English, 51% speak some other Indo-European language, 15% an Asian or Pacific Islander language, and 4% spoke some other language. Among those who spoke Spanish at home, 27% described their ability to speak English as "not well" or "not at all."²⁷ The MassINC/Center for Labor Market Studies report indicates that 136,890 adult immigrants and Puerto Ricans in 2000 did not speak English at all, or did not speak it well.

¹ U.S. Census Bureau, Census 2000. Table PH1-R. Internet Release Date: October 29, 2004.

² U.S. Census Bureau, Census 2000. QT-P1, Age Groups and Sex: 2000, Massachusetts. Internet Release Date: October 29, 2004.

³ US Census Bureau, 2004 Population Estimates Census 2000, Census 1990 at <http://factfinder.census.gov>.

⁴ U.S. Census Bureau, Census 2000. Boston City, Massachusetts. Internet Release Date: October 29, 2004.

⁵ U.S. Census Bureau, Census 2000. PHC-T-29, Table 9. Internet Release Date: October 29, 2004.O.

⁶ U.S. Census Bureau, Census 2000. Worcester City, Massachusetts, Table DP-1. Internet Release Date: October 29, 2004.

⁷ U.S. Census Bureau, Census 2000. Springfield, Massachusetts, Table DP-1. Internet Release Date: October 29, 2004.

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- ⁸ U.S. Census Bureau. <http://quickfacts.census.gov/qfd/states/25/25019.html> and <http://quickfacts.census.gov/qfd/states/25/25007.html>.
- ⁹ (www.absoluteastronomy.com/encyclopedia/F/Fr/Franklin_County_Massachusetts.htm).
- ¹⁰ The Massachusetts Rural Advisory Board determined communities considered *rural* in Massachusetts using a combination of federal criteria including those of the Census Bureau, the Office of Management and Budget, Rural Urban Commuting Area Codes.
- ¹¹ U.S. Census Bureau <http://quickfacts.census.gov/qfd/states/25/25007.html> and <http://quickfacts.census.gov/qfd/states/25/25007.html>.
- ¹² U.S. Census Bureau, Census 2000. PHC-T-2, Ranking Tables for States: 1990 and 2000. Internet Release Date: October 29, 2004.
- ¹³ Massachusetts Institute for a New Commonwealth, Center for Labor Market Studies, The Changing Face of Massachusetts, Executive Summary, 18 Tremont St., Suite 1120, Boston, MA 02108, June, 2005. Note that the report considers Puerto Ricans among those foreign-born, due to language and cultural variations. .
- ¹⁴ Ibid.
- ¹⁵ Ibid.
- ¹⁶ The Center for Immigration Studies, Background, November 2002; and Massachusetts Institute for a New Commonwealth, Center for Labor Market Studies, The Changing Face of Massachusetts, Executive Summary, 18 Tremont St., Suite 1120, Boston, MA 02108. June, 2005.
- ¹⁷ U.S. Census Bureau, Census 2000, PCT63D, Place of Birth by Citizenship Status (Asian Alone), SF 3.
- ¹⁸ U.S. Census Bureau, Census 2000, PCT63B, Place of Birth by Citizenship Status (Black or African American Alone), SF 3.
- ¹⁹ U.S. Census Bureau, Census 2000, PCT48, Place of Birth by Year of Entry by Citizenship Status for the Foreign-Born Population, Racial or Ethnic Grouping: Black or African American alone, SF 4.
- ²⁰ U.S. Census Bureau, Census 2000, PCT63H, Place of Birth by Citizenship Status (Hispanic or Latino Alone), SF 3.
- ²¹ Massachusetts Department of Public Health, Center for Health Information, Statistics, Research and Evaluation. Hispanic Births in Massachusetts, 1996-1999, Volume I: Statewide Data. Boston: Massachusetts Department of Public Health; 2001.
- ²² US Census Bureau. Statistical Abstract of the United States, Table 7: Estimated Unauthorized Immigrants by Selected States and Countries of Origin; 2000.
- ²³ Pew Hispanic Center. Unauthorized Migrants: Number and Characteristics. Washington DC: Pew Hispanic Center, 2005, p 2. The term “unauthorized migrant” refers to “a person who resides in the U.S., but who is not a U.S. citizen, has not been admitted for permanent residence, and is not in a set of specific authorized temporary statuses permitting longer-term residence and work.” The term “unauthorized migrant” encompasses groups also described as “undocumented immigrants,” “illegals,” “illegal aliens,” and “illegal immigrants,” some of whom may have counterfeit documents and are therefore not “undocumented” although their documents are not legal. The use of “migrant” instead of “immigrant” highlights the distinction that unauthorized migrants are more likely to leave the country than other groups.
- ²⁴ Ibid. p 21.
- ²⁵ Ibid. p. 3, 15.
- ²⁶ Massachusetts Institute for a New Commonwealth, Center for Labor Market Studies, The Changing Face of Massachusetts, Executive Summary, 18 Tremont St., Suite 1120, Boston, MA 02108, June, 2005.
- ²⁷ U.S. Census Bureau, Census 2000. PHC-T-37, Ability to Speak English by Language Spoken at Home: 2000. Massachusetts, Tables 23a and 23b Internet Release Date: October 29, 2004 and Excel file "[Boston population by race and ethnicity census 2000.xls](#)".

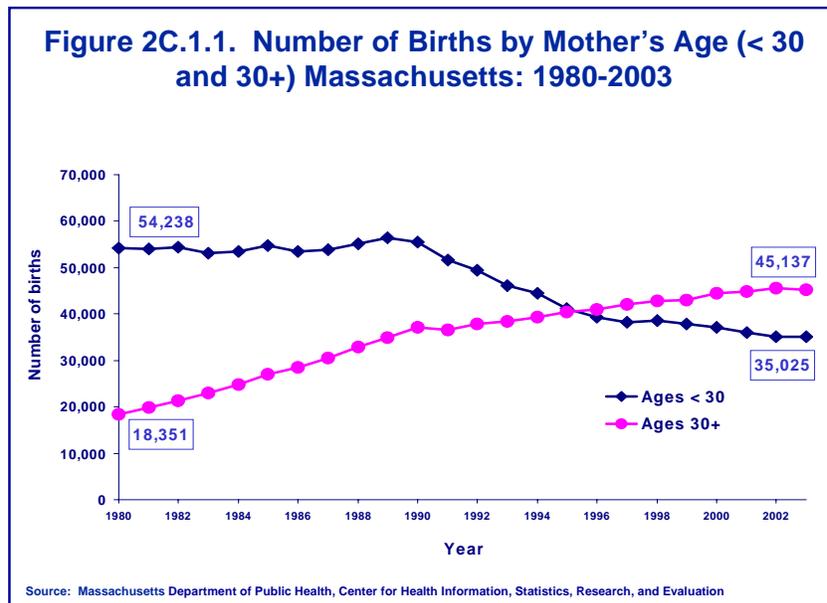
IIB: 2C. Pregnant Women, Mothers and Infants

2C.1 Massachusetts Births: Numbers, Rates, and Demographics

In 2003, the most recent year for which birth data are available, the number of births to Massachusetts' residents was 80,167.¹ The total number of births in Massachusetts has been declining. Births declined by 0.6% between 2002 and 2003; a total decline of 13% since 1990, when births totaled 92,461. The birth rate has declined by 9% since 1990, from 62.2 to 56.2 per 1,000 women ages 15 to 44 in 2003. The 2003 Massachusetts birth rate was 15% below the national rate of 66.1 per 1,000 women ages 15 to 44.

Births by Age

Births to older women have increased while births to younger women have decreased. In 1980, 1 out of 4 Massachusetts mothers were ages 30 and over, compared to more than 1 out of 2 in 2002.² While there has been a steady increase in births to women 30 and older, births to women under age 30 have been steadily declining. In 2003, 56% of births were to mothers age 30 and older. Massachusetts is the first state to have more births to women over the age of 30 than to those under 30 (See Figure 2C.1.1 below). The birth rate to women ages 40 to 44 increased from 6.9 in 1990 to 12.2 in 2003. The birth rate for women age 45 or more went from 0.3 to 0.7 per 1,000 women ages 45-49 for the same years. The health and social implications of this shift are yet not fully understood, and will be monitored closely over the next years.



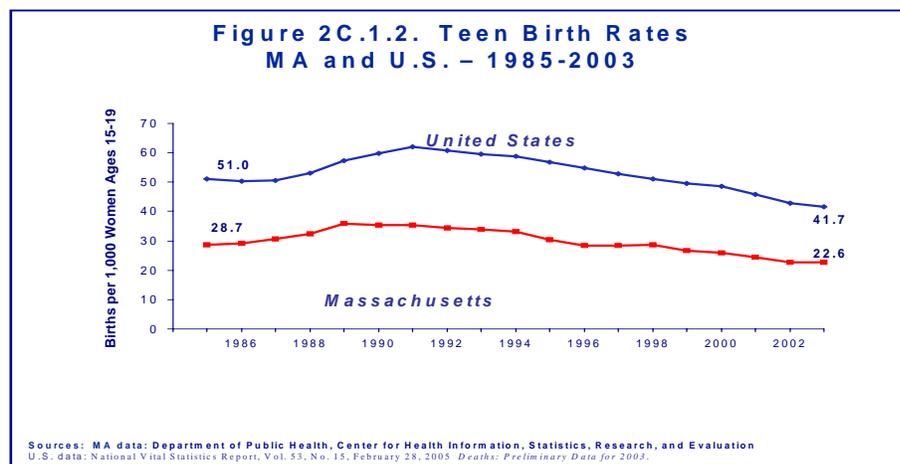
The birth rate for teens 15 to 19 was 22.6 per 1,000 teens 15 to 19 years old. The teen birth rate declined 29% between 1992 and 2003 (See Figure 2C.1.2 below). The Massachusetts teen birth rate is 46% below the preliminary U.S. teen birth rate (22.6 compared to 41.7 in 2003).³

Massachusetts continues to have a low teen birth rate relative to most other states and the nation as a whole, but some communities have teen birth rates that are much higher than the state rate. Communities with the highest teen birth rates in the state in 2003 included Holyoke at 91.9, Lawrence at 82.9, Springfield at 79.3, Southbridge at 66.5, Chelsea at 61.7, New Bedford at 56.7, Fall River at 55.9, Pittsfield at 52.9, Fitchburg at 49.4, and Lynn at 48.5 per 1000 women ages 15 to 19. These communities had rates of almost three to four times greater than the statewide rate of 22.6 per 1,000 females 15 to 19. All of these communities had a decrease in their rates in 2003 compared to the rates in 1993, except Pittsfield where a 40% increase was noted. The percentage of decrease ranged from 23% for the lowest to 43% for the highest.

The birth rate for teens also varied by rural clusters. Using a three-year rolling average of teen birth rates (2001-2003), clusters with relatively higher teen birth rates were North Quabbin Area (37.12), Central Franklin (35.47), and Blackstone River West (33), compared to 24.24 per 1,000 teens 15-19 for the state.

The age distribution of teen births has not changed much in recent years, with 31.8% occurring to women under age 18. The annual number of births to young teens (ages 12 to 14) continued to decline from a peak of 155 in 1994 to the current low of 56 (a rate of 0.27 births per 1,000 females aged 10 to 14). This is a 23% decline in this age group. The U.S. rate for younger teens was 0.7 per 1,000 females aged 10 to 14 years, which is 61% above the Massachusetts birth rate for young teens. Ninety-two percent of births to teens in Massachusetts are to unmarried women.

The percentage of births to teens with at least one prior birth declined in 2003 to 13%, with the most visible decrease in the younger age group (12 to 17). In 2003, there were 632 births to teen mothers less than 20 years of age with one prior birth. Of these, 274 (43.4%) had a short interpregnancy interval (less than 12 months), 315 (49%) had an interpregnancy interval between 12 and 35 months, and 43 (6.8%) had an interpregnancy interval equal or greater than 36 months.



Births by Race/Ethnicity and Mother's Place of Birth

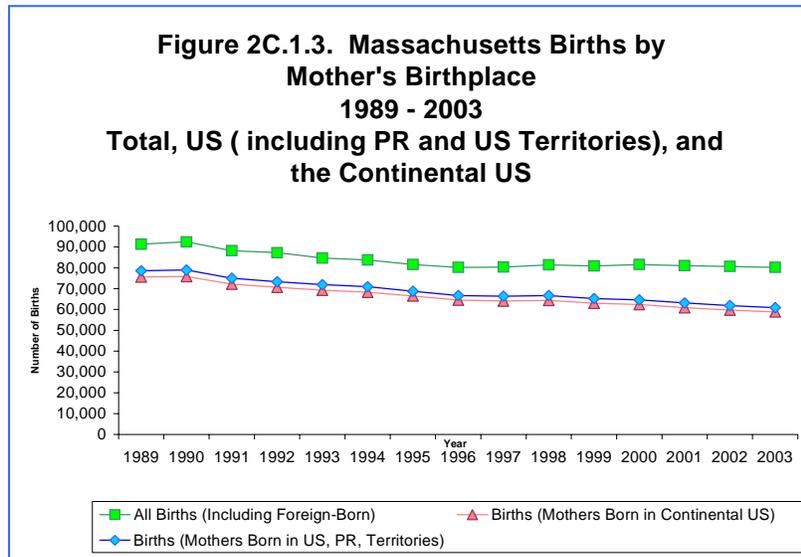
In 2003, 71.9% of Massachusetts births were to white, non-Hispanic women, 12.2% were to Hispanic, 7.4% were to black, non-Hispanic, 6.5% were to Asian, and 1.9% were to women who designated themselves as American Indian and other race. In comparison, according to the 2000 census, the distribution of Massachusetts women ages 15 to 44 is the following: white, non-Hispanic 81% (1,149,396), black, non-Hispanic 6% (84,645), Hispanic 8% (113,974), Asian 5% (71,691), and American Indian 0.2% (2,770).⁴

Of the 71.9% of births to white, non-Hispanic women, 10.6% were to women born in countries other than the US and 0.1 % were to women born in Puerto Rico, the U.S. Virgin Islands, and Guam. Of the 12.2% of births to Hispanic mothers, 48.9 % were to foreign-born and 19.5% were to women born in Puerto Rico, the U.S. Virgin Islands, and Guam. Of the 7.4% of births to black, non-Hispanics, 47.4% were to foreign-born, and 0.4% were to women born in Puerto Rico, the U.S. Virgin Islands, and Guam. Of the 6.5% births to Asian women, 89.9% were to foreign-born women. Of the 1.9% births to mothers who designated themselves as American Indian and other race, 61.6% were to non-U.S.-born women.

Forty-eight percent of teen births were to white, non-Hispanic women, 33% were to Hispanic teen mothers, 12% were to black, non-Hispanic mothers, 4% were to Asian mothers, and 3.2% were to mothers of others races.

Despite a decrease of less than 1% of overall births, births to some groups increased more than 10% since 2002. Births to Colombians increased by 21%, while births to Cubans and Mexicans have increased by 19% and 16% respectively. Births to “other Central Americans” have increased by 22%. Within this category, births to women from Guatemala and Honduras had the largest increases (up 26% and up 19% respectively). Births to Japanese mothers increased by 12%.

After decreasing in parallel from 1990-1997, since 1998 births to foreign-born mothers have increased while births to U.S. and Puerto Rican-born mothers have continued to decline. In 1989, births to women born outside the continental US (including Puerto Rico) were 17% of all births; in 2003, they were 27% of all births, an increase of 59%. This increase was among foreign-born women, not Puerto Ricans. The number of births to mothers born in Puerto Rico has declined 34% since 1989 from 2,886 to 1,880⁵(See Figure 2C.1.3). Special reports on various characteristics and health indicators related to births have been developed by the Massachusetts Department of Public Health (MDPH) Center for Community Health, Information Statistics and Evaluation, and are provided for black, Hispanic and Asian mothers. These reports provide a more specific description of births for each sub-group.^{6,7,8}



Multiple Births

In 2003, the total number of multiple births was 3,800 or, 4.7% of all births, a slight decrease from 2002 (4.9%). Of all multiples, 4.4% were twins (3,551) and 0.3% were triplets (249). Of the 3,800 multiple births, 2,109 (55.6%) were low birthweight (LBW) and 402 (10.6%) were very low birthweight (VLBW).

The percentage of multiple births has increased among women in both younger and older age groups. The percentage of multiple births to women less than 35 in 2003 was 4.1 compared to 2.5 in 1990; an increase of 64%. Among women 35 years and older, the percentage of multiple births was 7.1 in 2003, a 103% increase from 1990 (3.5%).

Method of Delivery

A steady decline in the percentage of Cesarean delivery was seen from 1990 (22.5%) to 1997 (19.8%). Since 1997, the percentage of Cesarean delivery increased by 48% from 19.8% in 1997 to 29.3% in 2003. In 2003, Cesarean section was the method of delivery for 29.3% of births occurring in Massachusetts, the highest rate ever reported; a 4% increase from the 2002 rate of 28.1%. The Cesarean section rate in Massachusetts in 2003 was 6% higher than the nationwide rate of 27.6%. Reports from individual hospitals in the Spring of 2005 indicate that the rate may be continuing to grow, with one institution projecting may be over 40%. The rise in Cesarean section delivery rate in Massachusetts mirrors the increase in the United States.

In Massachusetts, concern has grown that a proportion of these Cesareans were medically elective, though the consequences of such an intervention are not well understood. The Pregnancy to Early Life Longitudinal (PELL) database which links mother-child data from Massachusetts births, deaths, fetal deaths, hospital discharge, birth defects, and other data sets, created the opportunity to examine the outcomes of such births by (1) creating a category of medically low risk mothers who had a Cesarean and (2) examining the outcomes as measured by rehospitalization of those births. The category “no indicated risk” (NIR) births is based on earlier studies of low risk mothers using either the birth certificate or hospital discharge data.

With the linked PELL database, a team of researchers from Boston University led by Dr. Eugene Declercq was able to identify a subset of mothers who met the criteria of both measures and had a primary Cesarean. In the preliminary analysis, women who received an NIR primary Cesarean were several times more likely to be rehospitalized in the first month after birth than those mothers who had a spontaneous vaginal birth. The leading reasons for the higher rate of rehospitalization were factors associated with surgery. Initial examination of the cost data in PELL found Cesareans to have substantially greater costs both initially and as a result of rehospitalizations.

2C.2 Health of Women

A state priority is to improve the health and well-being of women in their childbearing years, with a particular emphasis on racial and ethnic disparities and on pre- and inter-conceptual health. In addition, a newly proposed state MCH measure focuses on perinatal disparities. Based on the 2000 Census, 1,422,476 Massachusetts residents (22%) are women between the ages of 15 and 44. Given the growing number of births to women age 45 and older, the range of childbearing age will likely be expanded in the future.

Preconceptual and Interconceptional Health

Findings from the Perinatal Periods of Risk (PPOR) analysis in Massachusetts suggest that maternal health/prematurity factors greatly contribute to fetoinfant mortality in Massachusetts, with 43% of fetoinfant deaths due to such factors (see Perinatal Deaths section for details). To improve maternal health/prematurity factors, prevention effort must include a focus on preconceptional, interconceptional health, and prevention of unintended pregnancy.

The goal of preconceptional (and interconceptional) health is to provide women and their partners with information to make informed decisions about their reproductive futures, including prevention of unintended pregnancies and identification of risk factors that could affect reproductive outcomes. Premature births, the largest contributor to low birthweight and infant mortality in the US,⁹ are related to conditions best addressed before pregnancy begins. Recent studies indicate that more than 50% of all pregnancies in the United States are unplanned.¹⁰ In Massachusetts, 25% of women ages 18 to 44 in 2002 who were pregnant in the past 5 years reported an unplanned pregnancy, a slight decline from earlier years.¹¹ Given that many pregnancies are unplanned, women may not even be aware they are pregnant in the crucial first eight weeks of pregnancy, when the baby's organ system is forming.

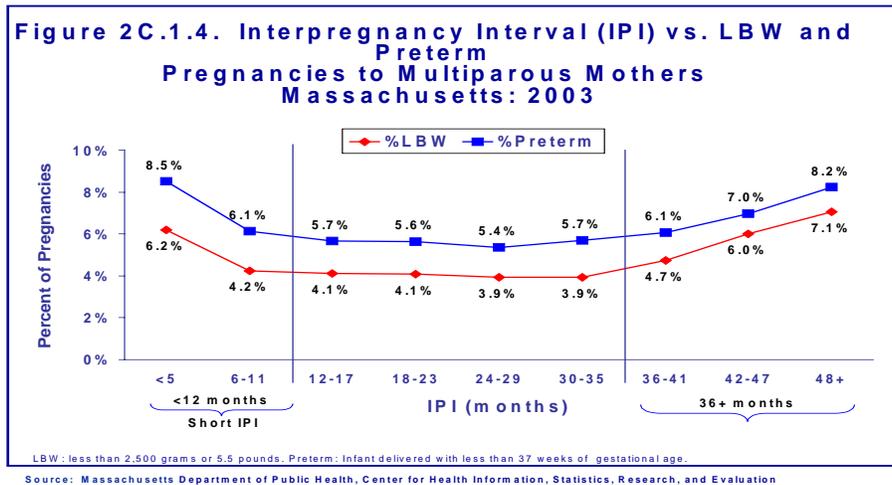
Aspects of women's health and their health access that may affect pregnancy outcomes include interpregnancy interval, insurance status and access to care, chronic diseases, and lifestyle and behavioral risks including alcohol, drug, and tobacco use, oral health. Each of these is discussed below. Data from the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) was aggregated over multiple years (1998-2003, or 1997-2002 depending on the timing of particular questions) to obtain sufficient sample size to look at differences by poverty status, race/ethnicity, and other characteristics among women of childbearing age. An approximate income level at or below 200% poverty was calculated from available income categories and household size. Given

many potential differences to report, for the BRFSS aggregate analyses, only differences by population characteristics with non-overlapping 95% confidence intervals have been selected, unless otherwise noted (See attached Tables 2C.2.1 to 2C.2.5 for detailed BRFSS analysis by race, poverty level, income, and insurance coverage of the mother).

Interpregnancy Interval (IPI)

IPI is defined as the interval in months between the birth or fetal death of one infant and the beginning of a next pregnancy. A short IPI is any interval equal to or less than 12 months. Short IPIs, particularly those less than 6 months, are linked to poor perinatal outcomes, including a significantly greater risk of preterm delivery and LBW^{12,13} and increased risk of maternal death, third trimester bleeding, premature rupture of membranes, puerperal endometriosis and anemia,¹⁴ and uterine scar failure.¹⁵ Short interpregnancy interval can be associated with unplanned pregnancy or inadequate use of family planning services after the end of pregnancy.

IPI data are available from both the annual birth data (retrospectively) and longitudinally linked birth data in PELL (prospectively and retrospectively). For the first time this year, using annual birth data, IPIs were analyzed by age of the mother, correlated with birth outcomes, and released as part of the annual public press event. Figure 2C.2.1 below, released at this event, shows outcomes by IPI. Very short and very long IPIs were associated with poor birth outcomes.



We plan to include IPI as an ongoing measure in the annual births release as well as develop program initiatives to decrease the percent of women giving birth who have short IPIs (<12 months). Short IPI and short IPI by risk group (for example, teen, MassHealth) data for 30 cities and towns were used for a family planning needs assessment. IPI measured using PELL data is a newly proposed state MCH measure with this application.

Insurance Status and Access to Care

Lack of integrated and comprehensive health care for women throughout their reproductive years is a major contributor to poor perinatal outcomes. A review of a

woman's medical, reproductive, nutritional, and family history are crucial to discover potential problems and possible interventions to improve health outcomes of both the mother and the infant. When women do not receive comprehensive preconceptional care, they may enter pregnancy with unaddressed medical and social risk factors that compromise the health of both infant and mother. Insurance coverage affects access and use of care.

Insurance coverage is further discussed in the needs assessment section on direct and enabling services; however, the following statistics from the BRFSS aggregate data for 1998-2003 provide information about the insurance status of women of childbearing age and health care access:

- Overall 5.6% of women of childbearing age responding to the survey had no insurance at the time of the survey. Hispanic and black women were more likely to have no health insurance when compared to white women (9.8%, 8.8%, and 5% respectively);
- Overall 88.4% of women had a regular physician. Hispanic and black women were less likely to have a regular physician when compared to white women (75.9%, 85.1%, and 91.1% respectively).
- Hispanic women were more likely to have inadequate health insurance when compared to black or white women (31%, 21.8%, and 16.5% respectively);
- Women without health insurance were much or likely to report that they had no regular physician (OR=9.7; CI 7.1-13.1), and women with government insurance were somewhat more likely to report no regular physician than women with commercial insurance (OR=1.5; CI 1.1-1.9).

Chronic Diseases

Women with specific pre-existing conditions such as diabetes mellitus, anemia, hypertension, thyroid disorders, gynecological disorders, epilepsy, systemic lupus erythematosus, disease, hyperphenylalaninemia, asthma, heart disease, deep venous thrombosis, kidney disease, hemoglobinopathies, cancer, seizure disorders, tuberculosis, rheumatoid arthritis, and mental health/psychiatric disorders are at increased risk for adverse pregnancy outcomes. It is important that these conditions be well controlled before and during pregnancy. Women on medication may need to modify, stop or be advised not to stop taking their medications depending on potential harm to the growing fetus.

The 1998-2003 BRFSS data provides the following statistics about prevalence and disparities related to certain chronic conditions among women of childbearing age:

- Overall, 1.5% of all women reported having diabetes. Black women were more likely to report diabetes than whites (3.8% and 1.3% respectively), with Hispanics not differing statistically from either at 2%. Of black women below 200% of poverty, 4.5% reported diabetes.
- Overall, 16.5% of all women reported having asthma with no statistical differences by race/ethnic groups. Women at or below 200% poverty were more likely to have asthma than those with higher incomes (20.3% vs. 16%).
- Overall, 8.7% of all women reported having high blood pressure. Black women were more likely to report having high blood pressure than whites

(16.1% vs. 7.8%), as were women in poverty compared to those with higher incomes (12.0% vs. 7.1%).

Gestational Diabetes

Gestational diabetes complicates between 2-5% of all pregnancies in the United States, endangering both mother and child.¹⁶ In Massachusetts in 2000, 2.74% of all women who gave birth had gestational diabetes.¹⁷ Women who develop gestational diabetes have a 40% higher probability of developing Type 2 diabetes later in life than other women.

The woman most likely to suffer from gestational diabetes is overweight or obese before becoming pregnant¹⁸ and is over the age of 35. Age over 35 alone makes her 8 times more likely to develop the disease than an expectant mother who is 18 or younger. This woman is also most likely to belong to an ethnic minority. Asian/Pacific Islanders in Massachusetts have a self-reported rate of gestational diabetes twice that of non-Hispanic whites (68 vs 27.1 per 100,000 pregnancies). Hispanics report the second highest rate (49.4), followed by non-Hispanic blacks (43).¹⁹ With rates of overweight among children and adolescents on the rise, gestational diabetes is poised to become an even greater problem. During pregnancy, the obstetrician provides care. However, care following the pregnancy may be provided through primary care providers. Thus, after the delivery, the information about gestational diabetes must be provided to the primary care provider so that these women can receive additional monitoring care and management as to prevent, identify and treat as early as possible Type 2 diabetes.

Infectious Diseases

Women with infections such as sexually transmitted diseases including gonorrhea, chlamydia, syphilis, HIV, hepatitis B and C before or during pregnancy should be appropriately treated to improve the outcome of both the mother and the baby. The immune status of women before pregnancy should be established to reduce adverse health outcomes for the newborn. Mothers who contract rubella (German measles) or chicken pox (varicella) during pregnancy have a high risk of giving birth to a baby with mental retardation, heart defect, and deafness. Therefore, it is important for women to have appropriate screenings, immunizations, and treatments when they are planning to be pregnant.

In 2004, confirmed infectious disease cases in women ages 18 to 44 reported to MDPH included: hepatitis A (169), hepatitis B acute (40), hepatitis B chronic (72), hepatitis C acute (3), and chronic hepatitis C (869). No toxoplasmosis or rubella cases were reported. MDPH follows up all cases of hepatitis A and C. In addition the Massachusetts Immunization Program follows up all women ages 14 to 44 who have a positive hepatitis B surface antigen screen for pregnancy status to prevent vertical transmission of hepatitis B. Infants of women who screened positive will receive hepatitis B-immunoglobulin at birth and appropriate doses of hepatitis B-vaccine.

Some minority women may be at higher risk for active or latent tuberculosis (TB). Pregnant women have been targeted for TB testing because sometimes, pregnancy is the first encounter with the health care system for minority women.²⁰ Pregnant women with untreated active TB can endanger the newborn at delivery. Between 2002-2004, there were 334 cases of TB among women, of which 183 (55%) were to women ages 15 to 44.

Of these 183, 24(13%) were white, non-Hispanic, 56(31%) were black, non-Hispanic, 36 (20%) were Hispanic, and 67 (36%) were Asian. Non-US born represented 89% (163) of the cases.²¹

Pap smears are important for screening for cervical cancer, vaginal infections such as bacterial vaginosis and STDs. According to the BRFSS data from 1998-2003, women of childbearing age with no regular physician were more likely not to have a Pap smear (OR=2.7; CI 1.8-4.2).

The incidence rate of chlamydia among women ages 15 to 44 rose from 545.5 per 100,000 women ages 15 to 44 in 2003 to 641.2 in 2004. Among adolescents ages 15 to 19 the incidence rate rose from 1,496.6 in 2003 to 1,746.4 per 100,000 in 2004. The incidence rates for gonorrhea and syphilis in 2004 were 99.2 and 5.3, higher than the rate for 2003 (86 and 4.9 respectively). These rate increases appear to be due in part to increased screening.

It is recommended that all women who are pregnant or planning to be pregnant be counseled and offered HIV testing. Testing in pregnancy is important because treatment is available that can improve mother's health and prevent vertical transmission to her baby. Prior testing does not rule out HIV. The HIV testing is voluntary and must be done with informed consent. Women may want to include their partners in the counseling session. The 1997-2002 BRFSS data provides the following statistics about HIV screening patterns by race and income among women of childbearing age and among women who reported that they were pregnant at the time of the interview or within the previous 5 years:

- Of women of childbearing age, 56% had ever had an HIV test. Blacks (72%) and Hispanics (67%) were more likely to have ever had an HIV test. Differences by race remained after stratifying by poverty level.
- The percentage of pregnant women ever tested was higher (76% for the period) and rose from 70.7% in 1998 to 77.9% in 2002.

The number of women with a positive HIV/AIDS status in Massachusetts has continued to increase. As of June 1, 2005, there were 3787 women ages 15-44 living with HIV/AIDS in Massachusetts (prisoners excluded from this figure). Of these, 1,193 (31.5%) were white, 1,458 (38.5%) were black, 1,056 (28.0%) were Hispanic, 35 (0.9%) were Asian/Pacific Islander, 11 (0.2%) were American Indian, and 34 (1.0%) were others. Two cases of vertical transmission were reported in 2004.²²

The prevalence of HIV/AIDS varied by Community Health Network Area (CHNA). CHNAs with more than two hundred cases of HIV among women ages 15 to 44 are:

- Alliance for Community Health (Boston/Chelsea/Revere/Winthrop) with a population of 203,008 women ages 15 to 44 had the highest number of cases: 1,018;
- Community Health Connection in Springfield, population of 62,411 had 350 cases;
- Community Wellness Coalition in Worcester, population of 65,087 had 331 cases;
- Partners for a Healthier Community in Fall River, population of 29,540 had 235 cases;

- Four Communities (Holyoke, Chicopee, Ludlow, Wesfield) population of 33,948, had 201 cases.

Lifestyle and Behavioral Risk

High quality preconceptional care includes attention to other lifestyle factors and behaviors related to nutrition (for example, vitamins intake and appropriate weight), physical activity (exercise habits), injury prevention and prevention or cessation of tobacco, alcohol, and drug use. Education to support daily intake of folic acid to prevent certain birth defects is important.

Smoking increases the risk for miscarriage, stillbirth, and low birth-weight. Also, babies exposed to second hand smoke are at much higher risk for sudden infant death syndrome (SIDS), asthma, and other respiratory problems.²³ Alcohol use during pregnancy at any time can cause fetal alcohol spectrum disorders or related birth defects such as heart problems, an underdeveloped face, a smaller than normal head, and mental retardation.²⁴

Healthy Weight

MDPH is proposing a priority and measure for healthy weight across the three MCH populations including women. Body weight before pregnancy will set the pattern for weight gain during pregnancy. Being overweight prior to pregnancy increases risk of gestational diabetes and poor outcome. Being underweight prior to pregnancy increases risk of infertility, anemia, and complications during childbirth. The 2003 Pregnancy Nutrition Surveillance System (PNSS) data from the Massachusetts Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) indicates that 38% of WIC participants were either overweight (24%) or obese (14%) prior to their current pregnancy and that 45.2% of WIC participants had excessive weight gain during pregnancy. The percentages of pregnant women with pregnancy weight gain greater than the ideal weight gain by race/ethnicity were the following: 50.2% for white, non-Hispanic, 43.2% for black, non-Hispanic, 42 % for Hispanic, and 27.8% for Asian.

The 1998-2003 BRFSS data provides statistics by race/ethnicity and income and disparities related to weight, physical activity, and fruits and vegetable consumption among women of childbearing age (See Tables 2C.2.1 to 2C.2.5 attached at the end of the needs assessment).

- Overall, 34.6% of all women reported being overweight; black and Hispanic women were more likely to be overweight than whites (56.6%, 52.2%, and 32.1% respectively).
- Overall, 21.9% of all women reported no physical activity; Hispanic and black women were more likely to report no physical activity than whites (50.3%, 33.9%, and 16.8% respectively).
- Overall, 12.1% of all women reported being obese; black and Hispanic women were more likely to be obese than whites (24.7%, 20.3%, and 10.8% respectively).
- Across all races/ethnic groups, women with moderate/high income usually report better health outcomes and behaviors than women with low income (approximately 200% of poverty level and below).

- Overall 68.5% reported eating less than five fruits/vegetables a day; all groups need to improve fruits and vegetables consumption, regardless of their race and income.

Smoking

Massachusetts has data about current smoking among women of childbearing age from the BRFSS and about smoking during pregnancy from the birth certificate. The two sources tell a similar story: declining smoking rates over the past 10 or more years with higher rates among poor, white, government-insured, young and less educated women. Smoking reported by women of childbearing age on the BRFSS decreased overall from 26.8% to 22.7% from 1998-2003 (aggregate data). During those years, 43.6% of white women ages 18 to 44 at or below 200% poverty level, and 49.5% with government insurance, reported current smoking. Smoking among black and Hispanic women below 200% poverty (26.3% and 18.5% respectively) and white, black and Hispanic women above 200% poverty (20.8%, 16.2%, and 14.5% respectively) did not differ.

The percentage of women who reported smoking during pregnancy on the birth certificate was 7.7 in 2003, a decrease of 60% from 19.3% in 1990. The percentage of teens under age 20 who reported smoking during pregnancy declined over the past 15 years from 31.7% (1989) to 16.6% (2003). A somewhat greater percent decline was seen among adult women age 20 and over from 20.9% (1989) to 7.1% (2003).

In 2003, of all women who identified themselves as light smokers (7.6%), 61.1% quit smoking during pregnancy. Of the moderate smokers, 81.2% either decreased the number of cigarettes smoked daily or quit smoking. Of heavy smokers prior to pregnancy 89% decreased the number of cigarettes smoked daily or quit.

The percentage of women who smoked varied by race/ethnicity. In 2003, white, non-Hispanics had the highest percentage of smoking during pregnancy (8.6%), followed by black, non-Hispanics (6.5%), Hispanics (5.9%), and Asians (1.4%).

Smoking decreased with increasing education level from 20.3% for mothers with less than a high school diploma, to 13.9% for mothers with a high school diploma, 1.2% for mothers with a college degree, and 0.5% for mothers with post-graduate education. Smoking during pregnancy declined with increasing education across all race/ethnic groups, with the highest percentage among white women with less than a high school education (38.3%) compared to black, Hispanic, and Asian women with less than a high school education (15.7%, 9.6%, and 5.2% respectively).

Smoking also varied by Community Health Network Area (CHNA) and by age. CHNAs serving the following communities had higher smoking rates during pregnancy among teen through age 19: Berkshire, Beverly/Gloucester, Franklin County, Plymouth, and Milford (41.5%, 40.6%, 37.7%, 35.1%, and 33.8% respectively). CHNAs serving the following communities had higher smoking rates during pregnancy among women age 20 or over: Berkshire, Fall River, Franklin County, New Bedford, and Holyoke/Chicopee/Ludlow/Westfield (19.6%, 17.2%, 15.3%, 15.1%, 13% respectively).²⁵

The Centers for Disease Control and Prevention's Smoking-Attributable Mortality, Morbidity, and Economic Costs (SAMMEC) software provides an application to examine the impact of smoking and to estimate the health and health-related economic consequences of smoking. The MCH SAMMEC provides an estimate of the number of

annual smoking-attributable deaths and years of potential life lost for infants, and neonatal medical expenditures for states.²⁶

Findings from the 2001 Massachusetts SAMMEC data indicate significant smoking-related loss of life and economic costs despite the recent decline in smoking rates. Massachusetts smoking costs were estimated at \$2.8 billion in personal health care expenditures, and almost \$20,000 per day was spent on neonatal health care expenditures related to smoking by women who gave birth in 1999. According to the SAMMEC data, nine Massachusetts infant deaths in 2001 were attributed to causes associated with maternal smoking. For 2001, these causes of death include short for gestation/low birthweight and Sudden Infant Death Syndrome. In the past, infants have also died from smoking-attributable respiratory conditions.²⁷

Substance Abuse

During FY 2004, approximately 1.9% (581) of all female admissions to substance abuse treatment service in Massachusetts were to pregnant women. Of these 581 women, 415 (71.3%) were white, 81 (13.9%) were black, 59 (10.2%) were Hispanic, and 26 (4.5%) were from other racial categories. Ninety-four percent of these women (546) were unemployed, 30.8% (179) were homeless, 50.4% (293) had received prior mental health treatment, 47.3% (318) were between the ages of 21-29, (with a mean age of 27.9 years), 45.1% (262) had children under six years of age (25.6% of these reported living with their children), and 43% (189) were the parents of children 6-18 years old (28% of which reported living with their children).²⁸

Alcohol: In FY 2004, of the 581 pregnant women over 18 who were admitted to substance abuse treatment services, 83 (14.2%) reported alcohol as primary substance of use.²⁹ The 1998-2003 BRFSS data provides the following related statistics about the prevalence of binge drinking and heavy alcohol drinking among women of childbearing age:

- Overall, 6.7% of women reported heavy drinking;
- White women were more likely to report heavy drinking than Hispanic and black (7.5%, 2.7%, and 5% respectively);³⁰
- Overall, 15.6% of women reported binge drinking;
- White women were also more likely to report binge drinking than blacks or Hispanics (17.6%, 7.8% and 8.8% respectively).

Drugs: Use of illicit drugs such as marijuana, cocaine, and heroin increase the likelihood of miscarriage, stillbirth, poor fetal growth. Children born to mothers who used these drugs during pregnancy often have behavioral problems and learning difficulties. Some researchers believe that the father's drug use before conception might increase the chances of birth defects in their children. Therefore, being drug free is important before, during and after pregnancy for both parents. Of all 581 pregnant admissions, heroin was most reported as the primary drug use for which they were seeking treatment in 54.4% of cases (316). Crack was reported as the primary substance of use by 61 women (10.5%), cocaine by 30 (6.5%), marijuana by 38 (6.5%), and other drugs by 53 (9.1%).³¹

Folic Acid and Multivitamin Use

The use of folic acid and multivitamins containing folic acid the weeks before

pregnancy and the early weeks of pregnancy is crucial in preventing birth defects of the spine and brain, such as spina bifida (open spine), anencephaly (a lethal defect involving the brain and the skull). In addition, many foods contain folic acid, such as green leafy vegetables, beans, asparagus, citrus fruit, and whole grain foods. A varied, balanced diet provides many vitamins and minerals. The 2000 and preliminary 2004 BRFSS data provides statistics on the use of multivitamins containing folic acid as well as knowledge of the benefits of taking folic acid for women ages 18 to 44.

- Overall, 42.2% of women reported taking daily multivitamins in 2000 compared to 50.5% in 2004.
- Overall, in 2000, 54.6% of women reported knowing that folic acid prevents birth defects, compared to 64.8% in 2004. This increase may or may not represent a true increase since the 2000 and 2004 questions were quite different.

Oral Health

Oral health is an important part of a woman's overall health. Recent studies suggest that gum disease may represent a threat to the pregnant mother and her unborn baby. Oral diseases are associated with serious health problems including cardiovascular disease, stroke, diabetes mellitus, respiratory infections, osteoporosis, and adverse pregnancy outcomes.³² Hormonal changes during pregnancy can cause swollen gums that bleed during pregnancy. Pregnant women are particularly susceptible to periodontal disease. Maternal periodontal infections are associated with premature birth, low birthweight, pre-eclampsia, ulcerations of the gingival tissue, pregnancy granuloma, and tooth erosion. These risks increase in women who smoke or experience nutritional deficiencies.³³ The 1998-2002 BRFSS data provides statistics regarding dental visits, dental insurance and missing teeth among women ages 18 to 44.

- Overall 81% of women reported having a dental visit in the past year, and 8% reported the loss of 6 or more teeth.
- Twenty-eight percent of women reported not having dental insurance (all statistics on dental insurance are from aggregated data from 1998-2001).
- Women with commercial insurance were more likely to report a recent dental visit compared to women with government insurance or no insurance (83.9%, 74.2%, and 61.6% respectively).

Unplanned Pregnancy

Unintended pregnancy has been associated with severe health, social and economic burdens including poor educational attainment, lack of or low-income employment opportunities, chronic poverty, and an increased need for public assistance.³⁴ Unintended pregnancies increase the risk of maternal and infant mortality.³⁵ Children born as the result of an unintended pregnancy are at an increased risk for abuse and neglect.³⁶ Therefore, increasing the percentage of pregnancies that are intended is a HP2010 objective and a state MCH performance measure.

In Massachusetts, 25% of women ages 18 to 44 in 2002 who were pregnant in the past 5 years reported an unplanned pregnancy,³⁷ a slight decline from earlier years. This estimate is lower than the national figures (34%-52%),³⁸⁻³⁹ and may be an underestimate due to methodology. Massachusetts has begun a pilot to shift to using the Pregnancy Risk Assessment Monitoring System (PRAMS) for this measure, as resources permit.

Women ages less than 18 years of age experienced the highest percentage (83%) of unintended pregnancy. In Massachusetts, women ages 18 to 24 were five times more likely to report an unplanned pregnancy in the past five years than women ages 35 to 44. In addition, women with lower levels of income and education, or women who are Hispanic were more likely to have an unplanned pregnancy. Among Hispanic women ages 18 to 44, 36% reported an unplanned pregnancy (OR=1.66 when compared to white). However, no difference remained after adjusting for age (OR=1) and for both age and education (OR=0.9). Compared to women in other Massachusetts regions, women who live in the Boston region have the highest unintended pregnancy rates.⁴⁰

The MDPH family planning program conducted an extensive literature and data review to assess family planning needs. In order to better understand family planning needs in certain populations, the program conducted a primary data collection using focus groups (black non-Hispanic women, Hispanic women, Brazilian Portuguese-speaking women, and women impacted by domestic violence), and questionnaires (adolescent girls, men, and rural women). Between 12 to 100% of focus groups participants were aware of family planning and other publicly funded reproductive health services in their areas. Friendly and helpful staff, low-cost services, and confidentiality, along with clinic hours/ease of getting appointments, were cited as of greatest value for services received.

Barriers identified include cultural attitudes and practices regarding health, a lack of communication and awareness about sexual health concerns including HIV and STD, and a lack of current information on birth control and reproductive health services.

Specific example included:

- Fear of results, a desire to “be strong” (not sick) may lead to avoiding health visits/tests;
- Denial or an inability to deal with reproductive health issues;
- Inadequate interpreter services or availability of reproductive health information that is linguistically and culturally accessible;
- Use of home remedies before visiting a doctor or clinic;
- Misinformation about some birth control methods including side effects, how they work;
- Extended waiting times at clinics and insufficient time with doctors.

Additional barriers included the inability or unknown ability to access family planning services from one’s own doctor, and insurance that does not cover birth control and/or uncertainty regarding the extent of one’s insurance coverage.

Possible strategies suggested to improve access and reproductive health care services include: increased availability of birth control and condoms, increased education on STD, HIV and, Family Planning, and the improvement of service delivery to become more linguistically and culturally appropriate to the needs of the particular population through strategies that ranged from provider training to the creation of population-specific clinics (for example, a “teen clinic”).

Prenatal Care

Adequacy of prenatal care utilization (APNCU) is currently being measured using the APNCU index. The APNCU index has two components: (1) adequacy of initiation, which measures the adequacy of when prenatal care began during pregnancy; and (2) adequacy of received services, which describes the adequacy of received prenatal visits

during the time period after prenatal care has begun until the delivery. The APNCU index uses five categories to characterize prenatal care. They are:

- *adequate intensive*-- a level of care exceeding recommended standards
- *adequate basic*-- the minimum recommended level of care for a pregnancy without complications
- *adequate intermediate*--prenatal care initiated within the first four months, but only 50-79% of expected visits completed
- *inadequate*--prenatal care initiated month five or later and less than 50% of expected visits were completed
- *total adequacy*-- the sum of adequate intense and adequate basic.

In 2003, the percentage of women receiving adequate prenatal care fell slightly to 84.5% from 84.7% in 2002. Between 2002 and 2003, adequacy rates increased 2% for black non-Hispanic mothers, and decreased slightly for white, non-Hispanic and Hispanic mothers (0.3% and 0.6%). In 2003, white, non-Hispanic women had the highest percentage of adequacy of prenatal care (86.8%), followed by Asians (81.9%), Hispanics (78.5%), and black, non-Hispanics (76.1%). More than 9 out of 10 mothers (92.8%) had adequate initiation of prenatal care. Half (50.4%) began prenatal care in the third or fourth month of pregnancy (“adequate basic” initiation) while 42.1% began care in the first or second month (adequate intensive). The total adequacy score was 92.8% on the adequacy of the initiation index.

The overall percentage of women beginning prenatal care in the first trimester (84.3%) continues to improve and is within 25% of reaching the Healthy People 2010 objective of 90%. Adequacy of prenatal care initiation also varies among racial and ethnic groups. Adequacy of prenatal care initiation increased for both black non-Hispanic women (from 84% in 2002 to 84.5% in 2003) and Hispanic women (from 87.2% to 88.5%). White, non-Hispanic women did not show any change from 2002 (95%). Three rural clusters had statistically lower first trimester initiation of care than the state average of 83.3%, aggregating birth data for 1998-2003: Central Franklin County (81.1%), Upper Cape Cod (78%), and North Quabbin (76%). Nantucket Country was at 81%, but estimates were unstable due to low numbers.

This indicator also varies by birthplace, with women born in the U.S. having the highest adequacy of prenatal care (94.2% in 2003). Adequacy of prenatal care was 90.1% and 89.1% for women born in Puerto Rico/U.S. Territory and non-U.S. born respectively.

Adequacy of prenatal care increased with age and education level of the mother. In 2003, almost 9 out of 10 women ages 30 or more received adequate prenatal care, while 1 in 5 women under 18 had inadequate prenatal (21.8%). Only 68% of teens less than 18 had adequate prenatal care and 10% received intermediate prenatal care. Women with more education were more likely to have prenatal care (90.4% of mothers with more than a college degree had adequate prenatal care while 70.7% of mothers with less than a high school education had adequate prenatal care). Mothers who smoked were over twice as likely to have inadequate prenatal care when compared to non-smokers, 15.8% vs. 7.1%. Mothers with higher birth order (fourth or higher) were almost twice as likely to have inadequate prenatal care than mothers giving birth for the first time (13.8% vs. 7.9%).

Women whose prenatal care was publicly funded were less likely to receive adequate prenatal care in all race/ethnicity groups. These women represented 28.9% of all births to Massachusetts women in 2003, compared with 28.5% in 2002.

Breastfeeding

The percentage of mothers breastfeeding in Massachusetts went from 76.15% in 2002 to 78.1% in 2003 and has been steadily increasing over the past 14 years. The rate of breastfeeding has increased 50% since 1989 (52.2%). Massachusetts exceeded the target for Healthy People 2010 since 2001. Many minority groups exceed the state average in 2003, with 82.1% of Asian mothers and 80.8% of Hispanic mothers breastfeeding at hospital discharge. However, some ethnic groups have much lower rates of breastfeeding, particularly Vietnamese, Cambodian, and Puerto Rican (66.4%, 50.4%, and 68.4% respectively).

The rates of breastfeeding among women enrolled in WIC and the MDPH funded Community Health Centers (CHCs) have also increased. The proportion of women enrolled in WIC who ever breastfed increased from 46.3% in 1994 to 68.4% in 2003, a 48% increase. The proportion of women enrolled in the WIC program who continue to breastfeed at six months has increased from 10.5% in 1990 to 24.9% in 2003. Breastfeeding rates at six months among Massachusetts women who participate in WIC and other DPH funded CHCs are still below the HP2010 goal of 50%.

Breastfeeding rates in among low-income communities are lower than the state average. The promotion of breastfeeding has been a major focus for the WIC program and, home visiting and prenatal programs. MDPH proposed Hospital Licensure Regulations include strong requirements related to the promotion of breastfeeding. A composite MCH state measure for healthy weight will also include a component on this issue.

2C.3 Infant Outcomes

Low Birthweight (LBW)

LBW is the greatest contributing factor to infant mortality and, particularly, to neonatal mortality.^{41,42} LBW is cause for concern. LBW as a percentage of births in Massachusetts continues to increase. Significant racial and ethnic disparities in LBW exist. In 2003, the percentage of LBW infants born to Massachusetts women (7.6%) increased by 5.6 % since 2001 (7.2%) and 31% since 1990 (5.8%). While this figure was the highest recorded in the state since 1980, it is still 2.6% lower than the national figure of 7.8%.⁴³

Much of the increase in LBW is attributable to multiple births. Of the 3,800 multiple births in 2003, 2,109 (55.6%) were LBW and 402 (10.6%) were very low birthweight (VLBW).⁴⁴ Eliminating the portion driven by the increase in multiple births would reduce the percentage of LBW in 2003 from 7.6% to 6.5% (See Figure 2C.3.1). Nevertheless, from 2002 to 2003, the percentage of LBW infants increased slightly among both singletons (5.2% to 5.3%) and multiples (53% to 55.6%).

Racial and ethnic disparities persist, with the highest percentage of LBW occurring among births to black non-Hispanic women (12.1%). This percentage is lower than the U.S. percentage for all black women (13.3%). From 2002 to 2003, however,

black, non-Hispanics were the only group to experience a decrease (4%) in the percentage of LBW from 12.6% to 12.1%, while rates for other racial/ethnic groups increased.

The proportion of LBW in 2003 increased by 3% for white, non-Hispanic mothers from 6.8% to 7.0%, by 1% for Asian mothers from 8% to 8.1%, and remained the same for Hispanic mothers (8.3%). The rate of LBW for Hispanic women (8.3%) was higher than the corresponding 2003 U.S. rate of 6.5%.⁴⁵ (Table 2C.3.1). In Massachusetts, the Hispanic population includes mainly Puerto Ricans, Dominicans, and Central Americans. The U.S. Hispanic population is mainly comprised of Mexicans and Cubans who tend to have relatively lower rates of LBW.

The proportion of very low birthweight (VLBW) babies in Massachusetts increased from 1992 to 1999 and then remained stable at 1.4%. The proportion of VLBW varies by mother's race and ethnicity. For the third consecutive year, black, non-Hispanic women had the highest proportion VLBW at 3.1% over twice that of other groups. In 2003, the percentage of VLBW was 1.3% for Hispanics, 1.2% for Asians, and 1.2% for white, non-Hispanics.

One reason for the increase in LBW and VLBW in Massachusetts appears to be related to a relatively new cohort of women who are over the age of 30, have private insurance and some college education. The highest percentages of LBW births in 2003 occurred among young teens and older women. Some of the underlying contributors to the incidence of LBW and VLBW such as maternal age, maternal education, maternal health status prior to pregnancy (cardiovascular diseases including high blood pressure, diabetes, depression/stress), maternal smoking, drinking, or use of drugs, and birth order are well known.

Teen mothers were more likely than adult women to have specific characteristics that may be associated with adverse birth outcomes. The percentage of LBW among births to teen mothers less than 20 was 9.3% in 2003 compared with 7.5% among births to mothers ages 20 and older in 2003. The percentage of LBW among teens less than 18 was 11.1% and 8.4% among teens 18-19 years old. The percentage of LBW was still fairly high among young adult women 20-24 (7.4%). Teens have higher rates of poor pregnancy outcomes, including IMR and LBW, and adolescent health is a state priority with a new measure proposed related to risk reduction.

Risk factors for LBW and VLBW are also associated with smoking and maternal social economic status.⁴⁶ In 2003, 11.5% of infants born to Massachusetts' mothers who smoked during pregnancy were LBW, compared to 7.3% of infants born to non-smoking mothers. Across all races and Hispanic ethnicity, the percentage of LBW was higher among women who smoked during pregnancy compared women who did not smoke. Others factors contributing to LBW are not well understood.

Low birthweight also varies by geographic residence of the mother, likely driven by differences in demographics including race and economic status. Of the CHNAs, for 2003, those covering the cities of Fall River, Greater Lowell, Springfield, Worcester, and Boston/Chelsea/Revere/Winthrop had a statistically higher percentage low birthweight births than the state percentage; those covering Greater Woburn/Concord/Littleton, Greater Haverhill; Milford; Northampton, and the Cape and Islands, had a statistically lower percentage LBW.⁴⁷ LBW also varies by rural cluster. Using an aggregate of five

years data (1999-2003), Nantucket County, Bristol, and Essex had a relatively higher percentage of LBW compared to the state (7.73, 7.53, 7.35, and 7.27 respectively).

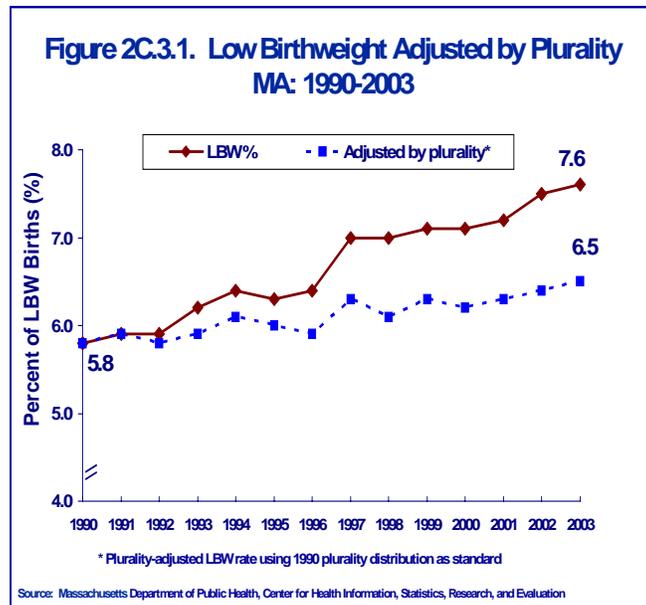


Table 2C.3.1. Percent of Low Birthweight by Maternal Race/Ethnicity: MA and US 2003

Race/Ethnicity	Number of LBW MA	Percent of LBW MA	Number of LBW US	Percent of LBW US
White	4,038	7.0	158,592	6.9
Black	715	12.1	77,376	13.4
Hispanic	805	8.3	57,383	6.5

Prematurity

The percentage of infants who are delivered before 37 weeks of gestation—preterm births—increased by 2% from 8.5% in 2002 to 8.7% in 2003. The preterm rate in Massachusetts was 29% lower than the U.S. preterm rate of 12.3%. Preterm births decreased for all race and Hispanic ethnicity groups, except for white, non-Hispanic, which increased by 6% from 2002. Black, non-Hispanic women had the highest proportion of preterm births (12%) and Asian the lowest rates (7.1%).

The percentage of infants delivered very early (before 28 weeks of gestation) has remained the same since 1997 at 0.6%. Black, non-Hispanic mothers had the highest proportion of infants delivered very early (1.7%), a percentage more than double that of any other race group.

Preterm birth percentages also varied by age of the mother. Mothers under age 20 had a slightly higher percentage than mothers 20 years or older in 2003 (9.1% and 8.7). The preterm birth percentage for teens ages 15 to 17 was 10.2% compared to 8.8% for teens ages 18-19.

Short and long IPI has been shown to be associated with adverse perinatal outcomes including preterm delivery. In Massachusetts, in 2003, of the 42,329 pregnancies to multiparous mothers, about 16% (6,715) had an IPI less than 12 months, 46% (19,508) had an IPI between 12 and 35 months, and 38% (16,106) had an IPI equal or greater than 36 months. The percentage of preterm delivery was higher in mothers with shorter or longer IPI (6.8% and 7.7% respectively), compared to mothers with an IPI between 12 and 35 months (5.6%).

In collaboration with the Massachusetts March of Dimes, the Center is piloting a question, for administration through the PRAMS survey, about whether mothers received information from their doctors about signs and symptoms of premature labor. Particularly given the increasing preterm birth percentage, it is anticipated that prematurity questions will be included if funding permits full implementation of PRAMS.

Multiple Births and Infant Outcomes

The increases in multiple births and low birthweight rates have been associated with two related trends: older age of women giving birth and increased use of fertility therapies (fertility drugs and Assisted Reproductive Technologies).^{48, 49, 50} The potential impact of Assisted Reproductive Technologies (ART) is now being recognized. Availability and use of fertility treatment is very important to families with infertility problems, who might otherwise not have children. In addition to the adverse health risks associated with multiple births, studies suggest that singleton infants conceived through ART may be at increased risks for low birthweight, very low birthweight, and preterm delivery.^{51, 52, 53} In 2002, Massachusetts had 1,344 ART procedures per million population; the highest rate in the United States.²¹ The ongoing trend of increasing number of infants conceived by fertility therapies is an emerging MCH issue since these infants may require additional medical assistance and services for their developmental health needs.

2C.4 Perinatal Mortality

Feto-Infant Mortality

Infant deaths reflect maternal health and other factors. Fetal deaths (stillbirths) are also indicative of maternal health. It is important to understand factors that are associated with fetal deaths to provide a more complete assessment of pregnancy outcomes.

A stillbirth is defined as a fetal death occurring at 20 weeks or greater gestational age, resulting in the delivery of an infant that does not breathe or show any other evidence of life, such as a heart beat, and does not respond to resuscitation.⁵⁴ Massachusetts state law mandates the reporting of a stillbirth that occurs in a hospital at 20 weeks gestation or more and weighs 350 grams or more. The Registry of Vital Records and Statistics maintains a file of fetal deaths for each calendar year.⁵⁵

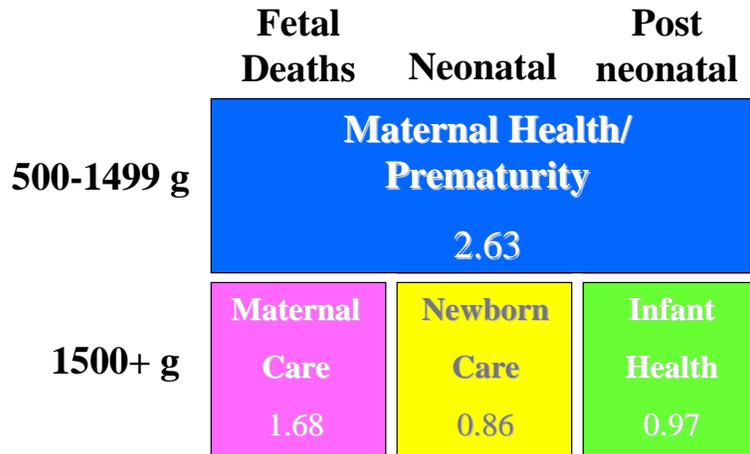
The Perinatal Periods of Risk Approach (PPOR) has been extensively used in many U.S. cities including Boston since 1997 to look at both fetal and infant deaths. PPOR is a community tool used by the World Health Organization (WHO) and CDC to look simultaneously at birthweight and age at death to determine strategies having the greatest potential for reducing preventable fetoinfant deaths.⁵⁶

The PPOR approach assesses fetoinfant mortality using four major categories: maternal health/prematurity, maternal care, newborn care, and infant health. Fetal deaths occurring at 24 weeks or more and infant deaths of very low birthweight (less than 1500 grams) are attributed to maternal health factors. Maternal health factors are, in turn, related to preconceptional health care. Fetal deaths occurring at 24 weeks or greater weighing 1500g or more are attributed to maternal care factors, largely related to prenatal care. Death in the neonatal period (0-27 days) of infants born with a birthweight of 1500g or more are attributed to newborn care factors. Death in the post neonatal period (28-364) of infants born with a birthweight of 1500g or more are attributed to infant health factors.

The PPOR approach then uses these four categories to suggest directions for preventive actions. For a geographic area with deaths related to maternal health/prematurity, preventive actions should be focusing on preconceptional health, unintended pregnancy, smoking, drug abuse, and specialized perinatal care. In areas with deaths related to maternal care, the focus of preventive actions is early continuous prenatal care, referral of high-risk pregnancies and appropriate management of diabetes, seizures, postmaturity, or other medical problems. For newborn care the focus is on advanced neonatal care and treatment of congenital anomalies. Finally, for infant health, community preventive actions target education on SIDS prevention, such as sleep position and bedsharing, as well as breastfeeding, injury prevention, and access to medical homes.⁵⁷

The overall fetoinfant mortality rate (FIMR) in Massachusetts between 1998-2002 was 6.1 per 1,000 live births plus fetal deaths. In Springfield, Worcester, and Boston, higher FIMRs were noted at 8.4, 8.3, and 8.1 respectively. FIMRs for the state overall and all three communities were 2 to 3 fold higher for black mothers compared to whites (MA RR=2.9, Springfield RR=3.0, Worcester RR=3.3, Boston RR=2.3). Figure 2C.4.1 shows the overall FIMR for the state and for each PPOR category.

**Figure 2C.4.1. Feto-Infant Mortality
Massachusetts:1998-2002**



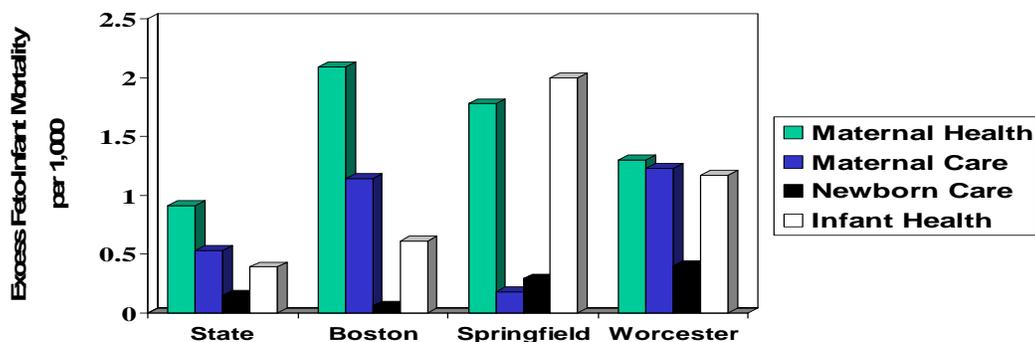
Overall MA FIMR (total of 4 categories) = 6.1

The FIMR for white, non-Hispanic women age 20 or greater with 13 or more years of education was 4.2. This group typically in US studies is considered the “reference group” to calculate “excess” feto-infant mortality in other groups.

The “excess” feto-infant mortality for the state, Worcester, and Boston was mainly due to maternal health/prematurity factors (46%, 69%, and 52% respectively). In Springfield, 47% of the “excess” feto-infant mortality was due to infant health factors. These findings suggest that maternal health/prematurity factors greatly contributed to feto-infant mortality in Massachusetts overall, Boston, Springfield, and Worcester. In Springfield, infant health made a major contribution to deaths. Prevention efforts, focusing on preconceptional health and postnatal factors are needed to improve women’s health in Massachusetts and these communities. For more details, excess mortality for each PPOR category for the state and selected cities is shown in figure 2C.4.2 below.

Further analyses will help to understand differences by community and by race, and strengthen community partnerships to reduce FIMRs. In addition to PPOR analysis, Massachusetts has begun to calculate feto-infant mortality as part of the annual release of birth data.

Figure 2C.4.2. Excess Feto-Infant Mortality by PPOR Component, Massachusetts and Selected Cities: 1998-2002



Infant Mortality

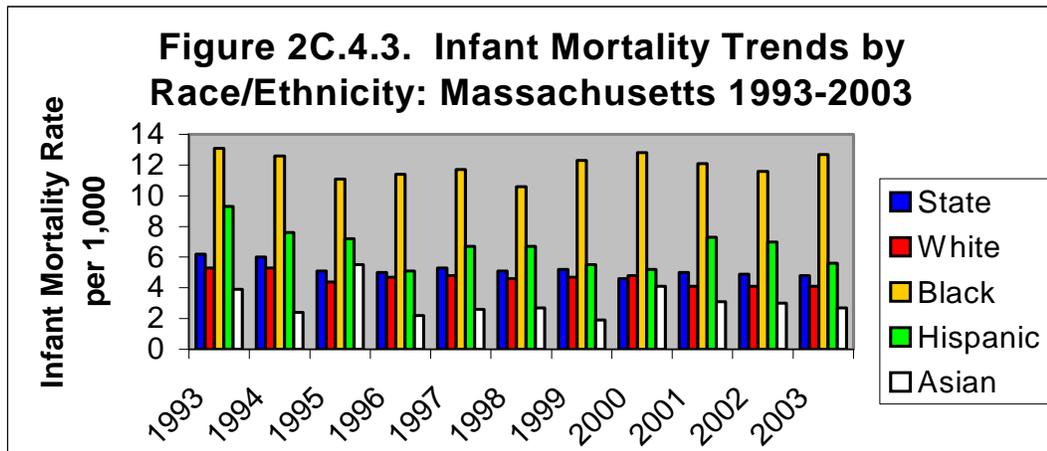
Five of the six Title V national outcome measures focus on infant mortality. In addition, several Healthy People 2010 (HP2010) objectives track infant mortality. The HP2010 objective for overall infant mortality is 4.5 per 1,000 live births; for neonatal mortality, it is 2.9 per 1,000 live births; and for postneonatal mortality, it is 1.2 per 1,000 live births. Infant mortality is a very sensitive indicator of health and social well-being in any given population. Infant mortality is used as the best indicator to measure not only infant health, but also the health of a community as well as the health of a nation.

The Massachusetts infant mortality rate (IMR) declined steadily from 1992 to 1996, increased slightly between 1997 and 1999, and then reached its lowest point ever in 2000 (4.6 per 1,000 live births). The infant mortality rate was 4.8 per 1,000 live births in 2003, 30% lower than the preliminary 2003 U.S. IMR (6.9 per 1,000 live births), which has also increased slightly in recent years.⁵⁸ The white non-Hispanic rate of 4.1 exceeds the HP2010 goal.

Infant Mortality by Race and Hispanic Ethnicity

From 1995 to 2001, the overall infant mortality in the U.S. declined by 11% from 7.6 to 6.8 per 1,000 live births, before slightly increasing in 2002. Infant mortality rate for most racial/ethnic populations declined from 1995 to 2002, but little change was noted in the differences between racial/ethnic populations.

In Massachusetts, there has been a substantial decline in IMRs among black and white infants since 1980. Nevertheless, substantial differences by race and ethnicity persist. From 1980 to 2003, the IMR decreased by 56% for whites and 37% for blacks.⁵⁹ The gap between white non-Hispanic and black non-Hispanic has persisted (RR = 3.1) and is of major concern. In 2003, black, non-Hispanics had the highest infant mortality rates (12.7), followed by Hispanic (5.6), white non-Hispanic (4.1), and Asian Pacific Islander (2.7). Also, the gap between Hispanic and white non-Hispanic has persisted after showing a little narrowing in 1996 (See Figure 2C.4.3).



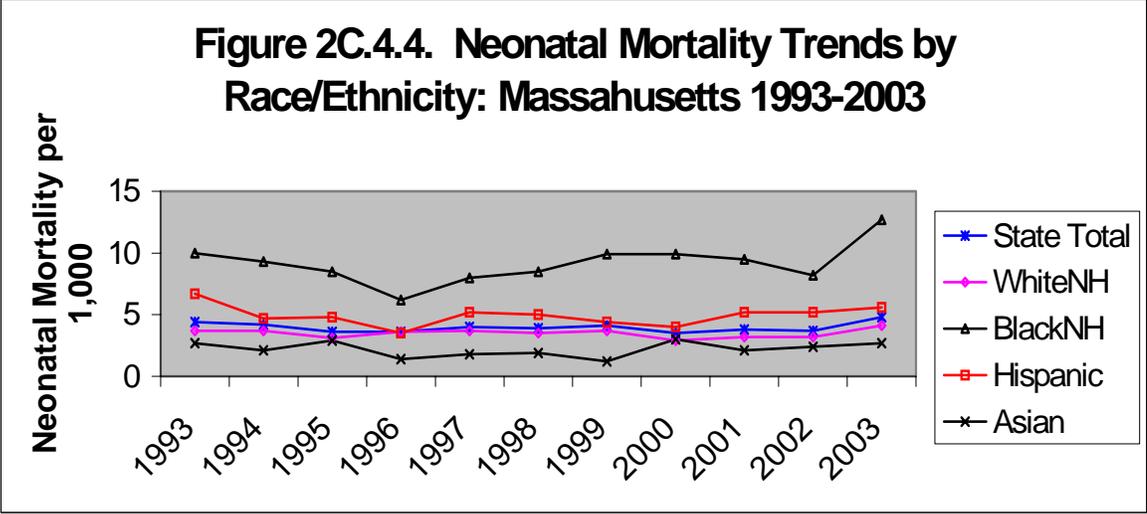
Infant Mortality by Residence of the Mother

Infant mortality rates vary by geographic area in which the mother resides, some significantly. Using three-year averages (2000-2002), for more stable estimates, three Community Health Network Areas (CHNAs) in Massachusetts were higher than the statewide three-year average of 4.86 per 1,000 live births: Fall River at 7.91, Worcester at 7.08, and Boston/Chelsea/Revere/Winthrop at 6.27. Each year, with the release of annual birth data, MDPH analyzes infant mortality rates by community. Communities with high three-year averages 2001-2003 were: Taunton (8.2), New Bedford (8.1), Worcester (7.2), Boston (6.8), and Springfield (6.8).

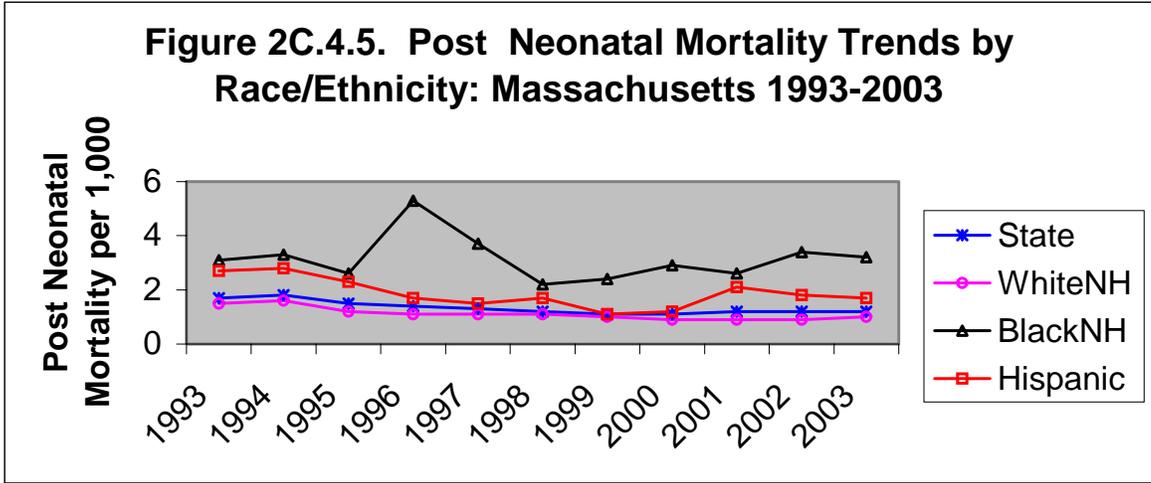
Infant mortality rates also vary by rural clusters. Aggregating four years of data (2000-2003) shows that some rural clusters had higher IMRs compared to the state. The top three included Nantucket County with 18.7, Lower Cape Cod with 7.9, and Hampshire Area with 7.6 per 1,000.

Neonatal and Post Neonatal Infant Mortality

The neonatal mortality rate in 2003 was 3.6, within 25% of reaching the target for the HP2010 objective of 2.9. With closer analysis, it appears that the neonatal period continues to be the major contributor to infant mortality for all race/ethnicity groups. In 2000, neonatal mortality was at its lowest among white non-Hispanic mothers and briefly met the 2010 objective. Asians have exceeded the HP2010 objectives for neonatal mortality and overall infant mortality since 1993. They continue to have the lowest neonatal mortality rate by race/ethnicity in the state (See Figure 2C.4.4).



The post neonatal mortality has remained the same at 1.2 per 1,000 live births from 2001-2003. The post neonatal mortality rate has exceeded the HP2010 objectives since 1999, although it has increased slightly since 1999 from 1.1 to 1.2. The white non-Hispanic group met the HP2010 objective for postneonatal mortality; other groups did not. Post neonatal mortality rates for black non-Hispanics showed no significant improvement over the past 10 years. The post neonatal mortality rate for black non-Hispanics was 3.2 per 1,000 live births in 2003. This rate is three times higher than the rate for white non-Hispanic, and more than twice as high as for Hispanics (See Figure 2C.4.5 below).



Causes of Death

In 2003, there were 366 infant deaths from the linked birth-death file. Of the 366 infant deaths, 271 (74%) occurred in the neonatal period and 92 (25%) occurred in the post-neonatal period. Of the 271 neonatal deaths, 93 (33%) resulted from disorders related to short gestation and low birthweight, 40 (14%) were due to congenital malformations, 33 (12%) resulted from maternal factors/complications of pregnancy, and 11 (3.9%) resulted from neonatal hemorrhage. One death was classified as SIDS. Of 92 post-neonatal deaths, 28 (29%) resulted from SIDS, 21 (21%) from congenital

malformations, 6 (6%) from certain conditions originating in the perinatal period, 6 (6%) from infectious and parasitic diseases, and 5 from intentional or unintentional injuries.

The incidence of Sudden Infant Death Syndrome dropped from 83 in 1990 to 22 in 1998, and totaled 29 for 2003. The substantial decline after 1990 was consistent with trends reported nationally, following the aggressive public education efforts regarding infant sleeping position.

Although Massachusetts has performed well in several perinatal health indicators, there are concerns in the provision of obstetrical care including the percentage of very low birthweight infants born in level III hospitals. Massachusetts has gone from 83.4% of VLBW infants born in level III hospitals in 2000 to 79.1% of VLBW infants born in level III hospitals in 2003 (1). These trends are falling away from the Healthy People 2010 National Objectives for 90% VLBW infants to be born in level III hospitals (Objective 16-8) (2). Massachusetts is in the process of revising the hospital regulations governing perinatal care including levels of care.

2C.5 Maternal Mortality and Morbidity

The Maternal Mortality and Morbidity Review Committee (MMMRC) established in 1997 by the Commissioner of the Massachusetts Department of Public Health (MDPH), reviews maternal deaths, studies the incidence of pregnancy complications and makes recommendations to improve maternal outcomes and prevent mortality. Maternal death, while rare, is a critical health indicator for women giving birth. There has been a dramatic decrease in maternal mortality in Massachusetts during the last half of this century, and the state now has the second lowest maternal mortality rate in the U.S. (3.3 /100,000). The leading causes of maternal death have also shifted from infections, pregnancy-induced hypertension, cardiac disease and hemorrhage to injury (suicide, homicide, and motor vehicle crashes) and pulmonary embolus. While the number of pregnancy associated deaths is relatively low in Massachusetts, the cause of one in three deaths of women while pregnant or during the first year postpartum is an injury.

In May 2000, the MMMRC completed a comprehensive medical review of pregnancy-associated deaths occurring between 1995 and 1998. A pregnancy associated death is defined as the death of a woman while pregnant or within one year of termination of pregnancy, irrespective of cause. Women who die from a cause related to pregnancy or childbirth either during pregnancy or up to 42 days after pregnancy termination are called maternal deaths and are a subset of pregnancy-associated deaths. Of the 88 pregnancy-associated maternal deaths occurring between 1995-1998, 60 were caused by medical conditions and 28 by intentional or unintentional injury, drug overdoses, and motor vehicle crashes. Massachusetts published a maternal mortality bulletin based on this review presenting data related to maternal causes of death and pregnancy-associated mortality ratios, summarizing case review findings, and suggesting strategies for improving maternal outcomes. Improved and expanded case-finding methods used in this study facilitate the identification of more deaths than previously noted, and demonstrate the importance of expert case review in conjunction with an active maternal mortality surveillance system. Of the 88 pregnancy-associated deaths, 30% teach lessons about preventing future deaths.⁶⁰

A second maternal mortality bulletin, published in May 2002, reviewed pregnancy-associated injury deaths occurring between 1990 and 1999. Of the 232 women who met the definition of a pregnancy-associated death, more than one-third (80) were injury-related. Among the 80 injury deaths, nearly half resulted from violence, more than one-quarter were caused by vehicle collisions, and one-fifth were caused by drug overdose. Many of the strategies recommended to prevent future mortality and morbidity stress the importance of a strong public health system to support the overall health of women during the child-bearing years.⁶¹ MCH priority needs selected in Massachusetts include injury and violence prevention across the three MCH populations.

In 2003, among women ages 18 to 44, injuries were responsible for 148,135 Emergency Department visits and 5,052 in-patient hospitalizations costing a total of \$102 million and \$16 millions respectively. The average length of stay associated with these hospitalizations, 4.4 days, may also translate into lost productivity and lost income, which magnifies the cost associated with these injuries.

The 1998-2003 BRFSS data provides statistics by race/ethnicity and income and disparities related to seat belt use and violence among women of childbearing age (18 to 44). Across all race/ethnic groups, women with moderate/high income usually report better health outcomes and behaviors than women with low income (approximately 200% of poverty level and below).

- Overall, 86.6% of all women ages 18 to 44 reported using seat belts.
- Among women ages 18-24, 81.6% reported using seat belts.
- Women with moderate/high income were more likely to report using seat belts than women with low income (88.2% and 82.7% respectively).
- Black women were less likely to report the use of seat belts than Hispanics or whites (81.7%, 82.9% and 86.5%).
- Overall, 5.6% of women reported intimate partner violence.
- Among women ages 18-24, 11.1% reported intimate partner violence.

In 2003, there were 15 pregnancy-associated deaths including 4 maternal deaths. The pregnancy-associated mortality ratio (PAMR) was 18.5 deaths per 100,000 live births and the maternal mortality ratio (MMR) was 4.9 per 100,000 live births. Since 2000, the PAMR fluctuated from a high of 35.1 to a low of 18.5.

Since injury-related deaths are a major contributor to pregnancy-associated mortality, Center staff are involved in a study of pregnancy-associated injury morbidity with researchers from Northeastern University and Boston University School of Public Health. Using the Pregnancy and Early Life Longitudinal (PELL) database, researchers are examining the intentional and unintentional injury morbidity rates for women during the antenatal period and up to one-year postpartum. Emergency department data, available since 2002, accounts for over 90% of injury visits. Preliminary results of a cohort of over 21,000 women show that 13.5% of all women who give birth or have a fetal death will have an injury related visit during their pregnancy. Further analysis will examine disparities and timing of these injuries in relation to the pregnancy outcome.

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IIB: 2D. Children and Adolescents

2D.1 Child and Family Demographics

Overview

Of Massachusetts' estimated 6,218,773 residents in 2003, the most recent year with Census estimates for children, 25.9% or 1,608,470 residents were children through age 19. Approximately 6.4% were children under age 5; 6.6% ages 5 to 9; 6.9% ages 10 to 14; and 6% ages 15 to 19. Between the years 2000 and 2003, the Census percentage estimates were essentially stable. Each age group had very slight decreases as a percent of the overall population with the exception of 15 to 19 year olds who had a slight increase.¹

Massachusetts is a comparatively wealthy state with a diversified economic base that includes health care, education, finance, insurance, telecommunications, computer technology, biotechnology, tourism, farming, and fishing. In 2003, the median family income was estimated at \$67,527 compared with \$52,273 for the nation; only 3 states (New Jersey, Connecticut, and Maryland) had higher median family incomes.² The state had the second highest percentage of college-educated individuals at 35.8%.³ The percent of children under 18 living in poverty in 2003 was estimated to be 12.3 compared to the national average of 17.7; 9 states had lower poverty rates.⁴ Based on 10 key indicators measuring child well-being in 2001, the Annie E. Casey Foundation Kids Count 2004 rated Massachusetts equal or better than the national average for each of the 10 indicators, ranking ninth compared to all other states.⁵ A child born in 2003 in Massachusetts has a life expectancy of 78.5 years compared with 77.6 for the US.⁶

Poverty and Disparities

Yet disparities between wealthy and poor, educated and not, persist. Massachusetts showed an improvement from 1996 to 2001 in only 4 of the Kids Count indicators.⁷ An estimated 118,124 families with children under age lived below poverty in 2003.⁸ Poverty rates for families at 7.5% and for individuals at 9.4%, while lower than the national averages of 9.8% and 12.7%⁹ respectively, have increased since the 1990 census when the poverty rate for families was 6.7%¹⁰ and that for individuals was 8.9%.¹¹ Significant disparities exist in poorer urban and rural areas, with poverty rates for children ages 0 to 17 as high in 13.6% in rural areas and 23.6% in urban areas.¹²

Although incomes are high, expenses are as well. Massachusetts has the fourth highest renter-occupied housing costs¹³ and the fifth highest owner-occupied housing costs¹⁴ in the nation. A 2004 report by the Massachusetts Family Economic Self-Sufficiency Project documented financial stress for low-income working families, estimating that 25% of Massachusetts families and nearly 50% of urban families earn less than the income needed to meet their basic needs without public or private supports. The report found that from 1998 to 2003 the real cost of living had increased from 17% to 35%, depending on the region of the state. To make ends meet, a family with one adult, one preschool child, and one school-age child, based on the report's estimates, needed to earn 228% to 336% of the federal poverty level.¹⁵

Food insecurity is also a significant issue for residents of MA. Project Bread's Status Report on Hunger in Massachusetts 2004 reports an estimate from the Economic

Research Service of 6.4% of Massachusetts individuals (412,000 people) being food insecure, with almost one-third regularly experiencing hunger. A 2003 Project Bread study with the Center for Survey Research at the University of Massachusetts found that in communities with poverty rates of at least 25%, 29% of households with children lacked adequate food. The report stated that the demand for emergency food had increased 38% over the preceding 4 years, with children over-represented among those receiving emergency meals.¹⁶

Income and education are related to English language skills. Of Massachusetts residents who speak only English, 77% are actively engaged in the labor force, compared with 59% who do not speak English well.¹⁷ Since language skills are also a determinant of the kinds of jobs at which one is employed, persons who speak English well earned, on average, two and a half times as much in 1999 as those who did not speak English well.¹⁸

The educational status of immigrant adults seems to impact the income and well-being of the families. While 15.2% of Puerto Ricans and foreign-born MA citizens have a Bachelor's degree and 13.9% have a Master's degree or higher, adult immigrants are more than three times as likely as native-born residents (29% vs. 8%) to lack a high school diploma.¹⁹ Education attainment levels also vary greatly by country of origin. For instance, more than 60% of Central American immigrants have not completed high school, versus only 15% from Asia. Conversely, 60% of Asian immigrants have a college education, compared to 7% from Central America.²⁰ Differences in educational attainment may help translate into the difference between family poverty and more comfortable living. The average annual salary of a 20-64 year old Puerto Rican or immigrant with no high school diploma is \$14,687; one with a Bachelor's degree earns, on average, \$40,179, and \$62,007 with a graduate degree.²¹

Race, Ethnicity and Language

Of children age 17 and under, 75% are white non-Hispanic (compared to 84% for the total population), 7% are black non-Hispanic, 11% are Hispanic, 4% Asian, and 1% other. These figures reflect families who chose to select one race category only. An additional 3% of families selected more than one race category to describe their children.²²

The Center for Community Health analyzes data provided by the Massachusetts Department of Education on children whose first language is not English via the First Language Not English (FLNE) Report. This report identified those communities whose FLNE public school population was 10% or more, and provided information on the smaller subset of children who are unable to perform their classroom work in English (Limited English Proficient students). These data are useful indicators of younger families who may be linguistically isolated or experience increased need due to their limited English proficiency. In 2002, one in seven (14.1%) public school students had a language other than English as their first language. In one out of two FLNE students, Spanish was the first language. Of these students, more than 37% were identified with Limited English Proficiency. In 42 communities FLNE students make up 10% or more of their student body and in another 23 communities FLNE students comprise between 5 and 9% of the student population. Children in Massachusetts classrooms speak 132 languages. The more frequently encountered languages include: Spanish (49% of total FLNE), Portuguese (10.3%), Cape Verdean Creole (6.1%), Chinese (5.9%), Vietnamese

(4.3%), Haitian Creole (3.2%), Khmer (3.19%), Russian (2.8%) and Arabic (1.2%). See Figure 2D.1.1 for a map of FLNE students by community.

Homeless Families

The number of homeless individuals and families has increased considerably in Massachusetts since the 1980s, paralleling national trends.^{23, 24} In 2000, homeless families with children accounted for 36% of the homeless population in the US. This number increased to an estimated 40% in 2004.²⁵ Families constitute about 58% of the homeless population in Massachusetts and about 20,000 children in the Commonwealth are homeless (51% of them under the age of 5).²⁶

An upward trend on the Department of Transitional Assistance (DTA) expenditures for services for homeless families shows that family shelter expenditures rose from 35.6 million in 1998 to 72.2 million in 2003.²⁷ A large portion of these expenditures were used to house homeless families in hotels or motels until they could be moved to shelter or community housing. This trend suggests an increased pressure on shelter use as well as in the number and needs of homeless families.²⁸ In June 2004, DTA used surplus FY 2005 funds to pilot a rapid re-housing program. DTA funded rental assistance for families for up to one year. Families in shelters, motels and hotels, who met certain eligibility criteria, were moved to community housing. This assistance led to a sharp decline in shelter census and discontinued use of hotels and motels to house homeless families.

At the end of November 2003, about 1,545 homeless families were living in emergency family shelters and motels funded by DTA. This figure represents 4,609 family members, of which over half were children (between birth and 18 years of age). Of these children, 48.7% were under the age of five. In 2003, 48% of shelter users were of African American (32%) and Latino (16%) backgrounds. Whites comprised 49% of homeless families.

Educational levels among homeless families in the Commonwealth vary, but the majority of heads of households had completed high school or obtained a GED.²⁹ Most homeless families were headed by a single mother. In March 2004, for example, 93% of household heads among homeless families in emergency shelters were female. Even though more homeless families are female-headed households, the number of homeless families headed by a single male increased from 10% in 1999 to 13% in 2001.³⁰

The three-person income limit for the DTA Emergency Assistance Program in the FY 2003 was \$15,284.³¹ During this period, one-half of the sheltered population had an average annualized income of \$4,584, all of which was cash assistance.³² Almost all homeless families in shelters were receiving food stamps as of March 2004 (more than 9 out of 10). The food stamps caseload in Massachusetts increased from 153,724 in March of 2004 to an estimated 165,969 in February 2005.³³

Homelessness threatens the health and well-being of mothers and children. Progressive morbidity and premature death result from the severe health problems found among members of homeless families.³⁴ Extreme poverty, delays in seeking medical care, lack of access to health insurance and other resources, non-adherence to therapy, cognitive impairment, and the risks posed by homelessness itself are among the factors contributing to disease severity in this population.^{35,36} Behavioral and emotional

problems, history of abuse, learning difficulties, injuries, asthma, and developmental delays are some of the health problems found among homeless children.^{37,38,39}

Children in homeless families get sick twice as often⁴⁰ and use the emergency room at higher rates than non-homeless children.⁴¹ Homeless children have twice as many ear infections and four times as many asthma attacks as other children.⁴² Babies born to homeless mothers have higher rates of low birth weight and infant mortality, and are four times as likely to have developmental delays.⁴³

Homeless mothers often suffer from depression, trauma and morbidity associated with sexual abuse and domestic violence, mental health problems, and substance abuse.^{44,45} Substance abuse and mental health combined were the most commonly self-reported disabilities found among users of Massachusetts' emergency shelters.⁴⁶ After financial problems and unemployment, substance abuse was the most common reason reported for homelessness among users of the shelter system in the state.⁴⁷ Domestic violence is one of the main reasons that women seek shelter, and is a situation affecting many homeless families in the Commonwealth.⁴⁸

DTA and MDPH collaborate to conduct the F.O.R. Families home visiting program, with a primary goal to assist families to transition from homelessness into permanent housing. Home visitors conduct family assessments and coordinate services for the families with community-based programs such as WIC, EI, primary care, MassHealth, community health centers, domestic violence services, substance abuse, and mental health treatment centers.

Currently, 61% of all family members receiving services from the F.O.R. Families program are female and 40% are children under the age of 10. Women head 90% of the families served by the program, mirroring a profile similar to national and state trends for heads of homeless households. Forty-seven percent of household heads are between the age of 20 and 30 years old. Twenty-nine percent of the families served by the program are white, 21% black, and 21% Latino. Most heads of household in the program have a high school diploma or have completed some high school.

Families in Substance Abuse Treatment Services

Family Substance Abuse Treatment Services provide structured and comprehensive services in a therapeutic, safe, structured and developmentally appropriate environment in which parents may obtain treatment services, while still maintaining custody and care of their children. Programs are expected to develop treatment models or specialties based on cultural, linguistic, gender specific treatment and best practices that meet the diverse needs of the families entering their programs. The original model was composed of two components, which provided services through 9 community family substance abuse treatment shelters which served 130 women and 174 children, and 5 specialized residential programs for women which served 215 women and children in residential settings.

Nationally and at the state level, there has been increasing recognition that services for homeless, substance abusing women with children must span the continuum, including an outreach, engagement and case management component. A joint decision was made by MDPH and the DTA to undertake a complete review of the existing model. A stakeholder team developed the following criteria for the new design:

- Expand the continuum of services to families to include outreach and engagement services, as well as structured housing environments for those unable to secure more permanent housing options and for those not ready for independent living arrangements.
- Provide enhanced therapeutic services, particularly family therapy and structured programming for children. Utilize standardized assessment tools and central intake to ensure proper patient placement.
- Preserve existing services for pregnant and postpartum women and residential services for Latina women not living with children, which did not fit into the family redesign model.

MDPH expects to serve an additional 25 families in programs and reach 1,000 families through outreach and engagement services. Based on this criteria, a new model was designed and in place as of July 1, 2005.

2D. 2 Massachusetts Framework for Adolescent Health

In 2003, the Governor's Adolescent Health Council and the MDPH jointly published the document called *A Shared Vision for Massachusetts Youth and Young Adults 2003: Summary Data on Youth Development in Relation to Key Strategic Goals* (generally called *A Shared Vision*). This document set an agenda for adolescent health in the Commonwealth.

The document, when published, was endorsed by the Council, the MDPH, and the Youth Development Advisory Council, and has been endorsed by additional state agencies over the past two years. It encourages a strength-based, broad youth development perspective in adolescent health activities. This perspective will be brought to bear on the new Massachusetts MCH priority need and related state measure to improve adolescent health through coordinated youth development and risk reduction.

A Shared Vision defines youth and young adults in Massachusetts as falling between the age range of 10 to 24 years old. Based on this definition, Massachusetts has an estimated 1.2 million youth and young adults, comprising almost 20% of the Massachusetts population. The number of adolescents increased dramatically from 1990 to 2000, an increase expected to continue through this decade. The proportion of youth varies by community. For example, in Provincetown, only 4% of the population is between the ages of 10 and 17. College communities such as Amherst (50% between 18 and 24) and Cambridge (22%) have high proportions of young adults. Massachusetts is home to many colleges, attracting this population group.

A Shared Vision articulated five goals for youth as follows:

1. All youth have access to resources to promote optimal physical and mental health.
2. All youth have nurturing relationships with adults and positive relationships with peers.
3. All youth have access to safe places for living, learning and working.
4. All youth have access to educational and economic opportunity.
5. All youth have access to structured activities and opportunity for community service and civic participation.⁴⁹

For this MCH needs assessment, indicators related to these goals were updated, when more recent data was available. Selected indicators are described in the remainder

of this section and accompanying tables and figures. This needs assessment uses data from both the 2003 Massachusetts Youth Risk Behavior Survey (YRBS) and 2004 Massachusetts Youth Health Survey (MYHS) depending on topics covered by each survey and analyses available.

2D.3 Overview of Child and Adolescent Health Indicators in Massachusetts

Attached at the end of this document are Tables 2D.3.1 to 2D.3.3, which draw data from the National Survey of Children’s Health (NSCH) to profile the health of children in Massachusetts along three dimensions: health status; health care; and family, school and neighborhood characteristics. Figures 2D.3.1 to 2D.3.3, below, profile middle and high school youth on two dimensions as reported on the 2004 Massachusetts Youth Health Survey (MYHS): Health risk behaviors and resiliency factors (also called “assets”) of middle and high school youth.

Figure 2D.3.1: Massachusetts Middle and High School Students Health Risk Behaviors, 2004

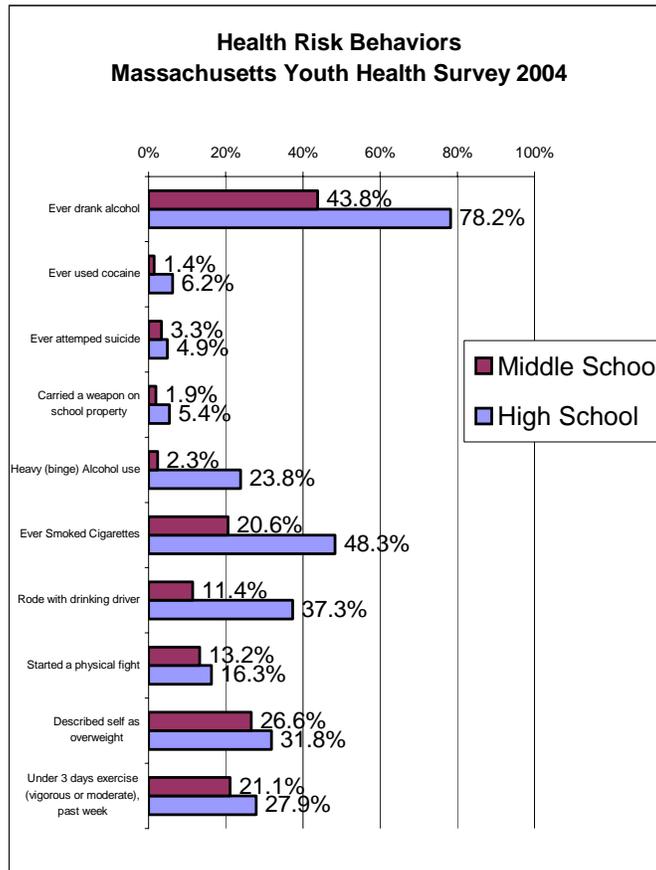


Figure 2D.3.2

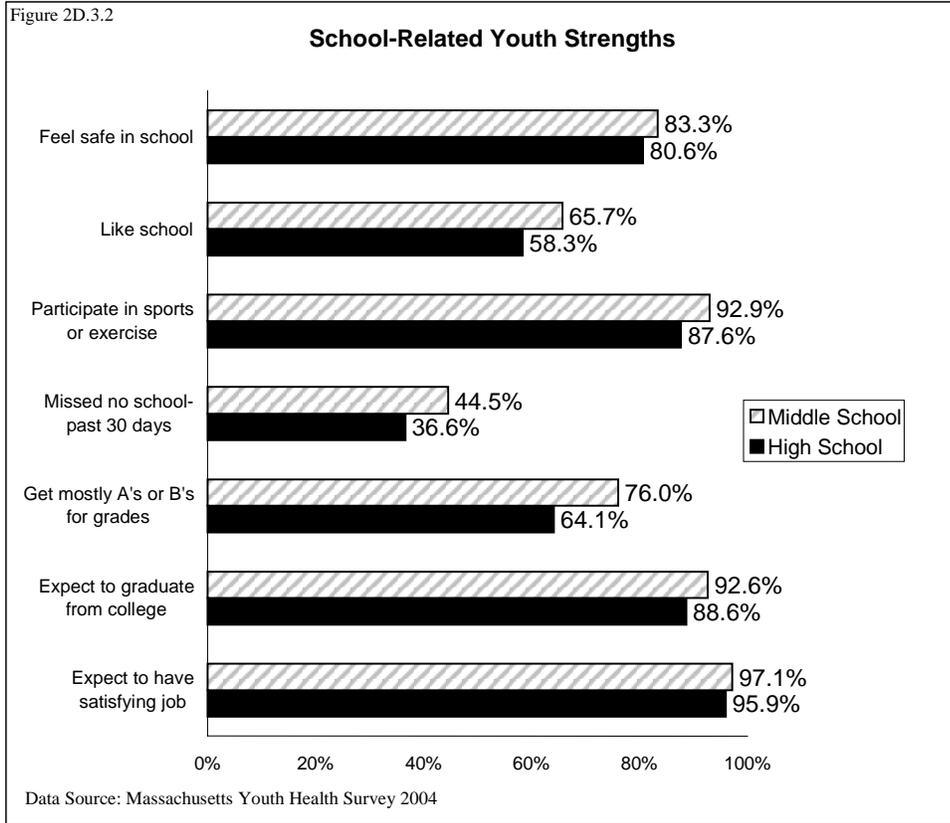
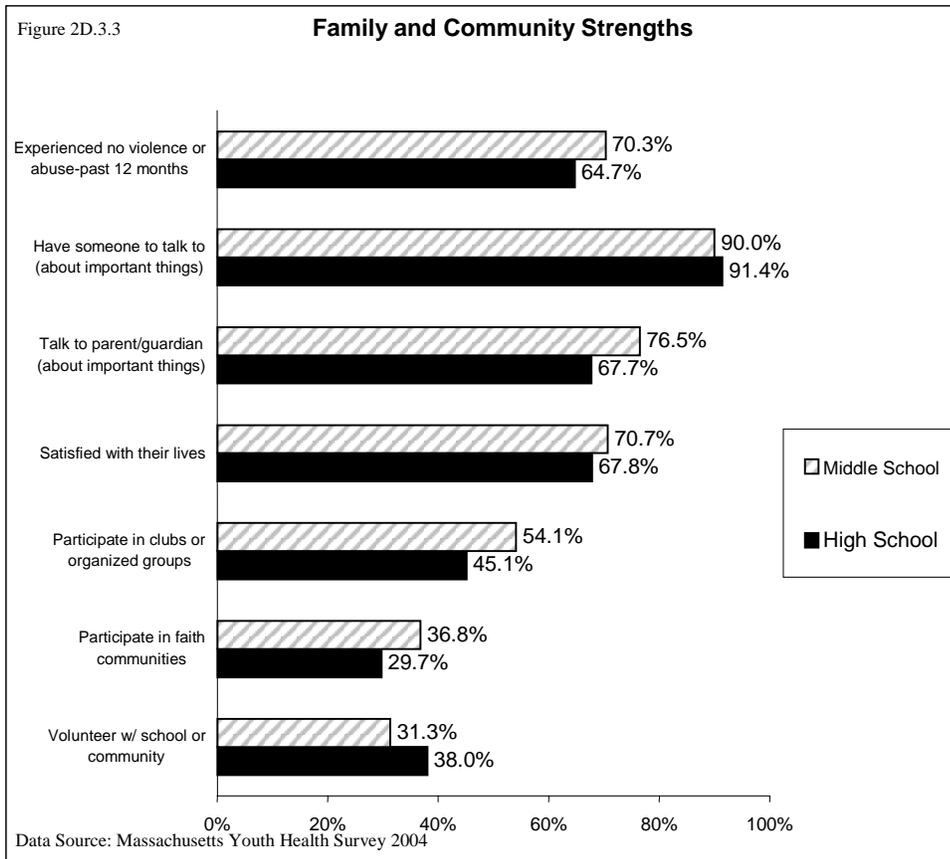


Figure 2D.3.3



The remaining sections discuss topics in child and adolescent health, including injury deaths and cancer. Relationships between risks and strengths are also reviewed.

2D. 4 Child and Adolescent Deaths

In 2003, there were 149 deaths among children age 1 to 14; 490 among youth ages 15 to 24. Injuries were the leading cause of death among children and youth, with 3.8 deaths per 100,000 children 1 to 14 (45 deaths) and 42.3 deaths per 100,000 youth 15 to 24 (347 deaths).⁵⁰ Cancer was second, with 23 deaths among 1 to 14 year olds and 17 deaths among 15 to 19 year olds. Congenital anomalies were third, with 14 deaths among 1 to 14 year olds and 5 deaths among 5 to 19 year olds.⁵¹

Injury Deaths

Increasing the integration of injury prevention activities into MCH programs is a new MCH priority need in Massachusetts. Injury deaths may be unintentional or intentional, such as suicide and homicide. “Unintentional” injuries are often portrayed as “accidental,” but from a public health perspective, they are preventable. Injuries can be caused by a range of mechanisms, such as a motor vehicle crash, poisoning, drowning, firearm, and so on.

In 2003, the rate of injury deaths among 1 to 14 year olds among males was nearly twice that of females (5.0 vs. 2.6 per 100,000 residents, respectively). The disparity was even wider among 15 to 24 year olds: the rate for males was 67.4 per 100,000 and 17.3 per 100,000 among females, in 2003.

Causes of injury deaths, 2003:

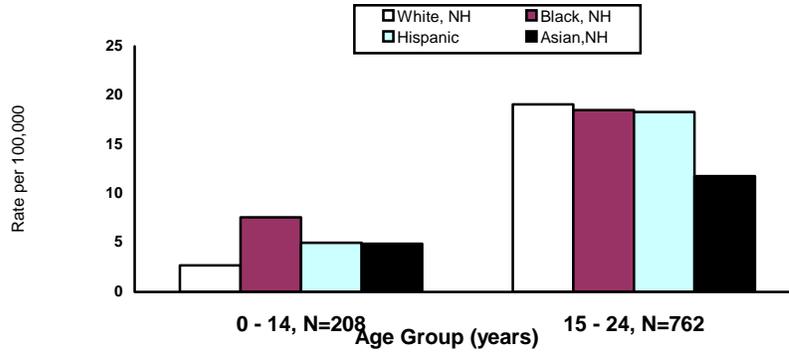
- *Motor vehicle traffic crashes* (including occupants, pedestrians, and bicyclists in traffic) were the cause of most injury deaths to children and adolescents: 29.8% (n=17) of children 0-14 years and 36.0% (n=125) among adolescents 15-24 years.
- *Poisoning, including drug overdoses*, were the second leading cause of injury death among 15-24 year olds, accounting for 93 (26.8%) of the total injury deaths in this age group.
- *Firearms* were involved in 47 of the 276 deaths among males ages 15-24.

Intentionality of injury deaths, 2003:

- 64.9% (n=37) of the total injury deaths among children 0-14 years were *unintentional* in nature (“accidental”), 21% (n=12) of injury deaths among this population were *homicides*, and 8.7% (n=5) *suicides*.
- 73% (n=254) of the total injury deaths among adolescents 15-24 years were classified as *unintentional or undetermined*, 13.5% (n=47) were *homicides*, and 13.2% (n=46) were *suicides*.
- *Suicides* were about equally split between males and females, but 92.7% of the *homicides* occurred among males.

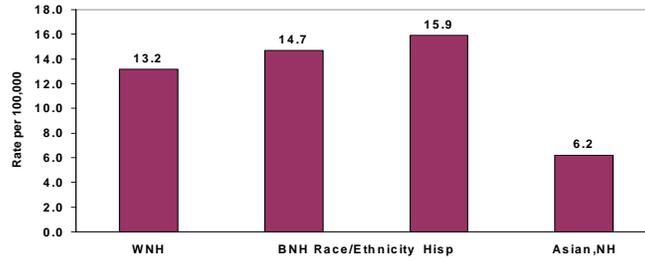
Analysis of 1999-2003 Massachusetts Vital Records death data indicates that the average annual rates of death due to unintentional and intentional injury vary by race and Hispanic ethnicity (see Figures 2D.4.1,2, and 3 below.).

Figure 2D.4.1 Average Annual Unintentional Injury Death Rates among Massachusetts Residents, by Race and Ethnicity, by Age Group, 1999-2003



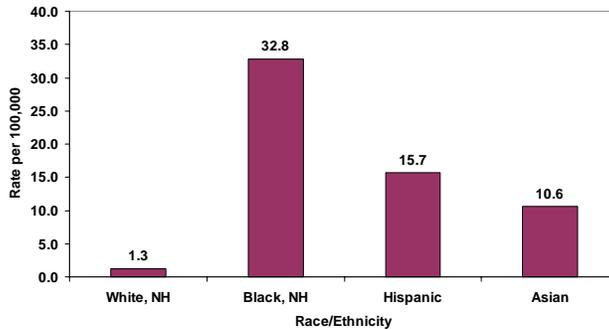
Source: MA Registry of Vital Records and Statistics
 Prepared by: The Injury Surveillance Program, MDPH

Figure 2D.4.2: Average Annual Motor Vehicle Traffic Injury Death Rates, MA Residents 15-19 Years, (N=265) by Race and Ethnicity, 1999 to 2003



Source: Registry of Vital Records and Statistics, MA Department of Public Health
 Prepared by: The Injury Surveillance Program, MA Department of Public Health

Figure 2D.4.3: Homicide Rates by Race and Ethnicity, MA Residents 15-24 Years, (N=47), 2003



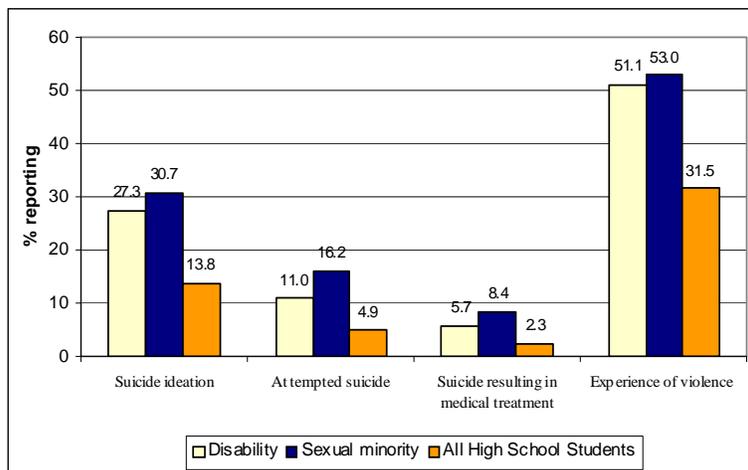
Source: Registry of Vital Records and Statistics, MA Department of Public Health
 Prepared by: The Injury Surveillance Program, MA Department of Public Health

In 2003, Black non-Hispanics, Hispanics, and Asians 15-24 years had homicide rates 25, 12, and 8 times that of White non-Hispanics in this age group, respectively.

Firearms were the leading cause of death among black, non-Hispanics under age 20 in Massachusetts during 2003. Among all children under 20, 77% of firearm deaths in 2003 were homicides and 23% were suicides.⁵²

The impact of youth suicide is magnified among certain groups. Of high school students who self-identify as gay, lesbian, bisexual or questioning their sexuality, 30.7% report that they have seriously considered suicide and 16.2% actually attempted suicide; for 8.4% of sexual minority youth, the suicide attempts resulted in medical attention.⁵³ For high school students with disabilities, based on the MYHS disability screeners, 27.3% report that they have seriously considered suicide, 11% actually attempted suicide; for 5.7% of these youth with disabilities, the suicide attempt resulted in medical attention.⁵⁴ Also, nearly 28% of those females reporting sexual assault in the 1997 YRBS had attempted suicide and 12% had attempted suicide resulting in an injury.

Figure 2D.4.4 Suicidal History and Violence among Massachusetts High School Students, by disability and sexual minority status (GLB/undecided), 2004



Source: MDPH Youth Health Survey, 2004

The 1997 YRBS data indicated that, of those females reporting sexual assault, 27.9% had attempted suicide and 12% had attempted suicide resulting in an injury.

Cancer Incidence and Deaths

Over the 4 years from 2000 through 2003, Massachusetts had 167 deaths among children under age 18 due to cancer. Of these, 39 were brain and central nervous system cancers and 42 were leukemia. Other cancer deaths occurred in smaller numbers.⁵⁵ The most recent analysis of childhood cancer is of trends from 1990 to 1999. During that time period, 2,688 cases of invasive cancer were diagnosed among children under age 20, about 53% in males and 47% in females. The annual age-adjusted combined rate was 16.7 cases per 100,000. Although numbers are small and data on race unavailable before 1995, the age-adjusted rates for black non-Hispanic at 19.6 per 100,000 and Hispanic

children at 19.7 per 100,000 are higher than those of other race groups. The age-adjusted cancer incidence rate did not increase or decrease substantially in the last decade. The three most common cancers -- leukemia, central nervous system cancers, and lymphomas -- accounted for 60% of cancers in males and 53% in females.⁵⁶

2. 5 Immunization

The vaccination rate of children in the US with the 4:3:1:3 series has increased according to the National Immunization Survey (NIS) results.⁵⁷ Massachusetts continues to be among the leaders in the nation in immunization coverage of 19- to 35-month-old children. Massachusetts was the second highest for vaccine coverage in the nation for 2003-2004 with the 4:3:1:3:3 series at 88.1%; the national average is 80.5%.⁵⁸ The city of Boston has had the highest immunization rates among the largest cities and urban areas surveyed in this age group for the past two years at 90.1% this past year.

Nationally, under-vaccinated children tended to be black, and to live in a household near or below poverty level, usually clustered geographically, which increases the risk of transmitting vaccine preventable diseases.⁵⁹ According to the 2003 NIS, Massachusetts had 97.3 % vaccination rate among black, non-Hispanics, compared to 75.2% at the national level.

The results of the 2004-birth hospital review by Massachusetts Immunization Program (MIP) confirmed that 92% of infants born in Massachusetts's hospitals have been administered the Hepatitis B birth dose, as compared to 91% in 2000 and 89% in 1995.⁶⁰

2D. 6 Healthy Weight among Children and Adolescents

Nationally and in Massachusetts increasing attention is being focused on children who are overweight or at risk of becoming overweight. The magnitude of the potential health consequences is great, including diabetes, heart disease, and other chronic diseases, particularly when weight gain begins early in life. Based on the 2004 MYHS, 10.2% of middle school and 12.6% of high school students are overweight. An additional 16.7% of middle school and 16.6% of high school students are at risk of overweight.⁶¹ Developing a system to promote healthy weight among all MCH populations is a newly proposed MCH state measure, and healthy weight is also an Massachusetts priority.

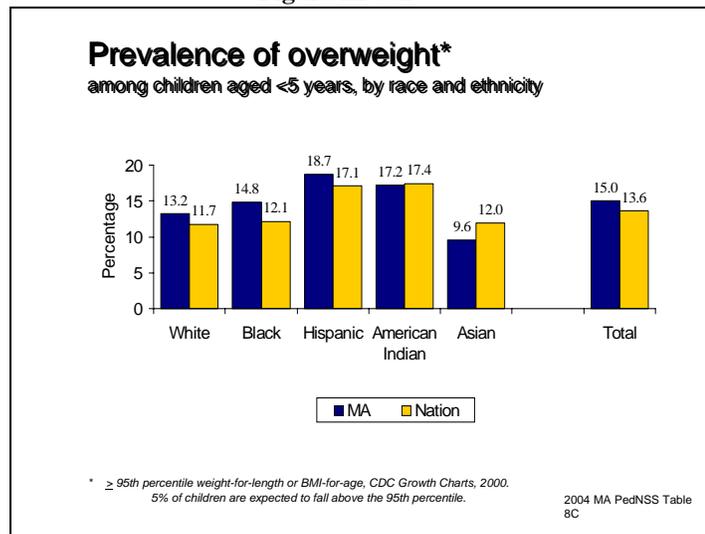
The 2004 Massachusetts Pediatric Nutrition Surveillance System (PedNSS) data analyzed by the US Centers for Disease Control and Prevention included records representing 123,263 children ages 0-59 months. Fifty-seven percent were minorities and enrolled in the WIC program. The analysis provides a summary of the following health indicators as described below.⁶²

- The prevalence of high weight (greater than 4000g at birth) was 8.2%, which is higher than the national percentage of 7.3%. High birthweight varied by race and ethnicity, with Asian (4.3%) and black, non-Hispanic (6.8%) having the lowest prevalence, and white, non-Hispanic (9.5%) and Hispanic (8%) having the highest prevalence.⁶³
- The prevalence of short stature among children under five (height-for-age <5th percentile) enrolled in the WIC program in Massachusetts was 4.6% compared to the national figure of 6.2%. Black, non-Hispanic (4.4%),

Hispanic (4.5%), and white, non-Hispanic (4.8%) have exceeded the HP2010 target for short stature of 5%. Asian (5.2%) and American Indian (5.6%) are close to the target.

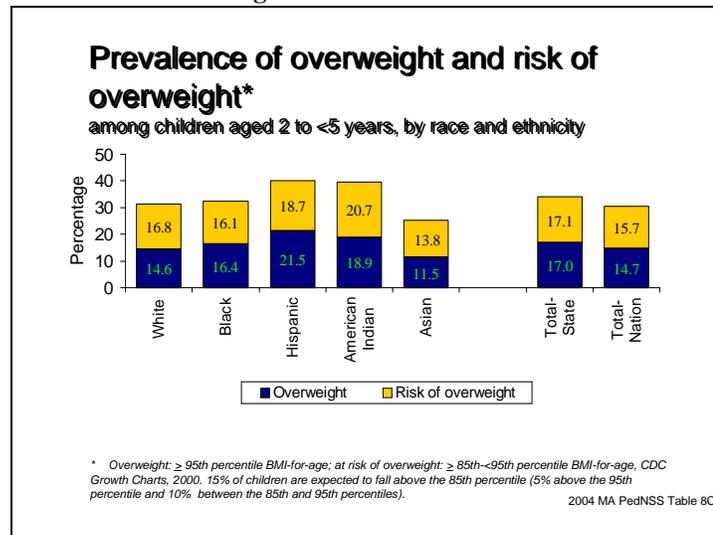
- The prevalence of underweight (weight-for-height < 5th percentile) among children less than five in the state was 5.7% compared to 5.2% nationwide. Statewide, black, non-Hispanic (6.5%) and Asian (6.25%) had the highest prevalence of underweight. The prevalence of underweight was 6.1%, 4.4%, and 4.4% for white, non-Hispanic, Hispanic, and American Indian respectively.
- The prevalence of overweight (weight-for-height > 95th percentile) among children under five in Massachusetts was higher than the national figure (15% and 13.6% respectively). Hispanic (18.7%), American Indian (17.2%) and black, non-Hispanic (14.8%) had the highest prevalence of overweight, and white, non-Hispanic (13.2%), and Asian (9.6%) had the lowest prevalence.

Figure 2D.6.1



- The prevalence of children ages 2-5 at risk of becoming overweight was higher in Massachusetts than the national figure (17.1% compared to 15.7% respectively) and varied by race/Hispanic ethnicity.

Figure 2D.6.2



Disparities in overweight also exist among adolescents by gender and race. Of high school males, 35.4% are overweight or at risk of becoming overweight compared to 23.4% of high school females.⁶⁴ Racial disparity mainly affected black students, Hispanic students, and students of Other or Multiple Ethnicity. Twenty percent of black students, 18% of both Hispanic students and students of Other or Multiple Ethnicity, 13% of White students, and 8% of Asian students were at risk of becoming overweight.⁶⁵

The rise of overweight among children and adolescents is worrisome not only because of the physical but also the sometimes complex psychological problems associated with being (or perception of being) overweight.

- More Massachusetts high school students worry about their weight (60.1%) than physical health or physical disability (38.2%) or becoming pregnant or getting someone pregnant (27.1%).
- Similarly more Massachusetts middle school students worry about their weight (47.5%) than physical health or physical disability (22.1%), drug or alcohol abuse by someone else (16.8%), or being physically attacked or hurt by someone else (14.0%).
- Among high school students with a healthy weight (with BMI between the 5th and 85th percentile), about 5.9% boys and 23.1% girls consider themselves as slightly overweight or very overweight. Among students above healthy weight (with BMI \geq 85th percentile) more than a third considered themselves as about the right weight. Similar patterns are observed for middle schools boys and girls (6.8% vs. 18.3%).⁶⁶
- Among high school students who engaged in unhealthy weight control practices such as intentional vomiting and non-prescription diet pills, 68% of females and 46% of males had weights within the normal range. Youth who self-identified with disabilities had similar levels of overweight, but were more likely to engage in unhealthy weight control practices.⁶⁷

Though mother's education and other socioeconomic factors are strong predictors of test score gains or academic performance, easily observable overweight status and

associated stigma may contribute to a lower academic performance.⁶⁸ According to 2003 Massachusetts YRBS, high school students who were overweight were less likely than their peers to report receiving mostly A's, B's or C's in school (89% vs. 81%).

The overwhelming majority of high school and middle school students consume fruits and vegetables far below the recommended five or more servings a day.⁶⁹ Between 1999 and 2003, high school students who reported eating five or more servings of fruits and vegetables decreased significantly from 13.9% to 11.4%.⁷⁰

Among Massachusetts high school students, 56.3% of females and 70.2% of males report engaging in vigorous physical activity three or more times per week for at least 20 minutes per time.⁷¹ Yet this estimate still falls far below the Healthy People 2010 target of 85%.⁷² The number of Massachusetts high school students attending physical education classes at least once a week declined from 80% in 1993 to 58% in 2003.⁷³ In 1996 the state mandate stipulating the amount of school time earmarked for physical education was eliminated. A higher percentage of males than females report drinking 3 or more non-diet sodas the day preceding the survey (13.4% vs. 6%), watching at least 3 hours of TV on an average school day (33.7% vs. 26.4%), and using the computer for 3 or more hours a day (27.4% vs. 24.6%).⁷⁴

2D.7 Child and Adolescent Violence and Injury Risk Behaviors

The physical and financial burdens associated with violence and injuries among residents of the Commonwealth are significant. Massachusetts children under age 18 experienced 187,323 injury-related emergency department visits in 2003; the total charges for these visits exceeded \$122 million. Injuries were also responsible for over 4,030 hospitalizations in this age group, with charges totaling over \$15 million. Detailed information about injury-related hospitalizations and emergency room visits is attached in Tables 2D.7.1 to 2D.7.4 in the supporting documents at the end of this needs assessment. The newly developed state MCH priority to address injury prevention in MCH programs and initiatives will help assure a more integrated response to these highly preventable events and their resulting health burden.

In Massachusetts, there has been a 20% decrease in the juvenile arrest rate for violent crime in the last decade.⁷⁵ Nevertheless, the statistics on youth violence are sobering. Data from the 2003 Massachusetts YRBS indicates that 14% of high school youth surveyed reported carrying a weapon in the 30 days prior to the survey and 3% reported carrying a gun; 6% reported being threatened or injured with a weapon on school property. Furthermore, 31% reported physical fighting in the past 30 days.⁷⁶ In 2004, 87% of 732 assault-related gunshot and stabbing injuries among individuals aged 0 to 24 years in Massachusetts were among males. Of these cases, 45.2% (319 injuries) were among males aged 15-19, a rate of 149.7 per 100,000 males.⁷⁷

In addition to gender, sexual orientation, race and disability status are correlated with risk for violent victimization or perpetration. Students identifying as gay, lesbian or bisexual seem to be at particular risk for victimization in school. Nearly 18% (17.7%) reporting skipping school in the past month because of feeling unsafe; 17.7% reported being threatened or injured with a weapon at school in the past year. Youth with disabilities (physical, cognitive or psychiatric) also have significantly higher rates of victimization. Minority youth are disproportionately affected by violence as both victims and perpetrators. For example, 79% of juveniles serving sentences in Department of

Youth Services facilities for the most serious crimes are members of racial and ethnic minority groups.⁷⁸ Although the reasons for such statistics are complex, and in some cases not thoroughly understood, intervention and prevention efforts should be appropriately designed to address these disparities.

Domestic violence and sexual assault are particular risks for the younger MCH population. Approximately 20% of female public high school students in Massachusetts report being physically and/or sexually hurt by a dating partner.⁷⁹ This same study also suggests that adolescent girls who experience dating violence are at risk for other health risk behaviors including substance use, high risk sexual behavior and suicidality. Data from the network of rape crisis centers in Massachusetts adds to this picture. In FY04, these centers responded to more than 11,000 hotline calls and provided services to more than 1,700 survivors of sexual assault. Current and former partners, dates, and boyfriend/girlfriends committed over one-third of reported assaults against survivors 13 years of age and older, while parents, caretakers, siblings and other relatives committed almost three-fourths of reported assaults against children under 13 years.

The Department of Social Services, the state's child welfare agency, reports that in 2003, 1,589 cases were referred to district attorneys' offices for supported allegations of child sexual abuse/assault.⁸⁰ An area of particular need in responding to the sexual assault of children and adolescents is appropriate medical care and examination.⁸¹ Beginning in 1995 MDPH implemented the Sexual Assault Nurse Examiner (SANE) Program to provide quality medical care and forensic evidence collection for sexual assault victims seeking services in hospital emergency departments. Prior to implementation of the SANE Program, sexual assault patients could expect to sit for hours in overcrowded emergency rooms before being seen by medical providers who were often unfamiliar with the standards of forensic evidence collection and were not connected to important victim services. Victims reported feeling re-victimized. Further, they were not connected to essential victim services that could aid in their healing and when they did feel able to report a crime, the evidence could be of such poor quality that cases were difficult to prosecute.

Since implementation of SANE services for adolescents and adults, the program has seen a 95% conviction rate, has assured appropriate clinical care (e.g. STD, HIV and pregnancy prophylaxis) and has worked closely with rape crisis center advocates to initiate healing and lessen the long term impact of sexual assault. However, the situation has remained unchanged for sexual assault victims under the age of 12. In Massachusetts, we have seen the incorrect use of the adult evidence collection kit – including the use of a speculum – on prepubescent children. There have been no protocols or standards for caring for young victims. There is a lack of statewide of trained pediatric providers with expertise in sexual assault and children are often waiting as much as three months for an exam.⁸² Working with a multidisciplinary group of experts, the SANE Program has developed the first of its kind *pediatric* forensic evidence collection kit and protocol with the principle of “do no harm.” MDPH has developed a performance measure to assure implementation of pediatric SANE services in the coming five years.

In addition to assuring a better immediate medical response and a coordinated criminal justice response to the sexual assault of children and adolescents, it is important to respond to the emerging data, as well as the anecdotal information of those who have

worked in the field, regarding the long term physical and emotional consequences of gender-based violence. In a study conducted by the MDPH STD Division between 1997 and 1999, 54% of patients seen in STD clinics reported past or current sexual violence. Studies dating back to the early 1990s have correlated domestic and sexual violence with chronic pain, HIV infection, gastrointestinal disorders, delayed entry into prenatal care, unintended pregnancy, smoking during pregnancy, and more.⁸³

Further, an increasing body of literature is detailing serious consequences for children who live in homes where there is violence. Data from the Adverse Childhood Experiences (ACE) study is demonstrating links between child abuse, domestic violence and sexual abuse, and range of negative health outcomes as adults. These include smoking, alcohol and other drug use, suicide attempt, chronic obstructive pulmonary disease, diabetes, and more.⁸⁴ In addition to the effects of witnessing violence, numerous studies show direct connections between domestic violence and child abuse. The Massachusetts Department of Social Services reports that 40 to 60% of its open child abuse and neglect cases involve violence against the children's mother. Further, from 1993 to 2003 Massachusetts saw increases in both the number of reports of child abuse and neglect (a 20% increase from 57,069 to 67,366 cases) and the number of supported investigations (a 48% increase from 14,734 to 21,834 cases).⁸⁵

The priority need identified by MDPH of addressing violence against women, children and adolescents will allow programs to develop creative and unique strategies for reaching their client populations through screening, referrals and appropriate responsive care.

2D.8 HIV/AIDS

As of July 1, 2004, 2% (263) of Massachusetts residents living with HIV/AIDS were 13-24 years old. Of these youth, 48% were female, compared to 28% of those age 25 years and older; 35% were Hispanic, compared to 24% of people 25 years or older. Of people of all ages living with HIV/AIDS in Massachusetts, 1,397 (10%) were diagnosed with HIV infection at ages 13-24 years. The proportion of adolescents diagnosed with HIV infection in Massachusetts is lower than the national proportion.⁸⁶

Of 42,433 HIV tests performed in 2003, 30% (N=12,782) were among 13-24 year olds, of which 0.3% were positive.⁸⁷ Within the three-year period 2001 to 2003, 190 adolescents and young adults age 13-24 years were diagnosed with HIV infection, accounting for 7% of all diagnoses reported in Massachusetts.⁸⁸

Among recently diagnosed adolescents, there is substantial variation by race/ethnicity, gender and geography. Among adolescents diagnosed with HIV infection within the years 2001 to 2003, 29% were Hispanic and 43% were female. Within certain Massachusetts communities the proportion of recent HIV infection diagnoses among adolescents is 2 or 3 times the statewide proportion of 7%. The city of Boston had the largest number of 13 to 24 year olds diagnosed at 59 (7% of HIV infections diagnosed). Among cities with over 20 people diagnosed with HIV infection from 2001 to 2003, Chelsea (18%), Holyoke (15%), Medford (15%), and Lawrence (12%) had the highest proportion of diagnosed individuals who were adolescents.⁸⁹

Among 257 children and young adults living with HIV/AIDS who were exposed to HIV perinatally and were enrolled in a statewide system that monitored perinatal HIV infection, 141 (55%) are currently age 13-24 years old.⁹⁰

A recent MDPH fact sheet on HIV/AIDS among adolescents and young adults is attached as Appendix 2D.8.1. It includes further details about age, race, gender, geographic differences, and mode of exposure.

2D. 9 Sexual Risk Behaviors

HIV/AIDS, STDs, and teen pregnancy are associated with an overlapping set of sexual, alcohol, and drug-related risk behaviors. According to the 2003 YRBS, there were significant decreases in the percent of students who report:

- Lifetime sexual intercourse (49% in 1993 to 41% in 2003)
- Sexual intercourse before age 13 (8% in 1995 to 6% in 2003)
- Four or more lifetime sexual partners (15% in 1995 to 10% in 2003)
- Having ever been or gotten someone pregnant (7% in 1997 to 4% in 2003)⁹¹

Nevertheless, many high school youth in Massachusetts are still engaging in behaviors that put them at risk:

- 30% of students report having had sexual intercourse in the 3 months before the survey.
- Male and female students were equally likely to report recent sexual intercourse; male students were more likely to report sexual intercourse before age 13 (7% vs. 2%) and the use of alcohol or drugs before their last sexual intercourse (33% vs. 18%).
- Older students were less likely to report condom use at last intercourse (48% of 12th graders vs. 59% of 11th graders, 66% of 10th graders, and 65% of 9th graders). Older students were more likely than younger students to report use of birth control pills or Depo-Provera.
- Eighty-five percent of students who had recent sexual intercourse used a method of pregnancy prevention the last time they had sex, with older students more likely to use pregnancy prevention method.
- Higher rates of sexual intercourse before age 13, four or more lifetime partners, and recent sexual intercourse were observed among Hispanic students, black students and students of other or multiple ethnicity more often than among white or Asian students.
- Sexual minority youth and students in urban communities had higher rates than their peers of most sexual risk behaviors.
- Approximately 12% of all students (25% of sexually experienced students) had ever been tested for HIV infection or other sexually transmitted diseases; 6% (7% of sexually experienced students) had been told by a doctor or other health care professional that they had a STD or were HIV positive. This represents a significant increase from 3% reported in 2001.

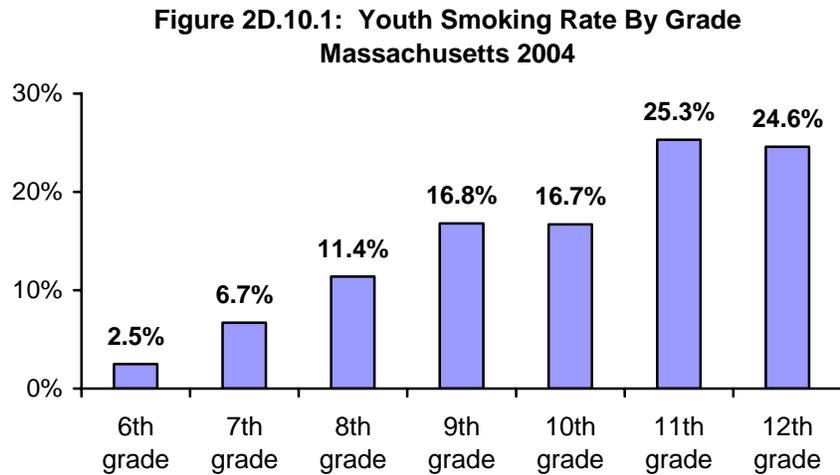
Based on reports from persons involved in HIV prevention activities with youth, out-of-school youth are likely to have higher rates of these risk behaviors than those in school. Youth involved in exchanging sex for life necessities are also at very high risk. Risk factors among out-of-school youth include: low perception of risk, lack of prevention education (including misconceptions about HIV transmission) low self-esteem, lack of parental and community involvement, family mobility, absence of healthy role models, multiple sexual partners in the course of maturity, substance abuse,

incarceration, low socio-economic status, under-age alcohol consumption, and peer pressure.

2D.10 Tobacco Use

Eighty-five percent of current adult smokers in Massachusetts had their first cigarette before age 18. Sixty-seven percent were smoking regularly before the age of 18. If adolescents can be dissuaded from starting to smoke, they will likely never become smokers.

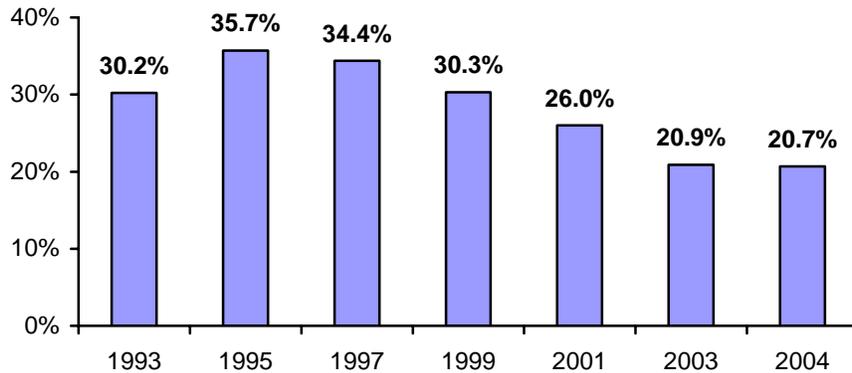
The percentage of youth who are current smokers, defined as those who smoked during at least one of the last 30 days, generally increases with age. Below is a chart of smoking rates for youth from grades 6 through 12 as reported on the 2004 Youth Health Survey. (See Figures 2D.10.1 and 2D.10.2, following page.)



Source: MA Youth Health Survey 2004

Current cigarette smoking (30 days prior to survey) among high school students in Massachusetts has decreased significantly from 35.7% in 1995 to 20.7% in 2004. This change represents a 42% decline in the smoking rate among adolescents in the past nine years.

**Figure 2D.10. 2: Youth Smoking Rates
(Grade 9 to 12)**

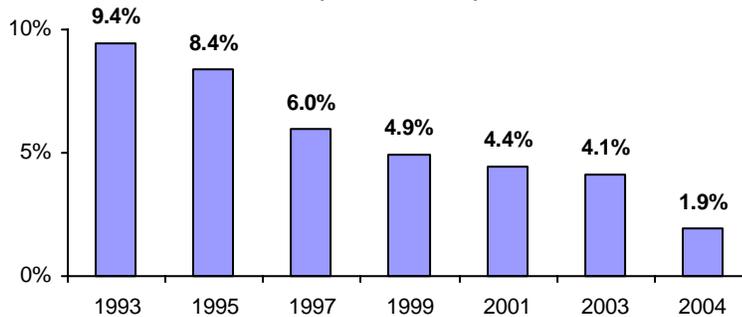


Source: MA Youth Risk Behavioral Survey 1993 to 2003;
MA Youth Health Survey 2004

Smokeless Tobacco Use

There has been a steady and significant decline in adolescent smokeless tobacco use from 1993 (9.4%) to 1997 (6.0%) to 2004 (1.9%). This decline represents an 80% decline in the use of smokeless tobacco among high school students. By 1996, Massachusetts excise taxes brought the tax to 75% of the wholesale price, accounting for much of the decline.⁹²

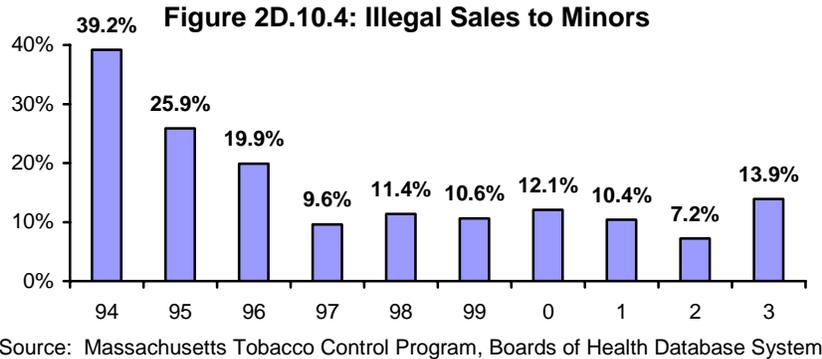
**Figure 2D.10.3: Smokeless Tobacco Use
(Grade 9 to 12)**



Source: MA Youth Risk Behavioral Survey 1993-2003;
MA Youth Health Survey 2004

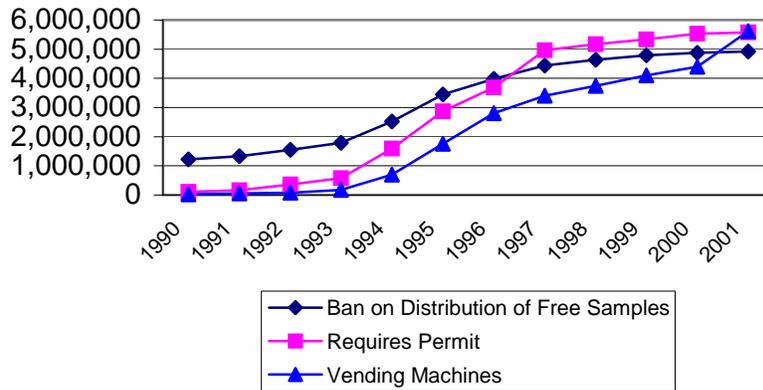
Youth Access to Tobacco

From 1993 through 2004, Massachusetts cities and towns adopted local ordinances that prohibit the sale of tobacco to minors. Illegal sales to minors have fallen from 39% in 1994 to just 10% in 1997. The rate has remained below 15% for the past seven years between 1997 and 2003.



Massachusetts cities and towns with a combined population in excess of 5.5 million have passed ordinances that require permits, restrict the use of free samples, and mandate lock-out devices on vending machines. As the number of communities requiring permits for tobacco retailers has increased, the number of illegal sales to minors across the state has decreased.

Figure 2D.10.5: Population of Massachusetts Cities and Towns with Ordinances Restricting Youth Access



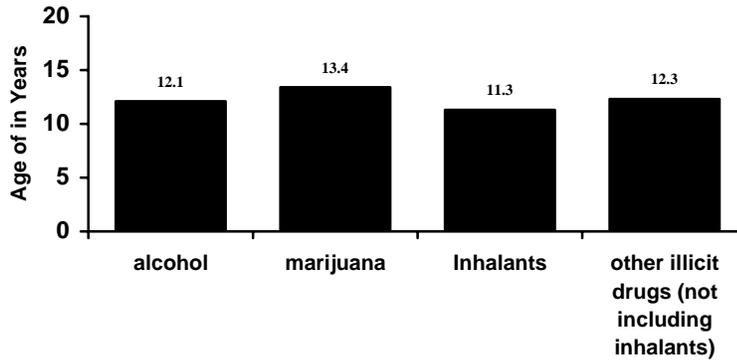
However, surveillance efforts have found that 76% of retail stores are selling flavored tobacco products, including candy flavored tobacco products. Pilot investigations suggest that sales rates of flavored cigars to minors are double the sales rates of cigarettes. Furthermore, availability of single cigars is 25% higher in urban areas than in suburban or rural areas.

2D. 11 Alcohol and Drug Use

In 2004 on MYHS, over half (58.9%) of Massachusetts middle and high school students reported no alcohol or drug use. This figure is the baseline for a new Massachusetts state measure, percent of students who report no alcohol or drug use.

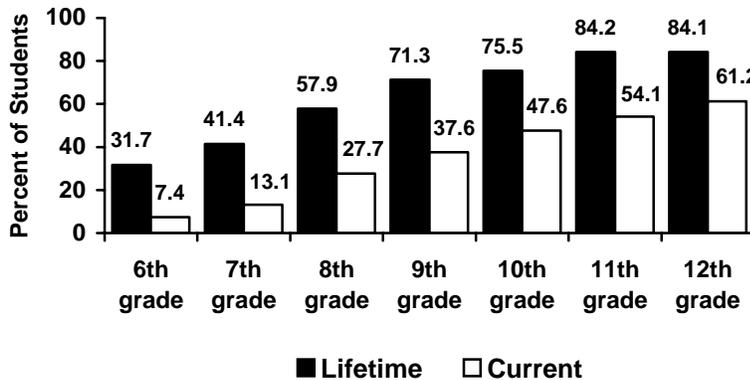
Early initiation of alcohol use among high school students (before age 13) decreased from 31.1% in 1995 to 25.2% in 2003.⁹³ Nevertheless, alcohol and drug use remains a substantial risk behavior among middle and high school youth:

Figure 2D.11.1 Average Age of First Use of Alcohol and Illicit Drugs



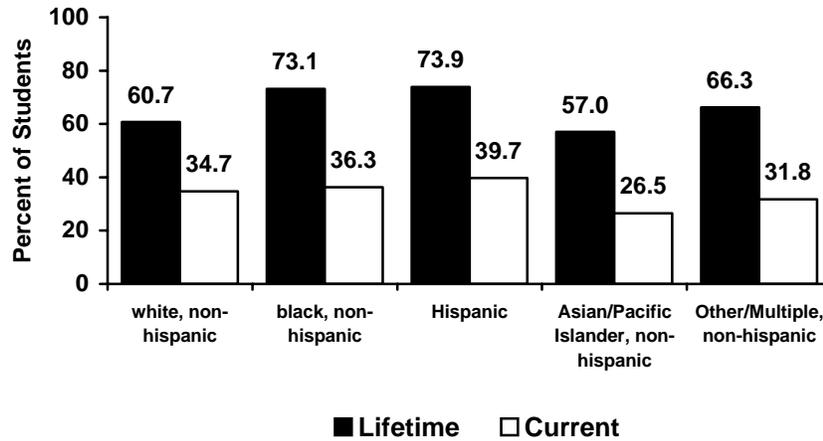
Source: MYHS, 2004

Figure 2D.11.2: Massachusetts Lifetime and Current Alcohol Use among Middle and High School Students, by Grade Level, 2004



Source: MYHS, 2004

Figure 2D.11.3: Massachusetts Lifetime and Current Alcohol Use among Middle and High School Students, by Race/Ethnicity, 2004

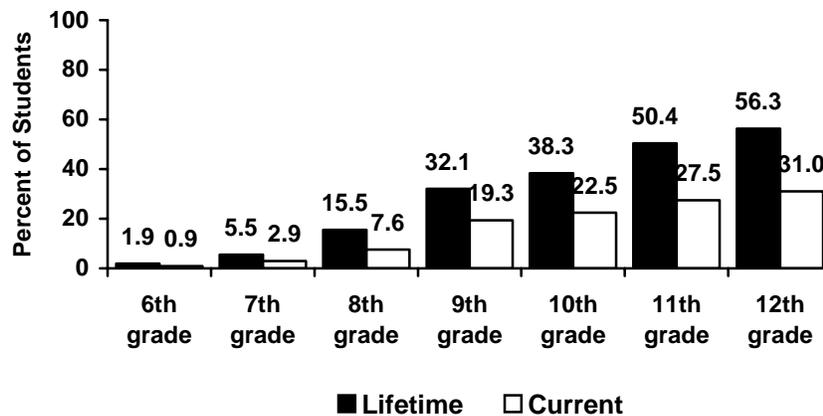


Source: MYHS, 2004

Both male and female students report similar lifetime and current alcohol use rates. Hispanic students report the highest use in both categories while Asian/Pacific Islander students report the lowest rates of both.

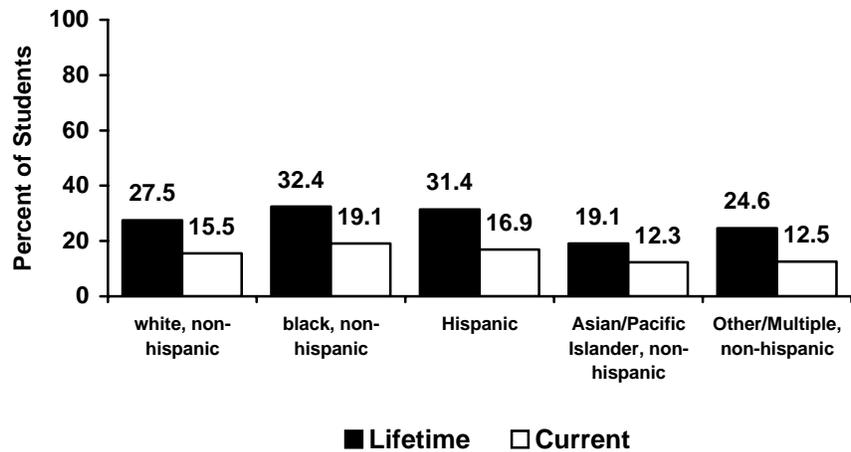
Both lifetime and current marijuana use increased with grade. Male students reported slightly higher rates of both lifetime and current marijuana use rates than female students. The highest lifetime and current marijuana use was reported by black non-Hispanic students rates while Asian/Pacific Islander students reported the lowest rates for both lifetime and current use.

Figure 2D.11.4: Massachusetts Lifetime and Current Marijuana Use among Middle and High School Students, by Grade Level, 2004



Source: MYHS, 2004

Figure 2D.11.5: Massachusetts Lifetime and Current Marijuana Use among Middle and High School Students, by Race/Ethnicity, 2004



Source: MYHS, 2004

Other illicit drugs include inhalants, hallucinogens (e.g., LSD, PCP), heroin, cocaine, crack, amphetamines, narcotics (e.g., heroin, methadone, morphine and codeine), club drugs (e.g., Ecstasy, Special K), and crystal meth. In addition, illicit drugs can be medical use drugs without a prescription (e.g., steroids, Ritalin, Oxycontin) and over-the-counter drugs for non-medical purposes.

Lifetime and current illicit drug use increased by grade. Although the rate of lifetime other illicit drug use was similar for male and female students, the rate of current other illicit drug use was higher for female students (14.3%) than male students (12.5%). Non-Hispanic multiple race/ethnicity students reported higher lifetime and current illicit drug use rates than those in other race/ethnicity categories. Non-Hispanic and Asian/pacific Islander students reported the lowest current other illicit drug use rate while white, non-Hispanic students reported the lowest rate of lifetime use.

Analysis for the 2005 Substance Abuse Strategic Plan based on available 2002 National Household Survey on Drug Abuse data, found that almost twice as many youth aged 12 to 17 perceived risk from cigarette use compared with marijuana use or binge drinking. Massachusetts rates of binge drinking and marijuana use significantly exceed national rates, while cigarette smoking does not.⁹⁴

2D. 12 Clustering of Adolescent Risks

Strong relationships exist between various adolescent risk behaviors. For example, current smokers are more likely than non-smokers to report drinking, marijuana use, and other illegal drug use in the 30 days before the survey. Compared to non-drinkers, students who report current alcohol use were more likely to report:

- Recent sexual intercourse (44% vs. 28%)
- Attempted suicide (11% vs. 6%)
- Carrying a weapon (20% vs. 9%)

- Being in a physical fight (40% vs. 28%)
- Experience of sexual contact against their will (13% vs. 9%)

Students who carried a weapon or engaged in physical fighting were more likely to report having attempted suicide (14% vs. 5%) and driving after drinking (19% vs. 7%).⁹⁵

2D. 13 Relationships between Adolescent Strengths and Risks

Factors often identified as “strengths,” “assets,” or “resiliency factors,” such as perceived adult support in and out of school, volunteer work, and other extra-curricular activities, are associated with lower levels of risk behavior. Tables 2D.3.2 and 2D.3.3 (attached at the end of this needs assessment) and Figures 2D.3.2 and 2D.3.3 provide data about strengths of Massachusetts children and youth.

Having an adult family member to talk to about important things is one such asset. According to the 2003 YRBS, 27% of students with perceived family support vs 39% of those without were current drug users. Somewhat lower rates of drug use were also reported by students who perceived they could talk with an adult in their school, who volunteered in the community, and who participated in extra-curricular activities. Being able to talk with an adult family member was also protective for drinking and driving and for sexual risk taking, including intercourse. Sexually active youth who talked with their parents about sexuality and prevention of pregnancy, STDs, or AIDS, were less likely to have used alcohol or drugs before the last time they had sex.⁹⁶

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IIB: 2E. CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

2E.1 Demographics

The National Survey of Children with Special Health Care Needs (NSCSHCN) is a random-digit-dial survey that provides national and state estimates of the prevalence and impact of special health care needs for children under age 18 and their families.¹ The NSCSHCN found that 12.8% of US children under age 18 have a special health care need (SHCN). The Massachusetts figure was higher: 14.7% (95% CI 13.4-15.9). The percentage of children under age 6 with special health care needs in Massachusetts (7.7%) was comparable to the national figure of 7.8%. Massachusetts percentages for older children were higher: 6 to 11 year-olds in Massachusetts, 16.2% vs. 14.6% for the nation; 12 to 17 year-olds in Massachusetts, 19.8% vs. 15.8%. In Massachusetts, 22.3% of households with children compared to 20% of households with children in the nation had one or more child or youth with a special health care need. The estimated number of children and youth with special health care needs (CYSHCN) in Massachusetts, weighted to population characteristics, was 221,840.²

Massachusetts reported a higher percentage of white (15.7%), Hispanic (13%) and multiracial children (17.2%) with special health care needs than the US average (14.2%, 8.5%, 15.1%, respectively), with blacks slightly higher (13.9% for MA vs. 13%) and other groups lower (4.1% vs. 7.8%). Most (81.3%) of CYSHCN in Massachusetts were white, 9.3% Hispanic, and 5.7% black. A higher percentage of Massachusetts children under 100% of poverty (17.7%) were reported to have SHCN than for the US (13.6%); but among children living in households over 200% of poverty, the percentage was lower in Massachusetts than in the rest of the US.

Massachusetts uses additional data sources to estimate prevalence and describe demographics of CYSHCN, depending on the purpose. The NSCSHCN facilitates national comparisons and tracking of MCH outcome measures. A second national survey, the National Survey of Children's Health, permits comparisons nationally and at a state level of children with and without special health needs on a variety of child health indicators, although its Massachusetts sample of CYSHCN is smaller. (These comparisons were previously referenced in Section 2D as Tables 2D.3.1 to 2D.3.3. These Tables are attached at the end of this needs assessment.) The Massachusetts Department of Education (MDOE) data provides information about special education students. The Massachusetts Youth Health Survey (MYHS) provides an estimate of self-reported disability in middle and high school and also enables comparisons between youth with and without disabilities on a wide range of health indicators. Similar comparisons are available for older adolescents and young adults with disabilities using the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) data.

According to the National Survey of Child Health, the prevalence of children with special health needs in Massachusetts is 22.2% compared to 17.6% for the nation.³ Differences between it and the NSCSHCN may relate to differences in the sample, differences in the positioning of the questions, or other methodological issues. The same definition of *special health care needs* is used in both surveys.

According to the MDOE, students with disabilities receiving special education services comprised 15.6% (n=154,391) of the entire Massachusetts public school students

population during the school year 2003-2004.⁴ Total enrollment has been relatively stable for the past three years. Students with disabilities were disproportionately (66%) male. Most students with disabilities were white (72.1%) with 13.9% Hispanic, 11.5% African American, 2.2% Asian and 0.4% Native American. About 20% of the total school population of Hispanics, blacks, and Native Americans are in special education compared with 15% of whites and 7% of Asians.⁵

The 2004 Massachusetts Youth Health Survey defined disability using three questions that are part of the 4-item self-report Youth Quality of Life-Disability Screener (YQOL-DS). In 1997, the University of Washington's Seattle Quality of Life Group developed and validated a 4-item self-report disability screener for use among youth ages 11-18. On the MYHS, 15.0% of middle school and 19.6% of high school youth in Massachusetts self-reported having a disability.

In addition, Massachusetts asks questions of adults using the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) to screen for disabilities. Applying the percentage of 18-21 year-olds in Massachusetts with disabilities based on the 2003 BRFSS to the 2000 Census, over 39,400 18-21 year-olds have a disability.

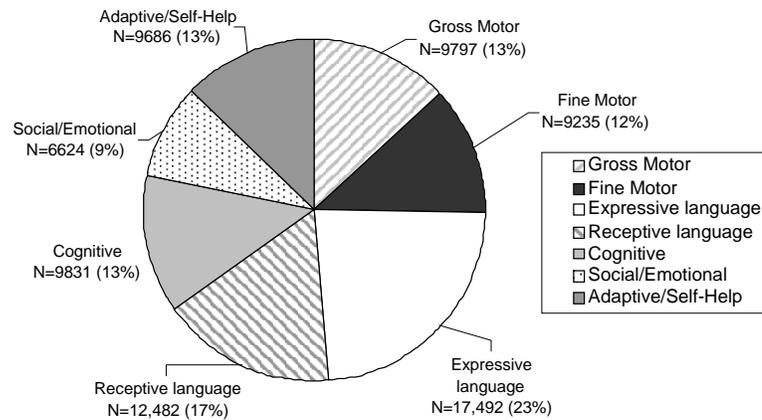
2E.2 Type of Special Health Care Need

Surveys and Programs Have Various Definitions for Type of SHN

The NSCSHCN used five questions to identify the type of special need, followed by a question about duration of the need, with at least 12 months duration defined as the minimum to count as a "special need." This definition is based on function rather than type of medical or other conditions. In Massachusetts, type of need was as follows: 10.7% of all children (with and without special health needs) needed or used prescription medicines; 7% needed or used medical care, mental health, or education services; 3.2% were limited or prevented in their ability to do things other children the same age could do; 3.3% required special therapies such as physical, occupational, or speech; and 5.1% had emotional, developmental or behavioral problems. Parents also rated the severity of the special needs as follows: mild, 29.3%; moderate, 48.9%; severe, 18.0%; and most severe, 3.9%.

Reasons that children were eligible to enroll in Early Intervention (EI) Program give an indication of type of special need. During FY 2004, of 29,384 children under age 3 enrolled, 78% had established developmental delays, 11% had been diagnosed with established conditions, 3% were deemed at risk based on meeting at least 4 criteria, and the remainder enrolled for other or unspecified reasons. In all, among the children with delays, there were a total of 75,147 delays, with children typically having 2 or more. For children enrolled with delays (not including those with established conditions who may also have had delays), the following chart provides information about the number and types of delays.

Figure 2E.2.1: Types of Delay among Massachusetts EI Participants Eligible Due to Developmental Delays, FY 2004. N=75,147



Data Source: Massachusetts Early Intervention Information System, 2005

According to the MDOE, the distribution by type of disability among students in special education in school year 2003-2004 was the following: 45.9% specific learning disabilities; 13.6% communication; 2.8% neurological; 0.3% sensory/vision; 3.2% autism; 0.2% deaf-blindness; 9% developmental delay; 8.6% emotional; 0.7% sensory/hearing; 8.1% intellectual; 3.4% multiple disabilities; 0.8% physical; and 3.5% health.⁶

For middle and high school youth, the screening questions used on the MYHS 2004 also provide an indication of type of disability or special health need:

- 8% of middle and 9% of high school students said they had “physical disabilities or long-term health problems.”
- 7.6% of middle and 12.2% of high school students said they had “long-term emotional problems or learning disabilities.”
- 5.3% of middle and 7.4% of high school students said they were “limited in any activities because of any disabilities or long term health problems, including physical health, emotional, or learning problems.”

2E.3 The MCHB Core Outcomes and National CYSHCN Performance Measures

The first six national MCH performance measures (NPM) concern CYSHCN. These measures also relate to the six MCHB core outcomes for CYSHCN, although they may be somewhat narrower. The NSCSHCN included questions to establish baselines for all but the first national performance measure, which is limited to newborn blood screening for metabolic disorders. The following table summarizes the core outcomes and NSCSHCN findings for Massachusetts and comparison geographic areas when available.

Table 2E.3.1				
MCHB core outcomes as measured by the NSCSHCN		% of families reporting that outcome has been achieved		
NPM #	(Broader) MCHB Core Outcome	National %	HRSA Region I %	MA %
1	All children will be screened early and continuously for special health care needs.	N/A	N/A	N/A
2	Families of CSHCN will partner in decision-making at all levels and will be satisfied with the services they receive.	57.5	62.1	64.4
3	All CSHCN will receive coordinated, ongoing comprehensive care within a medical home.	52.7	58.6	60.9
4	All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.	59.6	64.5	65.1
5	Community-based services for CSHCN and their families will be organized in ways that families can use them easily.	74.3	77.9	79.0
6	All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.	5.8	<i>MA estimate 2.7% (unstable); see discussion below</i>	

Although Massachusetts generally ranked higher on the core measures than most other states, room for improvement exists in Massachusetts. For example, of Massachusetts families: almost 36% reported that they do not partner in decision-making and/or are not satisfied with the services they receive; 39% reported that they do not receive care within a medical home; of the 11% of families needing care coordination, only 49% reported that they received the needed care; 29% reported that they did not receive family-centered care. While most Massachusetts CYSHCN have health insurance, 30.3% of the currently insured CYSHCN reported their coverage to be inadequate. Regarding other services, 21.9% of families reported need for, but inability to get, sufficient respite care, genetic counseling and/or mental health services.

Particular need exists in the area of transition services. NSCSHCN data indicate that only about 15% of Massachusetts (20% of US) CYSHCN received guidance on transition, including from physicians about changing needs and shifting to an adult provider.

The importance of these measures has been demonstrated in Massachusetts by two other measures: financial burden for the family and unmet need. Analysis of NSCSHCN data by researchers at Massachusetts General Hospital in conjunction with the Family Participation Work Group of the Consortium for Special Health Needs, in part to assist with this needs assessment, found that 38% of Massachusetts families reported a finance-related problem associated with their child's health status: 15% reported their child's health had caused financial problems; 16% that they needed additional income to cover health-related expenses; 28% that family members had cut work hours to provide

care; and 11% that family members had stopped working to provide care. Families with adequate insurance, a medical home, or services organized for ease of use, were less likely to report financial burden.⁷

Consortium members found the percentages of people reporting unmet needs (17%) in Massachusetts much lower than they expected. The types of needs they recounted were similar to that of parents surveyed and involved in focus groups: respite, home nursing, personal care attendants; difficulties with getting adaptive equipment or specific therapies or medications; difficulties finding appropriate and accessible child care, and others. The group requested further analyses that took into account characteristics of the child and family, in particular, the severity of the child's condition. Although the percentage reporting unmet need increased with increasing severity, overall, the group still thought that the survey underestimated unmet need. As with financial burden, however, the analyses indicated that families with adequate insurance, a medical home, who partner in their child's care, or find services organized for ease of use, were less likely to report unmet needs.⁸

Additional information from sources in addition to the NSCSHCN about Massachusetts' needs related to each of the six core outcomes follows.

Early and Continuous Screening for Special Health Needs

Newborn "Dried Blood Spot" Screening

For the national performance measures related to this outcome, MCHB focuses on newborn screening of "dried blood spots" for metabolic conditions. By state law, all infants except those whose parents have religious objections are screened for 10 core metabolic conditions and, with parental consent, for cystic fibrosis and 19 additional metabolic conditions. The statewide Newborn Screening Program is administered through the New England Newborn Screening Program (NENSP) at the University of Massachusetts Medical School. Hospitals submit to the NENSP a tiny "dried blood spot" from the newborn. In 2004, of the estimated 79,400 Massachusetts newborns, 79,142 were screened for the 10 core conditions; 78,652 and 78,656 were enrolled in screening for cystic fibrosis and 19 additional metabolic conditions, respectively. A total of 100 infants were diagnosed with one of the core conditions, 27 with cystic fibrosis and 9 with one of the other conditions. (For details, see Form 6 of the Massachusetts FY 2006 MCH Block Grant Application.)

With respect to infants with selected diagnoses who are likely to access services in Massachusetts, Table 2E.3.2 from the NENSP, attached at the end of this needs assessment, and the paragraphs below provide additional detail relative to the variance in rates and location of services.⁹

Cystic Fibrosis (CF): The variance by geographic area of incidence rates for cystic fibrosis births is not particularly wide. Southeastern Massachusetts and the Cape and Islands have the highest rates of cystic fibrosis births. Western Massachusetts and Boston proper have particularly low rates (likely due to residents of Hispanic and African ancestries respectively). There are five CF Centers across the state.

Medium-chain Acyl Coenzyme A Dehydrogenase Deficiency (MCADD): The pattern of incidence rates for MCADD mimics that of CF, although the actual incidence is much smaller. Currently, the genetics clinics accepting MCADD patients are located in central Massachusetts (1) and Boston (3).

Classical Galactosemia: Most infants affected with Classical Galactosemia reside in Boston, where services are delivered.

Hemoglobin Disease and Trait: As expected, hemoglobin disease and trait exhibit a significantly different pattern of geographic residence related to race/ethnic population distributions for affected infants than for CF and MCADD. The highest incidence rate and the highest annual number of affected births are in Boston proper, where there are three hemoglobin clinics. Other suburban areas (excluding the Cape and Islands) show moderate incidence rates and are served by clinics in Western and Central Massachusetts in addition to those available in Boston. Carriers of hemoglobin disease typically do not access tertiary care services and in-home trait counseling is available through the NENSP.

The NENSP has well-established mechanisms for referral for diagnosis and to pediatricians. MDPH contracts with the New England Newborn Screening Program (NENSP) for newborn blood screening and follow-up. Communication between NENSP and pediatricians includes information about linking positively screened infants and their families with the MDPH Community Resource Unit for information and referral. MDPH and NENSP are currently collaborating to help assure that those children identified by screening are linked with needed information and services.

Other Screening, Referral and Followup

MDPH's CSHCN program recently expanded on this goal in response to an MCHB proposal. The Massachusetts goal is to assure children in Massachusetts receive early and continuous screening and referral to appropriate comprehensive, coordinated intervention services that are family-centered, community-based, and culturally appropriate.

Additional screening occurs in nearly 100% of births for hearing loss and all births for certain characteristics that put infants at high risk through the FirstLink program. FirstLink receives daily data feeds of the electronic birth certificate and screens for risks such as very low birth weight and high parity among teens. Procedures are in place at MDPH for referral of children with hearing loss and FirstLink-identified risks to Early Intervention (EI) and the MDPH Care Coordination Program for CSHCN, which then assure connection to primary care and other services. Plans are underway to integrate birth defects surveillance with this system of follow-up.

Analysis of newborn hearing data linked to EI indicated that, for the two-year period of 2000 to 2003, 90% of the 1,525 children who did not pass their hearing test in at least one ear and were referred for diagnosis, received a diagnosis; 10% were lost-to-follow-up. Loss-to-follow-up was associated with certain indicators of public insurance, minority status, lower maternal education, and geographic areas of the state lacking state-approved diagnostic facilities.¹⁰ (Note that parents may use non-approved facilities and MDPH did not receive diagnostic reports.) Of those with confirmed hearing loss (403 children), 29% were not referred to EI. Infants with mild to moderate and unilateral hearing loss, and with normal birthweight, were less likely to be referred, with some variation by locality, possibly reflecting lower perceived need or value from EI services by parents or pediatricians.^{11,12} The newborn hearing screening program is exploring the demographic differences in loss-to-follow-up and educational strategies to encourage EI participation.

The Pregnancy to Early Life Longitudinal (PELL) database has linked birth certificates, fetal death records, birth-related hospital discharge data and other data on both mothers and infants starting with 1998 data. To evaluate referral of children to EI, the population-based PELL data and EI program data have been linked. In general, referral rates are excellent. Overall, 19% of infants born between 1998 and 2000 were referred to EI, 6% within one year of birth. Children at risk for developmental delay due to characteristics present at birth should be referred to EI soon after birth. First-year referral was very high among these infants, with 89% of infants born less than 1200 grams referred, 83% of infants 1200-1499 grams referred, and 84% of infants less than 32 weeks gestational age referred. First-year referral was high among infants with two (89%) and three or more (79%) documented birth risk factors.¹³

Nevertheless, gaps appear to exist. Although the vast majority of infants less than 1200 grams were referred, there were maternal racial/ethnic and socio-economic characteristics associated with later time to referral and lower overall referral. Infants born to black women had a median time to referral 18 days later than infants born to white women. Controlling for all other factors, these infants had twice the odds of not being referred at all. Infants born to women with government health insurance or no health insurance had a median time to referral 22 days later than infants born to mothers with commercial insurance, and had twice the odds of not being referred.¹⁴ Referral in this group also differed by hospital, ranging from 89% to 96%.¹⁵

Children at social risk for developmental delay are eligible for EI in Massachusetts. For the most part, children with low socioeconomic status (SES) indicators were more likely to be referred to EI, indicating the program is reaching socially at-risk children. Nevertheless, some groups were less likely to be referred to the program. Taking all factors into account, children of foreign-born women were 20% less likely to be referred compared to children of US-born women. Referral was also lower among children of non-English speaking women and children of Asian women. Once referred, children of teen mothers were 10% less likely to have an evaluation to determine eligibility compared to children of older mothers. Evaluation was also lower among children born to black mothers, children born to mothers with government or no insurance, and children living in high-poverty areas. Among eligible children, those born to teen mothers, black mothers, mothers with low education, government insurance, and those living in a high poverty area were less likely to enroll in the program.¹⁶

Pediatricians and hospital personnel overall appear to do an excellent job referring to EI. Two-thirds of new referrals to EI in FY 2004 came from physicians, hospitals, community health centers, and other medical providers. Nevertheless, based on this evaluation, MDPH is investigating the possible association with institutions, particularly hospitals, lacking designated personnel to complete referrals quickly and consistently. The data suggest a need for further formalization of follow-up from screening programs.

Primary care providers, school screenings, and the extent to which health plans encourage screening in their benefit packages all influence whether screening occurs after age three. Anecdotal evidence suggests that continuous screening for special health care needs is not institutionalized among Massachusetts providers. Among insurers involved in quality improvement initiatives with MassHealth and state agencies, attention focuses on HEDIS measures and, as an emerging issue, on encouraging pediatricians to screen for mental health issues, for both the children and parents.

Focus groups with families of CSHCN suggested that continuous screening and, especially, diagnosis, may be dependent on family advocacy and resources. With a high percentage of CYSCHN having emotional or behavioral conditions, families often seemed to identify the existence of problems themselves. At the same time, parents also praised individual teachers who had noticed unusual behavior by their children, helping them receive services early. Families typically discussed this issue in relation to schools rather than pediatricians.

At a focus group with mothers of children with autism spectrum disorder (ASD) from a high socio-economic group, children had been identified before or about age three, and the assumption was stated this timeframe was typical. Citing waiting lists and low reimbursement rates, these mothers said that parents may have to pay upfront as much as \$700-\$2000 or more for evaluation services, depending on the specialist and the type of testing needed. Later they are reimbursed by insurance. This tactic may not be available to lower income families. At a meeting involving very low income families on MassHealth or just above the MassHealth income guidelines, two children with ASD had not been diagnosed until middle school. Of 15 parents whose children had various and multiple emotional and behavioral disorders, only one mother reported that her child had been diagnosed without several years of delay after symptoms emerged. This child had lead poisoning and appears to have been identified by the Massachusetts universal screening during early childhood. Late diagnosis of autism likely reflects less understanding of the condition until recently; however, the families also cited many years' resistance on the part of the schools to external evaluation of their children's conditions. The school districts had identified them as needing special education and were providing services, but for other reasons. For ASD and a range of other conditions, both the higher- and lower-income families expressed concern that schools delayed clinical evaluations from external physicians.

Family Partnership and Satisfaction

Parent/professional partnership based on mutual trust, respect and cooperation is important for progress on all six outcomes. Systems of care for CYSCHN and their families are most effective when characterized by collaboration and cultural competence. Research and anecdotal information confirm that empowering families to participate as decision-makers at all levels – about their own children's care, at the service delivery level, at the planning and policy making levels, and in evaluation – enriches systems of care.^{17, 18}

Partnership about own child's services

Responses from Massachusetts families to questions about family partnerships in decision-making and satisfaction with the services they receive depend on the specifics of the questions asked and population subgroup. Although 64.4% of parents responded positively to the NSCSHCN that they partner in decision-making about their own child's care and were satisfied with the services received, for MassHealth recipients, the figure was 55%. Of the 600 families with CSHCN surveyed in the 2000-2001 MassHealth Managed Care Child Member Survey, 57% reported that their child's doctors or other health care providers always made it easy to discuss questions or concerns, while 52% reported that they always got the specific information they needed. Sixty percent

reported that their child's doctors or other health care providers always involved them in decisions about their child's care.

At the 2003 annual conference hosted by the Federation for Children for Special Health Care Needs virtually all parents said their child's doctor "listens to their concerns." About 80% of the parents responding said the doctor asks the parent to share his/her knowledge "as a caregiver of a child with special health care needs." Expansion of this effort is needed to reach parents who may be less involved with organizations that educate parents about family participation, as is outreach to the provider community. In addition, particular issues exist in obtaining information about community resources and additional services, with only 25% of conference respondents stating that their primary care provider offered this information.

In needs assessment focus groups, some families described issues that may affect those who do not consider their primary care provider to be supportive. Families recounted incidents when the primary care provider seemed to discount their concerns or was not able to answer their questions. This was particularly true for pediatricians and family practitioners who had never or seldom encountered the child's relatively rare disorder given their typical practices. According to the parents, some physicians were extremely uncomfortable informing the parents of the diagnoses and had little to offer in response to questions. Parents thought physicians needed substantial training in delivering such information, sensitive communication and listening skills in general, and in learning how to partner with parents when the physicians were not themselves "experts." On the other hand, some physicians fully extended themselves to learn about the condition and welcomed information parents collected from parent support groups, from specialists to whom they were referred, or by searching the Internet. With these physicians, families felt as though they had an expert partner in their search to understand how to respond to the condition.

Partnership at systems and policy levels

In 2002 and 2003, to assess family participation in broader systems, financial and policy arenas, the Family Participation Work Group (FPWG) of the Massachusetts Consortium for CSHCN surveyed 16 parent leaders from family organizations statewide. The survey concerned families, their knowledge of broad systems of care for CSHCN, and their interest in working beyond their own disability-specific agendas to impact statewide policy issues. In addition, the FPWG surveyed the Consortium's organizational membership (which includes state agencies, health plans, direct care providers, academic institutions, hospitals and other healthcare settings) to identify the extent of their own parent involvement in their organizations, their interest in expanding their partnerships with family members, and resources they would need to accomplish these goals. Responses to these surveys yielded genuine albeit cautious interest. Many respondents indicated a need for additional information, including understanding what it would mean to involve parents in organizations and to have parent participation in planning and policy activities. Parent leaders raised issues such as parents needing to understand the meaning of terms like "policy and financing activities" and the value of their involvement in them given the demands on their time. The Work Group recommended further educational activities for parents and professionals.¹⁹

Medical Home

A medical home is defined by the American Academy of Pediatrics (AAP) as a system of care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It is an approach to providing health care services, where families and physicians work together to identify and access all of the medical and non-medical services needed to help children and their families reach their maximum potential. Medical home is also an attitude, whereby families are recognized as the principal caregivers and the center of strength and support their children. The Massachusetts Medical Society, the Massachusetts Chapter of the AAP, and the Massachusetts Academy of Family Physicians have formally endorsed the principles of the Medical Home Policy Statements of the AAP.

Several important aspects of the medical home outcome are operationalized in the NSCSHCN. Massachusetts appears strong in children having a usual source of care (91%) and a personal doctor or nurse (95%). About 86% have “no problem” with referrals (including 85% of MassHealth recipients). About 70% received family-centered care (62% for MassHealth). Only 49% received coordinated care (the same for MassHealth recipients). The results are similar to local results from convenience samples. For example, a survey in 2000 of predominately MassHealth recipients in the Neighborhood Health Plan (a not-for-profit managed care organization with a large MassHealth-enrolled population) had similar findings.

In 2001, MDPH initiated the “Massachusetts Medical Home Project” (MMHP). As part of MMHP, MDPH transitioned regionally-based Care Coordinators for CYSHCN into selected primary care pediatric practices. Care Coordinators located in these practices provide care coordination services to families of CYSHCN in the practice. They also work with practice physicians and staff to incorporate other components of medical home into the practice, such as developing systems for identifying CYSHCN and providing family-centered care. A survey of 511 families of CSHCN in the Greater Boston area was conducted in early 2004 as part of the MMHP. These families were in practices that did not have a MDPH Care Coordinator on site. Although the response rate was low (26%), the majority of respondents were black and Hispanic, and they were lower income compared to the state population. Their responses suggested additional unmet needs in the minority, low income population:

- 43% reported needing care coordination in the past 12 months, while only 26% reported that they received assistance from a care coordinator.
- A substantial number of families reported that they needed but were unable to get transportation (34%), dental care (21%), genetic testing (36%), genetic counseling (47%), nutrition counseling (34%), and respite care (43%).
- 49% reported being dissatisfied with information from their primary care provider (PCP) about support groups, camps and other programs, and 45% reported little help from the PCP in identifying community school-based programs.
- 30% felt their PCP was not sufficiently aware of their child’s other caregivers.
- 41% reported unsatisfactory communication between health care providers and other services.

Adequate Insurance

Based on the NSCSHCN, all but about 2% of Massachusetts CYSHCN have insurance, with about 35% of CYSHCN on MassHealth. Because insurance is not always adequate, this objective was met for only 65% of respondents. About 89% of respondents reported their children's coverage allows care by the needed providers (83% for MassHealth members), while 85% of respondents said the coverage usually or always met their needs (79% for MassHealth); 74% believed costs not covered were reasonable (same for MassHealth). As of June 30, 2003, about 20,000 Massachusetts children under age 18 qualified for MassHealth because of a disability (including both required federal SSI eligibility and state options), a figure that has increased by about 5% since 1999.²⁰

Families with incomes above 133% of poverty may "buy-into" a Medicaid program called CommonHealth on a sliding fee basis as a secondary insurance. For many families this is a critical program, although some no longer find it cost-effective given recent fee increases. One focus group member "bought in" for the dental coverage because her child had to be anesthetized for checkups and dental work. A 2004 report highlighted the importance of diapers to a family on CommonHealth. They cost \$12-\$18 a package and the family needs at least two packages a day.²¹

Additional concerns about public and private insurance from focus groups as well as a survey and in-person interviews conducted during FY2005 included: restrictions to seemingly less-effective generic medications, restrictive definitions of "medically necessary," limits to mental health coverage, and restriction of coverage to professionals working in certain clinical settings when other options may be more effective for the same purpose. Additional concern was expressed about prior approvals and what appear to parents to be administrative actions or possibly inconsistent information about coverage of certain items, such as the frequency with which durable equipment may be changed as the child grows.

Applications to the state's Catastrophic Illness in Children Relief Fund (CICRF) also suggest that, while most CYSHCN are insured, coverage does not meet many families' needs. The CICRF was established by the state legislature in July 2000 to assist families facing extraordinary medical and medically-related expenses that are not covered by any private or public insurer or other funding source. The CICRF provides financial assistance to families of children and youth under age 19 when their child's annual out-of-pocket medical and medically-related expenses exceed 10% of the family's annual income. Approximately 423 families have received assistance from CICRF to date. The number of applications submitted has increased each year since the Fund's inception. Almost all applicants have had some form of health insurance coverage. Types of expenses for which families have required assistance include medically necessary hospital and physician services, medications, medical equipment and supplies, travel and lodging, therapies, respite, and home and vehicle modifications.

Community Services Organized for Ease of Use

Based on the NSCSHCN, 79% of Massachusetts families found services organized for ease of use, including 71% of families of children receiving MassHealth. At the same time, as noted above, families stated that their PCP does not provide them with information about community services. During focus groups, families were surprised to hear of resources they had never heard about that were used by other

families. They also noted that some of the most important information they had gathered came through friends, conversations with neighbors, other families with CYSHCN, on the Internet or television. They did not generally consider it easy to find information they needed. A few also noted that, for example, if their child was involved with more than one agency, there was typically little coordination between agencies. Transportation was often voiced as a concern. In addition, services might be difficult to use simply because they required the parents' time and attention, so that parents generally had stopped working or changed jobs, and siblings experienced a loss of parental attention.

The Family TIES program provides a toll-free line for families to obtain information about community based services. Over 2000 calls are received yearly. Among the most frequent issues are requests for information about Early Intervention; what to expect and where to go to access services; connections to parent support groups; ways to build community and make community resources more accessible and welcoming; information about navigating the health care system to ensure that children receive the services and supports they require; and information about opportunities to serve in advisory capacities on task forces, etc., as a way to have input into how services are developed and implemented. The top three areas for which the Family TIES coordinators, when interviewed for this needs assessment, said families needed more help were respite, funding and financial support, and advocacy services (related to school and issues across the lifespan). The key barriers families reported to them were lack of information or up-to-date information, lack of service coordination, and lack of funding. Family TIES coordinators said that information needs to be available through hospitals, doctors, and advocates. Written materials are needed for front-line staff and parents. On the other hand, the Family TIES coordinators thought that more information is available now than two to five years ago, given Internet use, support groups, and increasing attention to the medical home. When families call, coordinators report, they sometimes seem more frustrated because they are clearer about what they want for their children but they cannot find it. It may not be available or no financial assistance is available.

Flexible Supports

In 2002, the Massachusetts Legislature passed Chapter 171 of the Acts of 2002, "An Act Providing Support to Individuals with Disabilities and their Families." This law mandated state agencies to develop plans to provide flexible supports that would enhance community participation, based on substantial consultation with consumers. In order to develop its plan, MDPH conducted a needs assessment to elicit input from families regarding unmet needs that could be addressed through the provision of flexible supports from state agencies. MDPH conducted focus groups; met families at conferences, regional meetings, parent support groups; administered telephone and written surveys; and posted questions on web sites of family organizations. Through these methods, families identified the following as areas of need:

- Improved access to oral health care for children and youth with complex medical and physical needs.
- Assistance in identifying and training Personal Care Attendants.
- Support in planning for emergency situations.

Follow up interviews helped MDPH to prioritize family needs and embark on an initiative to help families to understand and prepare for emergencies and disasters.

Pediatric End of Life Care

The unique needs of children with life-threatening illnesses is an emerging area in end of life care, in which resources and systems of care have yet to be designed to fit children and their families. According to a study published in the *New England Journal of Medicine*, 80 percent of children dying with cancer in this country are suffering and their symptoms are not being adequately palliated.²² An Institute of Medicine report, *End of Life Care: Special Issues in Pediatric Oncology*,²³ outlines the challenges and introduces possible strategies to improve end of life care for children. Some of these strategies include investigating the barriers to optimal symptom control in pediatric oncology, developing ways to educate providers on communicating bad news, incorporating palliative and curative therapies simultaneously, evaluating models of informed and shared decision-making that are family centered, evaluating the needs of siblings, and addressing barriers to reimbursement for palliative care.

Currently the state has 15 hospice organizations with specific expertise in pediatric end of life care. Staffing and financial barriers impede efforts to further the skills of hospice providers to meet the needs of dying children. In addition, Massachusetts has begun to address the end of life needs of pediatric cancer patients with the following endeavors. The Catastrophic Illness in Children Relief Fund (CICRF) is a key resource for providing limited financial assistance to families with children who have medical needs beyond what is covered by their health insurance plan. Another effort by the Commonwealth for terminally ill children was the 2004 Guidelines for school doctors and nurses, issued by the MDPH, “for the care of students with comfort care/do not resuscitate orders.” This document provides guidance for schools to enable children to continue to attend and stay in contact with their support and social networks.

An assessment of programs and services that addressed pediatric end of life issues was conducted at MDPH. Key MDPH stakeholders involved with programs and services addressing needs of children with life threatening illnesses were invited to a discussion group on January 31, 2005 to discuss the types and scope of activity around end of life care for children. Key issues identified were the following:

- Addressing end of life issues from a life-span perspective is essential.
- Discussing end of life issues and losses related to children is very difficult.
- Care Coordinators are key people in helping families address end of life issues with children. They work with the family and the child with a life-threatening illness to determine needed supports. They are involved with out of hospital “Do Not Resuscitate” (DNR) orders and working with EMS, especially if parents are not at home.
- The CICRF plays an important role in funding services such as respite care, funeral expenses and transportation—assistance for a range of services that could reduce suffering and improve the quality of a child’s life.
- Children with DNR or “Comfort Care” Orders in School Setting.
- Medical Review Team is a resource for families with children with life-threatening illnesses.

As a result of the needs assessment and the identification of end of life issues from a life-span perspective, two strategies were included in the Comprehensive Cancer Grant addressing end of life support and needs of children. A resource guide has been made available online.²⁴

Youth Transition

NSCSHCN percentages applied to the 2000 Census indicate that approximately 61,482 youth aged 14 to 17 in Massachusetts may need transition supports; the Massachusetts BRFSS suggests that over 39,400 18-21 year-olds have a disability.

Compared with other NSCSHCN-measured outcomes, youth transition stands out as a deficit, and it has been chosen as an MCH priority need in Massachusetts. Successful transition is also related to each of the other MCH outcomes. For example, adequate public and/or private health insurance as YSHCN get older and enter adulthood may become an issue. At 25%, rates of uninsurance by age are highest among Massachusetts young adults ages 19 to 24, with and without SHCN. Training, information and referral are needed for 18 year-olds to apply to SSI. SSI Work Incentives help SSI recipients obtain or retain public health coverage while working, yet they are not widely known or understood.

Documented disparities between youth and young adults with and without disabilities are substantial. Massachusetts data mirror national findings as reflected in Healthy People 2010, Chapter 6: Disability and Secondary.²⁵ BRFSS data indicate that adults with disabilities in Massachusetts are significantly less educated, less likely to be employed, more likely to be out of the workforce, and more likely to have lower average household incomes than those without disabilities. According to the NSCSHCN, only 20% of YSHCN in Massachusetts were receiving training for an adult job.

Adults with disabilities are also less likely to report exercise and more likely to smoke, be obese, and report poor quality of life, physical and mental health than peers without disabilities.^{26 27 28 29} Disparities by disability status hold across race and ethnic groups, but among Massachusetts residents with disabilities, blacks and Hispanics report significantly lower levels of education, lower incomes, more health risks, less adequate insurance, and worse health status than whites.³⁰

These differences emerge by adolescence. Massachusetts Youth Health Survey 2002 and 2004 data show elevated smoking, risky weight loss strategies, and certain other behavioral risks among in-school youth with chronic illnesses and disabilities compared to their peers. For information about experience of violence and suicide, see Figure 2D4.4, in Section IIB: 2D. Young adults with disabilities aged 18-24 are significantly more likely to report 15 or more days sad, blue, or depressed in the past month, 15 or more days worried, tense, and anxious, and 15 or more days of poor mental health compared with peers without disability.³¹

To affect global transition outcomes, health professionals can help YSHCN understand how their health conditions or disabilities affect employment or post-secondary education, identify accommodations, and facilitate development of communication skills needed to obtain accommodations.³² They can also teach primary and secondary prevention strategies to promote optimal health and social participation.

The Massachusetts Consortium for CSHCN's Transition Task Force developed a *Background Brief* (2004) that summarizes needs, the current organization of services, strengths, and recommends next steps related to transition. It notes the insufficiency and fragmentation of transition-related initiatives. Even when provided federal entitlements, not all families receive the help needed. In Massachusetts, a law known as Chapter 688, often referred to as the state's "Turning 22 Law," provides an additional set of

protections and services to some of students with the most significant disabilities who will need assistance from state agencies after age 21. Services are, however, subject to appropriation. Many families report difficulties because of lack of funding and also with determination of the lead agency responsible. In addition, many youth with SHCN have needs that, while significant, do not meet the criteria for a state agency.³³ Family focus group members noted issues with compliance with special education plans.

Youth transition needs vary by individual. Substantial challenges exist for youth with extremely complex conditions. Young adults who require fewer or periodic supports to maximize their autonomy are much less likely to receive state agency supports. Each youth requires an individual assessment and plan.³⁴ At a presentation of data to a Central Massachusetts parent and provider group, a pediatrician working with adolescents with HIV provided an example. Of youth with whom she works, for example, some are healthy and very high performing in school. They have never been in special education. Others have accompanying behavioral and mental health issues. This group's transition needs are quite various. Compared with other youth with special health needs, they have an additional issue of determining when and to whom to disclose their HIV status.

The *Brief* also notes that “transition services” is itself a confusing term. The term implies a large, complex set of activities and planning. It also means different things to different people at different times. Because “transition services” for YSHCN is not a concrete set of activities and because there is no single system (e.g., health, education, social services) responsible for addressing transition needs, approaches for optimizing transition to adulthood remain elusive and confusing.³⁵

MCH needs assessment focus groups with parents discussed transition, and additional groups were held with youth with disabilities. Parents had a range of responses to transition issues. For some with young children, the topic was nearly taboo because they were not convinced their children would live to adolescence, let alone adulthood. Others were already fearful because their main support is special education. Still others had not begun to think about the issue; for some, hearing from other parents with older adolescents during the focus group led them to say they were just realizing they needed to begin to plan while their children were still very young. Several parents had begun to plan with their pediatricians for medical transition. Parents felt that little assistance was available, although some had received training through the Federation for Children with Special Health Needs. Of parents surveyed for the needs assessment, 28 had children under age 13 and 15 were interested in learning about transition. Of 20 parents with children over age 13, 3 had received information about education or job transition and only 1 said her doctor had mentioned transition to the adult care system. Sixteen of these parents were interested in further information.

Focus groups with youth and young adults with disabilities from ages 12 to 25 included questions about the degree to which youth were beginning to take responsibility for their own health care and the extent to which they thought about their own health. In general, youth were concerned with their own health as well as the health of their family members. Most saw themselves as being fairly healthy. They had ideas about maintaining their health, especially related to nutrition and physical activity. Among older youth, some were responsible for health self-management but more generally shared responsibility with parents or accede responsibility to parents. Some youth

expressed a desire for more independence in this area. They articulated the view that doctors should show respect for both youth and parents, and that good health care involved both listening and explaining.

At a meeting in 2005 of the Massachusetts Partnership on Transition (M-TAB) advisory board focused on needs assessment, young adults with disabilities and parents listed key concerns about transition. One was finding adult medical providers who know enough about pediatric onset or inborn conditions. The adult medical world does not seem fully equipped to welcome them, both in terms of medical knowledge and sensitivity to disability. A similar concern relates to education: Participants noted that, if a young person aspires to education beyond secondary school, there is no system in place to assist them with finding an appropriate school. Nor is there funding available for programs that develop skills and independence. There is consensus that transportation is a significant problem and barrier to independence. Access to personal supports and assistance, as well as information, are key. While material needs were noted, addressing attitudinal barriers and the importance of social and emotional supports to youth and families was also considered critical.

Among the actions planned to respond to the youth transition priority are the following:

- Curriculum development and implementation of “transition training” for care coordinators/case managers and parent-professionals from a variety of agencies and organizations statewide. Since these staff already work with youth and families, the training is to give them tools to increase their effectiveness in this area.
- Systematic transition planning and increased MDPH Care Coordination program activities in this area.
- Development of a Youth Advisory Council for MDPH and the Massachusetts Consortium on ongoing services and supports related to transition to the adult health care system, work and independent living.

2E.4 Conditions Related to Special Health Needs

Massachusetts monitors and develops interventions for childhood conditions such as asthma, that are high in prevalence, or such as autism and diabetes, whose rates may be increasing either due to increases in prevalence or changing definitions and surveillance methods. Massachusetts information about these and selected other conditions of long-standing MCH interest that may result in special health care needs is presented in this section.

Asthma

Asthma is one of the more prevalent health conditions among children. Proper management, including personalized medical care that educates the child, parents, teachers, and extended family about symptoms and the use of medications, can virtually eliminate hospitalizations and deaths and dramatically improve the child’s quality of life.

Prevalence

The Massachusetts BRFSS asks respondents about current asthma among children in their household. Based on preliminary 2004 BRFSS data, 10.1 of children younger than 18 had asthma. Prevalence rates increased with age among these children. Current

asthma among children younger than 5 years old was 6.8%, 11.2% for children 5-9 years old, and 10.5% for 10-14 year-olds, and 13.2% for 15-17 year-olds. Children living in a home with a household income less than \$25,000/year were twice as likely to have asthma as children living in a household with an income greater than \$75,000 per year (14.4% vs. 7.6%).³⁶

Asthma is the most prevalent chronic disease reported by youth on the 2004 MYHS at 19.6% among middle and 22.4% among high school students. These data were self-reported, and suggest extremely high prevalence rates among teens, but are not unlike findings from other states.

Data from a 2004 MDPH Environmental Health Tracking Grant survey about children 5-14 years old (grades K-8) provided a more conservative estimate. The lifetime prevalence of asthma among these children was 9.5%. These data were collected by school health nurses, who relied on school health records, parental reports, and prescription information.

Of medications administered by school nurses through the Essential School Health Program in 2004, asthma medications were the most common prescriptions taken on a “PRN” or “as needed” basis. The PRN prescription rate in 2004 was 30.2 per 1,000 students. There were 4,497 peak flow monitoring procedures and 1,604 nebulizer treatments per month among the 551,184 students in participating districts. Asthma was a major concern school nurses raised during the MCH needs assessment process.

Hospitalizations, Emergency Visits, and Deaths

In 2003, there were 3,205 hospitalizations for respiratory asthma and 6,843 asthma-related hospitalizations among Massachusetts children under age 20. Rates were 191.34 and 408.52 per 100,000, for asthma and asthma-related, respectively, among this group. Males were more likely to be hospitalized for asthma than females (225.17 vs. 155.99 per 100,000). When stratified by age, rates were highest among children under 5 years old for asthma (411.83 for 0 to 4 year olds; 146.97 for 5 to 14 year olds; 72.64 for 15 through 19 Years). Children under 5 also have the highest rate of asthma-related hospitalizations: 662.80.

Race was a risk factor at every age, with blacks and Hispanics always carrying the highest risk. Among black children age 4 and under, rates were 957.21 and 1,415.01, respectively, for asthma and asthma-related hospitalization; for Hispanic children, rates were 675.38 and 1,221.90, respectively. Whites and Asians had the lowest rates.

Based on preliminary 2003 Emergency Department (ED) data, there were a total of 13,899 ED visits among children younger than 20 years old with asthma as the primary cause and 7,257 with asthma as contributing cause (842.4 and 439.8 per 100,000, respectively). For ED visits, 0-4 year olds had a rate of 1,288.70 per 100,000, the highest of any age group. They also had the highest rate of ED visits with asthma as a contributing cause (587.4). Males were more likely to go to the ED for asthma than females (966.1 vs. 712.4 per 100,000).

Race was also a risk factor at every age. Among black children younger than 4 years old, rates were 3,525.0 and 1,066.3, respectively, for asthma as primary and as contributing cause. Among Hispanic children younger than 5 year old, these rates were 2,684.8 and 1,129.0.

While the total number of deaths from asthma for all ages and the age-adjusted death rates have remained relatively unchanged over the last decade in Massachusetts,

there is evidence that the age-specific rates for children are rising. Between 1992-2002, there were a total of 177 asthma deaths (underlying cause and contributing cause combined) in Massachusetts. Almost one-fourth of these fatalities (42 deaths) were children younger than 19 years of age. Gender, ethnicity, and age were all risk factors. Approximately 60% of these fatalities were among boys and 52% were nonwhite ethnic minorities. The highest rates were among children 15-17 years old and children younger than 5 years old. In 2003, there were 4 deaths from asthma among children under age 20.

Autism Spectrum Disorder (ASD)

Autism is a lifelong disability, coupled with mental retardation or other brain structure issues in about 70% of cases. Symptoms, including inability to communicate, emotional unresponsiveness, and self-destructive behavior, may be mild to extremely severe and affect the entire family.

According to the Center for Disease Control (CDC), there is not an exact incidence rate of ASD in the United States; however, the CDC conducted an epidemiological study in Brick Township, NJ and found a prevalence of as many as 4.0 per 1,000 (1 per 250) children with autistic disorder and 6.7 per 1,000 (1 in 150) children on the autism spectrum.³⁷ Most recent studies from leading research institutions concur with a rate of 1 in 150 children are currently diagnosed on the spectrum.³⁸ In Massachusetts, this rate translates to an estimated 10,000 children under age 18 with ASD.

During FY 2004, 775 children received ASD specialty providers through the Early Intervention (EI) program out of roughly 29,000 in the overall program. On a program basis this indicates a prevalence rate of 1 per 38 EI enrollees, or 800 children under age 3 with autism in the state. Preliminary numbers from the MDPH Bureau of Environmental Health Assessment (BEHA) based on Department of Education records suggest the prevalence of autism spectrum disorders is at least 45 per 10,000 children aged 3 to 21, or 1 in 222 children.

The Department of Mental Retardation (DMR) is developing a new division for autism services. The MDPH CSHCN program has been working with DMR on the development of this statewide program. DMR conducted an intensive environmental assessment this year concerning autism services including over 200 families in focus groups and 120 by survey, DMR staff, providers, Autism Support Centers, advocacy groups, other state agencies, and academic and clinical experts on autism. The environmental assessment highlighted needs for:

- family support resources to help bring stability home, including case management supports, access to respite providers who are trained to work with children on the spectrum, and contacts to available therapists.
- financial assistance because private insurers do not cover services related to their child's autism diagnosis and the burden falls on the family when they need additional supports outside those covered by their school district.
- a better coordinated system of care within the state agencies, especially around transitions from one program to another.
- pediatricians to be more informed about the early signs of developmental delays, thereby allowing families early access to proper support services.

- First Responders (police, fire and EMTs) to become adequately equipped to deal with the children's behavior during a crisis.
- recreational and after-school programs, with staff trained to work with children on the spectrum.³⁹

MCH needs assessment focus group participants whose children had ASD had similar concerns and added the following, particularly related to MCH goals:

- difficulties obtaining a diagnosis.
- difficulties obtaining primary and non-autism related medical care (for example, setting a broken bone) because of the extra time required (with no extra reimbursement) and discomfort physicians have with their children's communication and other behaviors.
- obtaining the high level of behavior modification and speech therapy children require, which is substantially more than is supported by schools and is not necessarily delivered by the types of clinicians covered by insurance.
- limited knowledge of how best to work with children with ASD, particularly given substantial variation by individual child in "what works."
- continuous uncertainty (called "the monster in the closet") about the near future and about transition to adulthood.
- lack of ongoing training (post-EI) of family members so that they could better work with their children (for example, supplement speech therapy).

Birth Defects

Birth defects include a wide range of abnormalities that can have very different consequences for a child's health. Some are life threatening, while others are less severe and preventable by prenatal medical intervention or correctable after birth. Many birth defects can cause a range of disabilities, both mental and physical.

The Massachusetts Birth Defects Monitoring Program

The Massachusetts Center for Birth Defects Research and Prevention conducts population-based active surveillance throughout the state and participates in the National Birth Defects Prevention Study. The primary focus of the program is the identification of major structural birth defects, with or without a chromosomal abnormality, and non-chromosomal malformation syndromes.

The Center uses multiple sources of ascertainment. Birth and tertiary care hospitals in Massachusetts routinely submit discharge lists and nursery data on infants born with birth defects. Two Rhode Island hospitals that deliver Massachusetts residents and Massachusetts Eye and Ear Infirmary are also included. Fetal death reports and infant death certificates are reviewed. Birth certificates are checked for additional information such as residency of the mother. Potential birth defects cases, reported from these varied sources, are assigned to medical record abstractors who review medical records of potential cases.

Birth Defects in Massachusetts 2000-2001⁴⁰

- The overall prevalence of birth defects among births to Massachusetts residents in 2000-2001 was 140.47 per 10,000 live births.
- The most common defects were cardiovascular defects including Patent Ductus Arteriosus, Septal (Atrial and Ventricular) Defects and Tetralogy of Fallot. Other

common non-cardiovascular defects included Cleft Lip, Cleft Palate, Hypospadias, and Obstructive Genitourinary Defects.

- Overall, 1.4% of births in the state had one or more birth defects. Among the 162,596 live births to Massachusetts residents in 2000-2001, 2,224 had one or more birth defects. In addition, 60 stillbirths were identified as having a birth defect.
- Of all 2,284 birth defect cases (infants and stillborns), 62.5% had a single defect and 37.5% had multiple defects.
- The birth defect prevalence rate was 135.19 for singletons and 255.91 for multiple births (more than one infant) per 10,000 live births. The number of multiple births is increasing with the use of IVF technologies.
- Birth defects that more commonly occurred in multiple births included Pulmonary Stenosis (Valvular), Rectal and Large Intestine Atresia, Esophageal Atresia/Tracheoesophageal Fistula, Septal Defects (Atrial and Ventricular), Hypospadias, and Lower Limb Reduction Defects.
- The birth defect prevalence rate was 119.83 for females and 160.32 for males per 10,000 live births.
- The prevalence of birth defects varied by maternal age group. For live births only, rates per 10,000 live births were 152.12 for mothers younger than 20 years, 135.87 for those 20-24 years, 130.24 for those 25-29 years, 126.53 for those 30-34 years, and 155.57 for those 35 years and older. Monitoring birth defects by maternal age is important since the number of births to older mothers has been increasing over time in Massachusetts.
- There was a strong association of Down Syndrome with advanced maternal age. Women 35 years and older had a live birth Down Syndrome rate of 26.73 per 10,000 births. This rate was three times that of any other maternal age group.
- Younger mothers (age 19 and under) had the highest rate (16.26%) of Gastroschisis. This association has been shown in previous studies.
- Nearly three percent of cases with birth defects were classified as “severe” and most did not survive.
- About 19% of cases were affected with a “serious” birth defect. These defects may be correctable but most of these children will have long term needs.
- “Moderately severe” birth defects comprised 71% of the total cases; all of these needed medical follow up; many may have required a number of surgeries and extensive treatment.
- “Mild” birth defects comprised nearly 8% of the affected infants. These defects may or may not have required corrective treatment. These children will have minimal long term needs.

Diabetes

There is limited data on the prevalence of diabetes in Massachusetts. Self-reports from the 2004 MYHS indicate that 1.7% of Massachusetts middle school children have Type 1 diabetes and 1.4% have Type 2 diabetes. Among high school children, the prevalence of both types of diabetes were higher (2.4% for Type 1 and 2.1% for Type 2). National studies suggest anywhere from 8% to 45% of children newly diagnosed with diabetes have Type 2.⁴¹

The 103 districts that participate in the ESHS program report that blood glucose testing was the most common procedure school nurses performed, at a rate of 38.8 procedures per 1,000 students each month. The prescription rate for daily insulin administration has risen from 0.2 per 1,000 students in 2000-2001 to 0.6 in 2003-2004 (likely an underestimate given that daily administration may not be nurse administered) and from 0.5 to 1.2 per 1,000 students for as-needed administration.

Fetal Alcohol Spectrum Disorders (FASD)

The CSHCN program has been working with the Bureau of Substance Abuse Services on FASD. FASD encompass four conditions including a range of physical, mental, behavioral effects and/or learning disability that can occur in an individual whose mother drank alcohol during pregnancy. FASD may have lifelong effects, impacting the three MCH populations. The four conditions are: fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

FAS and FASD are not genetic and are found in all racial and socio-economic groups. The Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that FASD occurs in about 10 per 1,000 live births each year. FAS affects somewhere between .5 and 2 live births per 1,000. While SAMHSA further estimates the cost to the Nation at \$4 billion annually, the National Organization for Fetal Alcohol Syndrome (NOFAS) projects the cost in 2003 at \$5.4 billion, noting over \$1 billion in indirect costs, such as productivity loss.⁴²

Based on the BRFSS (1999, 2001-2003), which appears to underestimate alcohol consumption, 16.5% of Massachusetts women aged 18-44 report binge drinking and 7.1% heavy drinking in the past month. Among currently pregnant women, 3.4% report binge drinking and 16.2% drinking any alcohol in the past month.

Perinatal and CSHCN staff are working with the Bureau of Substance Abuse to develop an integrated plan to further understand the extent of the problem in Massachusetts and to enhance current program activities to prevent and address the need.

Lead Poisoning

Over the last decade, there was a decrease in the prevalence of both lead poisoning (blood lead levels [BLL] of 25 mcg/dL or above) and elevated lead levels (BLL of 20-24 mcg/dL) among children ages 6 months to 6 years. The combined statewide incidence of levels greater than or equal to 20 mcg/dL fell to 2 per 1,000 screened in 1999 and to only 1 per 1,000 screened in 2004. The 5-year average rate per 1,000 screened for the period 1999 – 2004 is 1.3. A disproportionate share of all cases of lead poisoning and elevated lead levels continue to occur in the Boston MDPH Region (Boston, Brookline, Chelsea, Revere, and Winthrop). This region has only 10% of the

population under age 5 but had 17.2% of all cases in 2004. The primarily suburban Metro West region, with 23% of the under 5 population, has only 16.5% of the cases. These regional disparities are decreasing.

The Massachusetts Childhood Lead Poisoning Prevention Program (MACLPPP) provides a range of primary and secondary programs. The Childhood Lead Poisoning Prevention Program (CLPPP) within the MDPH Bureau of Environmental Health Assessment (BEHA) is responsible for administering the statewide population-based lead screening and follow-up services. The goal of the CLPPP is not only to identify lead-poisoned children, but also to ensure that they receive adequate medical and environmental services, and prevent further cases of lead poisoning. The surveillance data is then compiled to allow the CLPPP to monitor the effectiveness of its programs and better direct resources to areas of greatest concern.

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2F. State Maternal and Child Health Capacity

The national and Massachusetts Maternal and Child Health Programs assess capacity to meet the needs of the MCH population on three levels:

1. *Direct and enabling services*, which include one-on-one patient care, medical services, and such services as provide access like insurance, outreach and other supports that help people utilize available care;
2. *Population-based services*, which are preventive and personal health services developed for a whole population, such as screenings of all newborns and educational materials for the general public; and
3. *Infrastructure-building services*, which are the foundation for MCH activities such as the state legislative and regulatory framework for MCH, partnerships to improve comprehensive systems of care, and information systems. Massachusetts capacity in each of these areas is described in the remainder of Section 2F.

2F1. Direct and Enabling Services

The Massachusetts Title V program is actively engaged on the state, regional, CHNA and local community levels in assuring access to and availability of direct and enabling health care services for the MCH population. Health care and insurance reform is currently on the agenda for the Governor and Legislature in Massachusetts, with Title V at the table. Massachusetts also has a wide array of Title V and collaborating programs within the Center for Community Health, other MDPH Centers, other state agencies, and community-based organizations that support the MCH population.

2F1.1 Financial access

Health Care and Health Insurance Reform Efforts

Massachusetts has been a leader in health care reform and is currently actively involved in developing strategies to expand coverage to the projected 460,000 uninsured. The current system provides access to health care across the state, with the highest quality ratings in the nation. The state has a strong network of high quality, not-for-profit hospital and community-based safety net services for the poor and disabled, as well as a generous culture of employer and public subsidized coverage. Thus the state has a low uninsured rate of 7%. The state has made a large commitment to supporting care for the uninsured primarily through the state's Uncompensated Care pool.

Nevertheless, several issues exist that challenge the current and future systems if they are not addressed. Health care costs are growing at unsustainable rates with state health care cost increases, primarily Medicaid crowding out other basic services. The cost of care for the uninsured is estimated to be more than \$1 billion annually and must be recognized as everyone's problem. The regulatory environment has limited insurer innovation and there is a lack of transparency of both price and quality.

As in other states, the Massachusetts health delivery system has been impacted by many competing and related factors over the last decade. In its 2003 release, *Massachusetts Health Care Trends: 1990-2001*, the Massachusetts Division of Health

Care Finance and Policy addressed six major paradigm shifts that have had and continue to have implications for services to infants, children, youth, and pregnant women:

State-initiated Increases in Access to Health Services: Interlocking state laws and programs have decreased the number of uninsured through Medicaid expansion, small group and individual insurance reform, and the Children's Health Insurance Program (CHIP). Massachusetts ranks 4th in the nation for health insurance coverage with just under 7% of the population uninsured in 2005.

Dilution of HMO Networks: Massachusetts HMOs started the decade with tightly controlled exclusive provider networks and lower premium costs to purchasers. It ended it with nearly identical universal panels of providers, under pressure from consumers for greater choice, that left HMOs with deep discounts for volume and shrinking fiscal margins.

Health Care Role Blurring: Clear distinctions among providers, insurers, payers, purchasers and patients have become blurred as doctors began to share financial risks with insurers, insurers became providers who employed doctors and owned hospitals, employers became self-insured, and Medicaid moved from payer to purchaser as it expanded managed care, etc.

Changing Health Services Cosmology: Health care became less centralized around hospitals as managed care, enabled by technology and pharmaceuticals, reduced hospitalizations and inpatient days dramatically over the decade. This created a bulge in home health care and prescription drug use as well as a more fragmented health care landscape, presenting challenges to both professionals and patients.

Swings in Regulation. The decade saw a shift away from strict rate-setting to calls for a return to state involvement by patient advocates and industry experts. The cause of this is the dismal fiscal condition of many Massachusetts hospitals, nursing homes, and community health centers as well as lack of oversight over provider closings, sales of institutions to for-profits, medical errors, etc.

Increased Consumerism: The long-standing paternalistic patient-physician relationship has been challenged as patients become clients and consumers and more information and options become available.¹

In response to these issues, the Governor is proposing a health care reform initiative that is a "comprehensive, market-based program that will focus on controlling health care costs and increasing access." The plan has four main elements:

- Increased Medicaid enrollments (106,000 persons)
- Affordable health insurance premium for individuals and small business through a new Commonwealth Care program for those with incomes up to 300% FPL (204,000 persons)
- Safety Net Care managed care plan for those with incomes between 100-300% FPL to replace the Uncompensated Care Pool (150,000 persons)
- Transitional coverage to new employees and the short-term unemployed (36,000 persons)

In addition, two proposals have been put forth in the Massachusetts Legislature:

- S. 755, An Act to Establish the Massachusetts Health Care Trust, seeks to establish a single payer health insurance system that insures everyone in the state equally through a single pool of public and private funds.²

- S. 738 and H. 2777, The Health Access and Affordability Act, seeks to restore and expand MassHealth coverage, requires employers to provide health coverage or pay a fee to the state, provide assistance to individuals and small businesses, increase payments to MassHealth providers, and promote state leadership on health care quality and cost.³

It is expected that the discussion related to expanding access to health care coverage will continue over the next year. There are many building blocks in place which can be built off of and the momentum is growing. Expansion of coverage will greatly benefit both children and families.

The Uninsured in Massachusetts

To propose a solution, we must understand who the uninsured are in Massachusetts. According to the Health Insurance Status of Massachusetts Residents, 4th Edition,⁴ estimates for insurance status by age and gender for non-elderly residents in 2004 were:

Table 2F1.1 Insurance Status By Age and Gender, MA 2004			
Age	Uninsured		Insured
0-18	11.9%	54,740	32.6%
19-39	49.9%	229,540	27.4%
40-64	<u>38.2%</u>	<u>175,720</u>	<u>40.0%</u>
	100%	460,000	100%
Male	56.4%		47.8%
Female	43.6%		52.2%
	100%		100%

Of the 460,000 uninsured, this study indicates that 11.9% of the uninsured were children (0-18) in 2004, remaining at 3.2% of the total population statewide as was the case in 2002, an improvement from 4.5% in 1998. Uninsured children were less likely (62%) to have visited a physician in 2004 than insured children (91%). Uninsured and insured children were likely to not visit an emergency room at similar rates (71-77%). Women were less likely to be uninsured than men in 2004, 44% compared with 56% of the uninsured. Hispanics tended to have the highest rate of uninsurance, followed by blacks and Asians, correlating with unemployment status in 2002.⁵

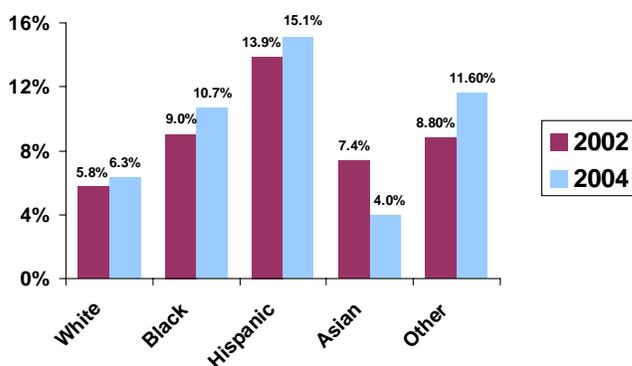
The uninsured, based on information developed for the Governor's Health Reform initiative, are not a homogenous group, but they are likely to:

- Be employed, and to be employed full-time
- Have been born in the US
- Be single
- Be white
- Be between 25 and 64
- Have at least a high school education
- Have moderate incomes and reportedly willing to pay for health insurance

- Be living in Boston or north/south of Boston
- Be healthier⁶

At the same time, as a proportion of their respective populations, those without insurance look quite different from the above. Although 68.5% of the uninsured were white, a higher proportion of minority individuals were likely to be uninsured, with 10.7% of blacks and 15.1% of Hispanics uninsured in 2004 compared to 6.3% of whites.

Figure 2F1.1 Uninsured Rates by Race/Ethnicity (2002-2004)

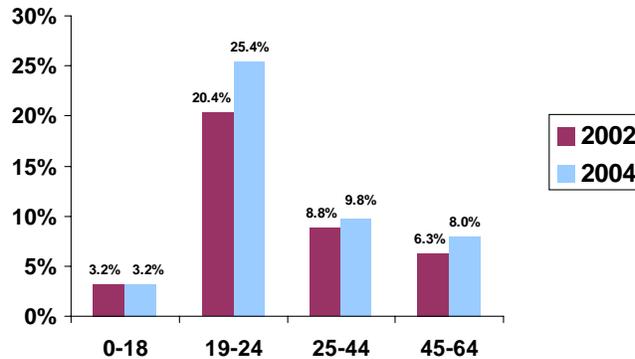


- Uninsured rates vary by race/ethnicity, with blacks and Hispanics more likely to be uninsured than whites. No significant differences were found between 2002 and 2004.

Source: MA Governor’s Presentation, The Uninsured in Massachusetts, September 9, 2004

Although older adults age 25 and older are the majority of the uninsured, the highest proportion is in the transitioning young adult population aged 19 to 24, of whom 25.4% are uninsured in 2004.

Figure 2F1.2 Uninsured Rates by Age (2002-2004)

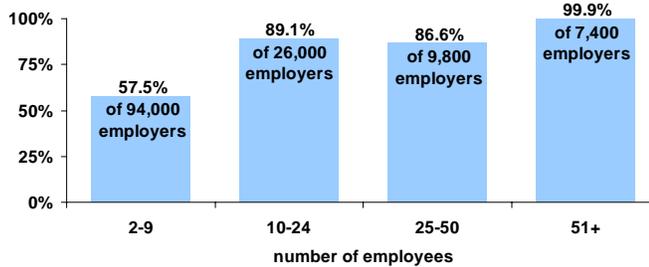


- Younger adults have higher uninsured rates.
- Health insurance coverage for children remains good. There was no change in the uninsured rate for children between 2000 and 2004.

Source: MA Governor's Presentation, The Uninsured in Massachusetts, September 9, 2004

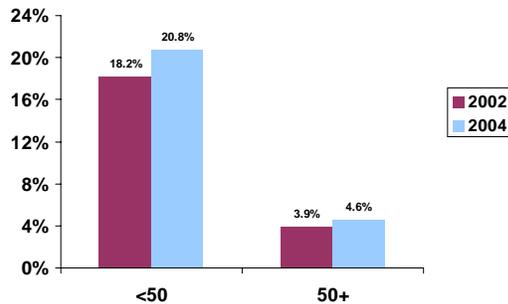
Although a larger percentage of the uninsured were in the higher income categories, the proportion of lower income persons who are uninsured was higher. The northeastern part of Massachusetts had the highest proportion of uninsured residents, at 12.1%. Rates of uninsurance were much higher for those without a high school degree and the lowest for those with a college degree; and they were lowest for those working full-time jobs. Of persons working less than 20 hours a week, 25.4 were uninsured compared with 6.8% of those working 35 or more hours a week. People working for small firms were more likely to be uninsured than those working for larger firms.

Figure 2F1.3 Percent of Employers Who Offer Health Insurance, by Size (2003)



Source: MA Governor's Presentation, The Uninsured in Massachusetts, September 9, 2004

Figure 2F1.4 Uninsured Rates by Size of Firm (2002-2004)



- People working for small firms are more likely to be uninsured than those working for larger firms.
- Increases in uninsured rates were found for both large and small firms from 2002 to 2004.

Source: MA Governor's Presentation, The Uninsured in Massachusetts, September 9, 2004

Of the 168,000 who could afford insurance but elected not to purchase it, 100% had household incomes about 300% of the federal poverty level (FPL) with 60% earning more than 400% FPL.

The administration has identified the 460,000 uninsured individuals as fitting into 4 groups:

Medicaid eligible but un-enrolled	106,000
Those who can afford insurance, but don't buy it	168,000

Short-term unemployed and new employees 36,000
Eligible for Uncompensated Care Pool – Safety Net Care 150,000

The Governor’s Health Reform Proposal addresses all four groups of uninsured, as well as the issues raised by a new 3-year Medicaid waiver extension.

Insurance Coverage

The Commonwealth estimates that currently 93% of the population is insured either through employer, individual, Medicare, Medicaid or another public source. A study by the Urban Institute using Current Population Survey demographics for the Blue Cross and Blue Shield of Massachusetts Foundation entitled “Roadmap to Coverage” for the years 2002-2003 states that 71% of children below 200% FPL are insured by MassHealth and 86% of children above 200% FPL are covered by their parents’ employee insurance.⁷ Massachusetts has one of the highest penetrations of managed care in the nation. The market continues to be dominated by locally based, not-for-profit organizations (there is one locally based for-profit health plan in the state), and these health plans consistently rank highly in national consumer satisfaction ratings and on HEDIS measurements.

The health plans, especially HMO-like plans, in Massachusetts (as well as throughout the country) have come under increasing pressure to expand services and reduce restrictions. Consumers and employers have demanded a broader choice of doctors and hospitals, resulting in a move away from tightly managed health benefit products, increased PPO and POS product offerings, and reduction in the number of procedures requiring prior authorizations. Consolidation among hospitals and physician groups has increased their bargaining clout. The Legislature also enacted laws mandating coverage of specific types of services and new measures for regulating health plans. These changes combined with the aging of the population, the accelerating introduction and use of new drugs and medical technologies, has led to higher health care costs.

In response to the rising cost of health care and employers’ desire for more choice in how they control their health care costs, health plans have continued to modify the insurance products available. This has included significant increases in deductibles and co-pays as well as tiered deductibles based on the site of care. Consumer-driven plans are currently being offered by more and more employers. Pediatricians have expressed concern that the consumer-driven plans may result in families delaying care, electing to not have follow-up care or make a choice on price only.

To protect patients and providers, the Patient Bill of Rights in the Managed Care Reform Act (Chapter 141) of 2000 was enacted. This is a comprehensive patient protection law that put medical decision-making firmly in the hands of doctors and their patients. The law provides consumers important rights when dealing with their health plans, including the ability to seek a binding, independent review of coverage disputes involving questions of medical necessity. The solvency laws of Chapter 141 in the Acts of 2003 established minimum net worth and risk-based capital requirements consistent with national standards for health plans.

Medicaid and SCHIP

MassHealth, as the state Medicaid program is known, provides comprehensive services through Medicaid, SCHIP, Children’s Medical Security Plan and

CommonHealth. Two public health programs, Children’s Medical Security Plan and Healthy Start, which provide insurance coverage for pregnant women and children not eligible for Medicaid, were transferred at the start of FY 2005 to the Office of Acute and Ambulatory Care to be integrated with Medicaid and SCHIP. The Health Access component at MDPH was eliminated.

Currently 985,000 individuals are enrolled in MassHealth. Of this number, 416,500 are children up to the age of 18. With the increased FY 2005 funding for CMSP, the waitlist for CMSP disappeared, and as of June 2005 the number of children on CMSP was 30,217. Detailed information for the Healthy Start population is no longer available with integration into the SCHIP program. Medicaid was the source of the prenatal care payment for almost 23% of 2003 births.⁸

With identification of approximately 106,000 individuals as Medicaid eligible but unenrolled, steps are underway to increase outreach and facilitate enrollment of all who are eligible. It is projected that 40,000 will be enrolled by the end of FY 2005. The newly renewed Medicaid 1115 Waiver expands coverage to some selected special populations within the existing Medicaid populations and allows the state to establish a new program referred to as Safety Net Care. This program would provide coverage to eligible uninsured individuals within certain FPLs. Currently, multiple options are being considered to redesign the health care delivery system for MassHealth managed care members and other publicly assisted populations such as Safety Net Care.

MassHealth began moving toward managed care in 1991 with its first HCFA 1915b waiver and continued to expand this system with its 1115 waiver and SCHIP. Most children and pregnant women covered by MassHealth, including SSI recipients, were enrolled in a managed care program by 1998 with the exceptions of CommonHealth, for which managed care enrollment is optional, the MassHealth Family Premium Assistance Program (MHFPAP), and children and youth in state custody. A total of 603,373 or 62% of all 985,000 Massachusetts MassHealth enrollees are currently in managed care plans.⁹

The Medicaid managed care program is very well integrated into the overall health care delivery system through two different managed care program types: a Primary Care Clinician (PCC) Program and a Managed Care Organization (MCO). The years 2000-05 saw a dramatic shift away from PCC plans to MCO plans. Of the 985,000 enrolled in MassHealth, including SCHIP (568,900 adults and 416,500 children), 603,373 were in MassHealth managed care plans in 2005:¹⁰

Table 2F1.2
Changes in PCC and MCO Enrollment

	<u>2000</u>	<u>2005</u>
MCO	146,059	323,470
PCC	<u>437,265</u>	<u>279,903</u>
	583,324	603,373

Managed care enrollment in PCC plans shifted from 437,265 or 75% of all managed care recipients in 2000 to 279,903 or 46% of recipients in 2005. There were 1,128 participating medical sites, including 516 individual physicians, 529 group practices, 42 community health centers, and 38 hospital OPDs. Medical providers caring

for patients enrolled in the PCC program are reimbursed on a fee-for-service basis with an add-on case management fee for gate-keeping responsibilities. Medicaid contracts with 4 MCOs to provide services on a capitated risk basis while the MCOs contract with a provider network to offer their members services statewide. The four Massachusetts MCOs saw a dramatic increase in MassHealth managed care membership, shifting up from 146,059 members in 2000 to 323,470 members in 2005 for a gain of 177,411 new members.

In February, 2005, the Commonwealth received a 3-year renewal of the 1115 waiver. The terms of this waiver extension are compatible with the Governor's health reform proposal. The major changes will be phased in over the next year. These changes include:

- Capping as of 7/1/05 the MCO supplemental payments and leaving the disproportionate share hospital (DSH) cap at the current annual allotment.
- No longer using intergovernmental transfers (IGT's), as of 7/1/05, for hospital rate supplements to finance the 50% "non-federal" share.
- Establishing as of 7/1/05 a Safety Net Care Pool (SNCP) to provide health care services to uninsured and to cover "unreimbursed Medicaid costs;" 10% may be used to "improve health care delivery to SNCP populations."
- For FY 2006, continuing to make supplemental payments to and using IGT's to access federal matching funds.
- Terminating supplemental payments to Boston and Cambridge MCO's and IGT's as of 7/01/06.
- Phasing out, as of 7/1/06, expanded federal match for services provided in Institutions for Mental Disease.

These changes end the use of the existing IGT mechanism and signal a return to a more traditional Medicaid funding process. They will permit a transition to "Certified Public Expenditures." The changes have the potential to dramatically affect the existing safety net providers as well as two MCO's. The waiver allows more flexibility for a range of possible approaches especially for the Safety Net Care Pool. It is anticipated that over the next few months the Safety Net Care Pool Program design will be finalized. Services for mothers and children will be a key part of any solutions that are identified. Title V will stay at the table and be active in the design of the program as well as developing the implementation plan so as not to disrupt current services and decrease access.

2F1.2 Availability of Prevention and Primary Care Services and Specialty Care

Preventive and primary care services in Massachusetts are delivered almost exclusively in private practice or organized health care settings (for example, staff model HMOs, community health centers and hospital outpatient departments). Massachusetts has an extensive and strong network of high quality, not for profit hospitals, and a community-based safety net system that provides primary and preventive health care services to MCH populations. Massachusetts also has a wealth of medical education and training programs, with four medical schools and three dental schools. There is no public delivery system of primary care for MCH populations. Title V and state resources have helped to support safety net providers at the community level for those unable to afford or otherwise access care.

Among Massachusetts women ages 18 to 44, 88.4% reported having a regular physician.¹¹ Of middle school students in 2004, 90.6% reported a usual source of care with either a physician or clinic, for example, at a community health center; of high school students, 91.6% reported a similar usual source of care.¹² Based on the National Survey of Children with Special Health Care Needs (NSCSHCN), almost 95% of Massachusetts CYSHCN had a personal doctor or nurse (vs. 89% nationally), and only 8.2% relied on emergency rooms for their usual source of care (vs. 9.3% nationally).

Health care is a major Massachusetts industry, and families come from other states and countries to obtain care from Massachusetts specialty providers. For example, based on the NSCSHCN, Massachusetts CYSHCN who needed specialty care were less likely to have problems getting a referral compared to CYSHCN nationally (13.7% vs. 21.9%). Areas of strength, including selected Center for Community Health programs, and of concern are described below. For additional information on Center programs, see Appendix 2F1.2.1, attached at the end of this needs assessment.

Preventive, Primary, Maternity, and Child and Adolescent Health Care Resources

The State continues to have a relatively large physician provider workforce (29,330 physicians), according to the Massachusetts Board of Registration in Medicine. The following chart shows the distribution of nonfederal primary care physicians by field.

**Table 2F.1.3
Massachusetts Primary Care Physicians, 2003**

Specialty	# of Physicians
Internal Medicine	5,416
Pediatrics	2,091
Family Practice	1,234
Obstetrics/Gynecology	1,082
General Practice	204
Total Primary Care	13,708

Data Source: American Medical Association, Physicians Professional Data, Special Data Request, 2004.

In addition, according to the Massachusetts Board of Registration in Medicine, 122 Massachusetts physicians in 2005 identify adolescent health as a specialty.

After several years of hearing that, in Massachusetts, obstetricians were discontinuing obstetrical practice deliveries largely due to escalating malpractice rates, in 2004 MDPH conducted a survey of chief obstetricians in Massachusetts hospitals. The survey found that, from 2002 to 2004, 7.6% of obstetrical providers (including certified nurse midwives and family practitioners) and 8.5% of obstetricians were lost in Massachusetts. Level I facilities and those in Western Massachusetts lost the most obstetricians. In May of 2005, one of two in-state nurse midwifery programs also halted admissions. The ability of women to access care in areas with the greatest losses will be monitored over time.¹³

Hospitals

The number of hospitals and hospital beds has been declining in Massachusetts for more than a decade. There are currently 61 hospitals with licensed maternity units and two freestanding birth centers. Proximity to a maternity hospital is less than about 30 miles. There are sufficient beds and proposed new hospital licensure requirements will clarify levels of care.

Pediatric beds have also declined, in part due to the declining need for inpatient hospitalization among children. There remains sufficient availability and distribution of specialized and tertiary pediatric services. However, children's hospitals nationwide are suffering financial problems and this is true in Massachusetts also. Children's Hospital in Boston, the premier children's hospital in the nation, has shown an improvement in revenue and in the last three years has generated an operational surplus. This hospital is focusing on expanding access and improving quality of care for all Massachusetts' children.

To assure access, rural hospital services have been a major focus of both MDPH and the Massachusetts Hospital Association (MHA). The Office of Rural Health in BFCH received a Rural Hospital Critical Access grant from HRSA and, working in partnership with the MHA, three Massachusetts hospitals have converted to Critical Access Hospitals (CAHs). These include Fairview Hospital in Great Barrington and the sole hospitals on the islands of Nantucket and Martha's Vineyard. Two other hospitals continue to undergo financial feasibility studies to assess the benefits of conversion to CAHs. The Massachusetts Legislature recently voted to establish a state definition of rural that will help protect the three currently designated Critical Access Hospitals and enable the two additional small hospitals to receive this designation. The action by the Legislature will ensure that Massachusetts retains the authority to have its own, state-specific, definition of "rural" as the term applies to eligibility for the certification of small hospitals in rural communities as Medicare CAHs. The ability to qualify for this designation is essential because CAHs receive enhanced, cost-based, federal Medicare reimbursement to assist with maintaining the viability of local health care services in the more remote and less densely populated rural communities of the Commonwealth.

Community Health Centers and Safety Net Programs

As Massachusetts does not have a county- or city-based health services system, Community Health Centers (CHCs) along with a few remaining hospital outpatient departments serve as the key safety net providers. Low-income uninsured and underinsured, high-risk Medicaid recipients and other individuals facing barriers are able to access health care through a statewide network of CHCs regardless of ability to pay. MDPH-BFCH contracts with 54 CHCs, many of which have multiple sites statewide to provide perinatal, pediatric, adolescent, and adult comprehensive preventive and primary health care. Figure 2F1.2.1, attached, identifies the CHCs in Massachusetts. CHCs are non-profit, community-based organizations that serve approximately one out of every 10 patients in the state. In 2004, they provided over 2,760,00 medical visits and over 4,485,000 overall visits. Comprehensive primary and preventive health care, including reproductive health care and family planning services, are available to anyone in need regardless of their medical status, ability to pay, culture or ethnicity. Services provided are culturally sensitive and are designed to meet the needs of the individual communities.

CHCs have experienced financial pressure due to numerous changes in the health care reimbursement and support environment. CHCs have access to the uncompensated care pool to cover services for the uninsured. The MDPH CHC Support and Enhancement Program provides state funding for operational support to 54 CHCs. Individual CHC contracts are approximately \$78,000 per year.

The Support and Enhancement Program supports CHCs to provide necessary primary and preventive health care to high-risk, low income families and individuals by funding essential services not supported by other sources. Essential services include screenings, medical care, case management, outreach, tracking and follow-up as well as health information and education. Specific initiatives that have been prioritized for funds through this program include: mental health services, oral cancer prevention and screening, general oral health services, and programs for special populations such as the elderly, immigrants or other identified high-need groups. These services include linking patients with crucial primary health and other social services, avoiding more costly interventions should the individual not receive timely care. In addition to increasing access, a goal is to decrease the costs of providing urgent or emergency care through increased prevention and screening.

The Combined Primary Care Program (CPCP) funds 40 vendors, of which 95% are CHCs, for direct and enabling services to enhance basic primary care perinatal, pediatric and adolescent health programs. Nutrition, social services, outreach, and case management are the major services supported through this program. The statewide CPCP provides funds to these community-based health care providers to increase their capacity to provide comprehensive and coordinated primary care with essential support services for low income, uninsured or underinsured, pregnant and postpartum women, children and adolescents. These services are particularly directed to those most at risk for poor health outcomes and those with special health care needs. CPCP communities have significantly elevated rates for low-birthweight, infant mortality, teen pregnancy, inadequate prenatal care and/or other identified health risk factors. Programs address disparities, for example, in prenatal care for minorities and teens.

As part of Health Care Reform, Massachusetts' statewide system of community health centers has been designated "essential community providers." The Center for Health Policy and Research (CHPR), University of Massachusetts Medical School is finalizing an assessment of the capacity of CHCs to absorb increased patient enrollment and a profile of provider types that are key to service delivery redesign. As these redesigns unfold, with a concomitant redesign of MassHealth and uncompensated care pool funding mechanisms, it is expected that more community patients will be directed and linked to CHCs and other community based providers, particularly those providing behavioral health services. It is also anticipated that these will form the foundation for the state's new Safety Net program.

The Center provides partial funding to 49 school-based health centers (SBHCs) across the state, often operated by CHCs. SBHCs operate in communities selected based on at-risk populations and limited access to primary care. The map displaying all SBHCs and ESHSs is attached in Figure 2F1.2.2. SBHCs engage youth in the health care system, screen and refer for various youth risks, and provide primary care. SBHCs are staffed by experienced nurse practitioners, mental health professionals, and physician's assistants who work in close partnership with school nurses, guidance counselors, teachers, school

administrators and community social service agencies to coordinate care and provide referrals for required services. Students seen in SBHCs can be diagnosed, treated for illness, receive health risk assessments including mental health and obesity screenings, without interrupting class time or requiring parents to miss work. A new focus of the program this year has been an emphasis on mental health screening and treatment as well as more attention placed on the problem of obesity/physical activity. All practitioners have received extensive training on best practices in these two areas of focus. All benefit from the direct involvement of the medical staff from their sponsoring agencies including pediatric and adolescent psychiatrists who consult to SBHC staff on complex cases pertaining to mental health.

The underlying mission of this program is to serve all children regardless of their ability to pay. According to the SBHC providers, barriers remain in that services provided to uninsured children are not reimbursable and the complex nature of case management and care coordination does not lend itself to “billable coding,” with the expectant result that few centers are self-sustainable. Reimbursement systems may become more able to capture the fiscal value of prevention efforts and render the model more financially viable as the value of this model of care becomes better understood.

Family Planning

The BFCH funds 12 qualified community agencies to provide comprehensive family planning services at 75 sites in Massachusetts with a particular emphasis on high-risk communities with populations in need. Of 149,165 clients served by the Family Planning programs in 2004, DPH funded 46,687. The long-term goal of the Family Planning Program is to prevent unintended pregnancies and sexually transmitted diseases (STDs) in populations at highest risk: low-income women, men, adolescents, new and emerging populations and communities of color. The program also seeks to:

- Prevent the early initiation of sexual activity;
- Improve the reproductive health of these populations, with reductions in the rates of sexually transmitted diseases, cervical cancer and HIV infection;
- Improve the health status of infants, and reduce infant mortality through planned pregnancies and increased spacing of births;
- Reduce repeat pregnancies in adolescents; and
- Reduce the need for abortions.

Funded agencies provide comprehensive, voluntary, and confidential family planning services as defined in the MDPH Family Planning Program Standards. These services include, but are not limited to:

- Clinical and preventive services to maintain reproductive health based on current clinical standards: medical exams, pregnancy testing and options counseling, screening and treatment for STDs, HIV counseling and testing, screening for cervical cancer, and appropriate referrals to primary care and other health care services;
- Timely and accessible initiation and management of all FDA approved methods of contraception, including emergency contraception;
- Individual, client-based reproductive health education and counseling;
- Essential community education and outreach on family planning and sexual health services; and

- Community linkages and collaborations that support program goals and benefit the target populations/communities.

Providers of family planning services (primarily the MDPH and Title X grantees) have been very interested in the development of a Family Planning Waiver for Massachusetts. A positive CMS report found that Family Planning Waivers do avert births and are budget-neutral,¹⁴ and the fact that 19 other states have Family Planning Waivers has increased interest and advocacy around Massachusetts developing a waiver.

Family planning waivers allow states to expand eligibility for Medicaid covered family planning services to individuals not otherwise eligible for Medicaid. By implementing a family planning waiver in Massachusetts, the Commonwealth could expand the availability of family planning services to low-income individuals, while supplementing, and in some cases supplanting, state-only funded programs.

Currently, DPH and the Office of Medicaid are meeting regularly to discuss the development of a waiver. There is also legislation pending in the legislature that would mandate the waiver development. Discussions have included program eligibility, covered services, operations, and cost.

School Health Services

MDPH-funded Essential School Health Services (ESHS) programs, and school nurses perform direct and enabling services. The ESHS programs are required to assess all children for health insurance and primary care providers and refer as needed. There are approximately 2,100 school nurses in the state, with most of whom the ESHS program works in a direct or consultative capacity. (See the map of all SBHCs and ESHSs attached in Figure 2F1.2.2.) School nurses act as a safety net and provide entry into the health care system as needed. The school physician position description has been revised to discourage “sports physicals” in schools, and to have the student go to the PCP instead. In 2004, 1,317 school nurses in the 103 funded ESHS districts reported serving 551,184 students (418 on average per nurse) during the 2003-2004 school year, with an average 515 encounters per month. A third of the encounters were nursing assessments, about 18% first aid, 17% medicine administration, and 9% medical procedures. A goal of the ESHS program is to support the educational process, and 88.7% of students were returned to their studies after visits to the school nurse. Dismissals were generally due to illness (93%).¹⁵

Oral Health

Oral health is a current and continuing Massachusetts state priority across the three MCH populations. For children enrolled in MassHealth, including with special health care needs, it is a measure as well. The Massachusetts Oral Health Report found that in 2003 nearly half of Massachusetts third graders had a history of dental disease, 26% had untreated disease, and 7% had urgent dental needs. Of third graders with MassHealth, 16% had urgent needs compared to 4% with private insurance.¹⁶ A 2004 statewide survey of Head Start children found that 37% had cavities and/or fillings, 29% had untreated disease, and 8% had urgent dental needs.

An estimated 5,100 dentists have clinical practices in over 6,000 office locations.¹⁷ The overall ratio of 1,429 residents for every one dentist is higher than the national average.¹⁸ Although there is not an overall shortage of dentists in

Massachusetts, disparities exist in access. The distribution of dentists is uneven, with a significantly higher concentration of dentists in the eastern third of the state. An estimated eighty communities lack any dentist. Figure 2 F1.2.3, attached at the end of the needs assessment, is a map that shows these communities and additional communities with dentists who do not accept MassHealth. These communities are predominantly in the western and central parts of the state. Many of these are also the communities without community water fluoridation.

Like medical primary care services, dental services for the maternal and child health population are provided largely at private dental offices and safety net providers such as CHCs and hospital outpatient departments. The Center's Office of Oral Health (OOH), which administers public oral health programs for the Commonwealth, does not directly provide any services. It does, however, fund a program to provide dental care for developmentally disabled children and adults at eight sites across the state through the Tufts Dental Facilities.

The MassHealth dental program provides dental care for children and persons with disabilities; for adults, coverage was eliminated in FY 2001 except for emergency services. MassHealth dental program is the insurer for almost 15% of the Massachusetts population. The program provides dental care through provider agreements with community dentists and with safety net providers. MassHealth reimburses for dental care on a fee-for-service basis and expects dentists to serve all MassHealth members who request care. In FY 2001, the MassHealth dental program received an increase of \$21 million to increase dental reimbursement rates and in March 2001, the pediatric dental fee schedule was raised. Current reimbursement rates continue to be well below the median customary fee. As increasing numbers of dentists have stopped participating; those left as MassHealth providers face overwhelming demand to serve patients that they feel unable to meet. In many Massachusetts communities today, there is no MassHealth dental provider. Health Care for All, a statewide health care consumer advocacy group, has filed suit against MassHealth.

The Office of Oral Health currently maintains a data base of private and safety net dental providers who have disability access, serve substantial numbers of disabled patients, offer a sliding fee scale, and offer services in languages other than English.

CSHCN experience difficulty obtaining preventive and restorative dental services. In FY 2004, the Office of Oral Health created the Children with Special Health Care Needs Oral Health Initiative. With support from the MCHB's State Oral Health Collaborative Systems Grant, the Office dedicated a part-time dental hygienist to serve as the program coordinator and Initiative participants began meeting in January 2005. The outcomes of the session, and thus the future plan for meeting the goals of the *Massachusetts Children with Special Health Care Needs (CSHCN) Oral Health Initiative* include: 1) conducting a multi-model oral health needs assessment/survey of Massachusetts CSHCN; 2) establishing objectives and action steps, using survey results; 3) prioritizing action steps; and 4) establishing subcommittees to work on specific strategic planning activities.

Both consumer and professional groups who met as part of the MCH needs assessment highlighted oral health as an area of need, for all three MCH populations, particularly for low income families and CYSHCN. Community health workers, such as

those working with Early Intervention Partnership Program (EIPP) program, cite referrals for dental care as particularly difficult.

A number of initiatives to increase access to dental screening and care have moved forward:

- The dental safety-net continues to grow. Public and private funds have supported the expansion. There are currently 58 safety-net dental clinics in Massachusetts located in community health centers, hospitals, schools, dental and dental hygiene schools and other community locations. All are MassHealth dental providers and have a sliding fee scale, and some provide free care under the state's compensated free care pool.
- The Commonwealth Adolescent Mobile Oral Health Services Program (CAMOHS) has dramatically increased access to oral health care services for over 5,000 low-income, Head Start and CSHCN youth in Massachusetts in the past couple of years. The program has expanded to 95 sites, serving youth enrolled in the Division of Youth Services (DYS), and Division of Social Services (DSS), Head Start and other school based sites. The CAMOHS program's capacity to readily provide routine dental services in school-based or facility-based settings, with referral to a fixed clinic for advanced treatment procedures, accounts for its market success and acceptance by all stakeholders.
- The OOH has partnered with BFCH School Health Services to strengthen the ability of school systems to increase access to sealants for schoolchildren. A new requirement for the 103 schools receiving DPH funds for Essential School Health Services (ESHS) is that they include an oral health component. The OOH has provided training and technical assistance to school nurses on various issues related to oral health services and education. Dental sealant and fluoride varnish programs were implemented in several ESHS sites.
- The OOH is also expanding its fluoride mouth rinse (FMR) program in non-fluoridated communities through partnership with the ESHS school systems. Presently over 45,000 students participate in the FMR program.
- In 2003, the OOH conducted a statewide oral health survey of third grade children. The survey screened 3,936 children in 95 schools across the Commonwealth. The report of the survey has provided the basis for multiple communities to develop oral health initiatives resulting in funding from private foundations.
- In 2004, the OOH conducted a statewide oral health survey of Head Start children. The survey includes data from 12 grantees across the Commonwealth. 1,673 Head Start children were screened. The report is expected to be released shortly.
- The OOH is in the process of conducting a new statewide survey of safety-net dentists with specific resources, skills, and interests to serve special populations. Similar to the survey completed by dentists in 2000, the survey will result in a directory, which will include information on disability access and equipment, services provided in languages other than English, and sliding fee scales.

A key effort that has provided the impetus for many of these positive developments is the strong collaboration that has developed among diverse stakeholders

in dental health as a result of the work of the Special Legislative Commission on Oral Health. A statewide Oral Health Taskforce with over 40 member organizations provide the forward thrust of oral health initiatives in Massachusetts.

Rural Health

While absolute distances in Massachusetts are relatively short compared to many larger states, rural and small town culture, a lack of resources such as transportation, and family and work-life needs are such that it is difficult for many rural residents to travel to cities to receive services on a regular basis. The Rural Health Advisory Council was formed in 2000 to provide input to the Department regarding issues and gaps in service and develop a definition of rural.

Availability of primary care services in rural areas has improved in the past five years, due to local community efforts in conjunction with BFCH, the Office of Rural Health, the Primary Care Office, the Primary Care Association, DPH CHNAs, University of Massachusetts Medical School, the Massachusetts Hospital Association, and MassHealth. Since 1997, three new CHCs have opened in rural areas and are currently opening satellite sites. In addition, on Cape Cod on the southeastern Massachusetts coast, the CHC serving the rural Outer Cape towns with two centers opened a third site to serve another community. Care for MCH populations is a significant component of the newly available services at each of these CHCs.

In addition to the CHCs, a free-standing federally certified and state licensed Rural Health Clinic (RHC) opened last summer in Dukes County to serve as a safety net provider for the uninsured and underinsured on Martha's Vineyard. This is the first RHC in Massachusetts. Feasibility of expanding this model to other areas is being explored.

Family planning clinics are located in some larger rural towns with only limited services in more remote areas. The MDPH Family Planning Program and the Office of Rural Health conducted a preliminary needs assessment to look at rural communities and plan to conduct a more intensive needs assessment. New family planning and women's health services models are being explored for rural communities that build on the positive assets and community programs in rural communities.

Without county government and regional planning agencies in most parts of Massachusetts, local communities frequently lack the infrastructure and expertise needed to secure grants. The federal CAP program and the Rural Health Outreach Program have provided valuable assistance to rural communities establishing plans and securing funding for new safety net sites.

The development of formal rural health provider networks to collaborate on the development of new services and sites that optimize federal and state funding and bring benefits and value back to the network and its member organizations, has proven valuable in improving the overall viability and sustainability of the system. For example, the Network for Rural Healthcare is a rural health network in western Massachusetts comprising three rural federally qualified health centers, four hospitals, and two health systems with technical and resource support from the MDPH Office of Rural Health and University of Massachusetts Medical School. This Network is working horizontally sharing resources and technical expertise from CHC to CHC, and vertically between the CHCs, hospitals, and health systems, on developing new services, including new safety net sites, and using resources and developing systems across the network that will

enhance the cost effectiveness and quality of care. A vertical rural health network has also been forming through the Dukes County Health Council (Martha's Vineyard) to look at how best to collaborate and form an integrated and accessible financially viable network of primary care, mental health, oral health, and specialty services needed in their rural communities.

Interviews, surveys, and focus groups with parents and MCH service program participants repeatedly stress the need for greater flexibility in service availability. This seems to be a critical factor in keeping individuals involved and getting potentially eligible families enrolled. Current WIC participants, for example, are more satisfied with traditional office hours, but when former WIC participants and non-participating eligibles were asked, the vast majority have a need for evening and Saturday hours. Now that more families are working, flexible office hours have become even more critical. (WIC has recently mandated that all local programs have some evening and Saturday hours.) This is also evident in the FOR Families program which utilizes a variable hour schedule to contact families and conduct home visits with many contacts occurring not during traditional 9-5 Monday - Friday work hours. Other traditional barriers to service access continue to be a challenge for Massachusetts families, including transportation. This is especially problematic in the more rural areas of the state, with the relative isolation of many residents. The Rural Health Advisory Council reported that among rural parents and providers, a frequently heard frustration is that most services are based in the cities with the expectation that rural people will go to them, but that this expectation contradicts the reality of rural families' lives and stresses.

Selected Additional Services and Service Linkages

The Center provides an array of MCH services and service linkages, a selection of which are described here and in the section below on reducing disparities. Not all services are described. Please see Appendix 2F1.2.1, attached at the end of this needs assessment, for a listing and brief descriptions of Center programs.

Early Intervention

Early Intervention (EI) is a comprehensive, community-based program of integrated developmental services which uses a family-centered approach to facilitate the developmental progress of children between the ages of birth and three years whose developmental patterns are atypical, or are at serious risk to become atypical through the influence of certain biological or environmental factors. EI services are focused on the family unit and the child's natural environments. The program recognizes the crucial influence of the child's daily environment on his or her growth and development. Therefore, EI staff work in partnership with those individuals present in the child's natural environment, which may include locations both in the child's home and other settings. The program seeks to support and encourage the caregiver's growth in planning for the child's continuing and changing needs.

The Massachusetts EI system, administered by the MDPH, has broad eligibility, including serving children at risk of development delay. Based upon the percentage of all children under the age of three receiving services on 12/1/03 (a point-in-time non-cumulative count), including those at risk of delay, Massachusetts served 5.92%. Only Hawaii was higher at 7.70%. If at-risk children were excluded, Massachusetts was first

nationally at 5.75% and Hawaii second at 4.43%. For comparative purposes, the national average was slightly over 2%.¹⁹ Over the past several years the cumulative number of children served has continued to increase, from 27,891 in FY 2003 to 31,764 projected for FY 2006. Utilizing the cumulative numbers served, the percentages cited above would approximately double.

Home Visiting Services

The Early Intervention Partnerships Program (EIPP) provides outreach and screening for some of the most difficult to serve women during the perinatal period. These women may be unauthorized immigrants and many have substance abuse issues, are depressed or have other mental health issues, experience violence in the home, and lack understanding of basic child care (from changing a diaper to sleep position to not shaking a baby). EIPP teams link with enabling services but have difficulty resolving transportation and housing issues. Similarly staff working with HIV positive women in the MassCARE program report difficulties with housing insecurity and transportation.

F.O.R. Families is a home visiting program of the Massachusetts Department of Transitional Assistance and the MDPH. The primary goal of the program is to assist families to transition from homelessness into permanent housing. Home visitors conduct family assessments and coordinate services for the families with community-based programs such as WIC, Early Intervention, primary health care, community health centers, domestic violence services, substance abuse, and mental health treatment centers.

Violence Prevention and Intervention Services

Violence Prevention and Intervention Services (VPIS) includes programs that provide direct service to victims of violence and/or support the provision of direct services through community-based providers. Most also involve capacity and standards development or specific service development to address disparities, which are further described in the disparities and infrastructure-building services sections that follow.

The Sexual Assault Prevention and Survivor Services Program supports a network of 19 rape crisis centers, some with multiple sites, across the Commonwealth to provide comprehensive services to adolescent and adult victims of sexual violence as well as to the friends and loved ones of victims. Services provided include: 24 hour toll-free sexual assault crisis intervention, information, and referral hotline; accessible short-term individual sexual assault crisis counseling for adult and adolescent survivors and their friends, partners, and family members; support groups for survivors; accompaniment, support, and advocacy throughout the medical, legal, and police processes; and information about and referrals for health concerns, such as HIV, pregnancy, substance abuse, and Post-Traumatic Stress Disorder, as well for legal, economic, safety planning, and other needs. Many of rape crisis services are available in multiple languages. In 2004, rape crisis centers responded to 11,059 hotline calls, and provided counseling services to 1,944 clients.

Through the Sexual Assault Nurse Examiner (SANE) Program, MDPH provides compassionate and coordinated medical care and forensic evidence collection to victims age 12 and over who enter designated hospital emergency departments within five days of a sexual assault. The SANE program currently has more than 100 nurses responding through a regionally based on call system to 22 designated sites across the

Commonwealth; 24 hours/day, 7 days per week coverage is provided in greater Boston and the Northeast and Southeast regions. Expanded weekend coverage is provided in Central and Western regions. The SANE program has developed a pediatric sexual assault forensic evidence collection kit and begun to train specialized pediatric SANEs to provide services to victims under the age of twelve. In state FY 2006 funding has been allocated by the Massachusetts State legislature to support initial implementation of pediatric SANE services.

The Massachusetts Rural Domestic Violence and Child Victimization Project (MRDVCVP) provides direct services to children who witness domestic violence and their mothers in rural areas of Western MA. Rural victims of domestic violence and their children face additional issues of availability of local services, isolation from family and friends, lack of confidentiality, transportation to services, and lack of supporting services such as housing and legal support. The MRDVCVP has attempted to address these issues through a service delivery model that includes placement of additional program sites and/or working with survivors and their children in their homes as well as coordinating a constellation of service providers.

MDPH works closely with and funds community-based Batterer Intervention programs to work with perpetrators of domestic and dating violence. The goals of these programs are safety for victims as well as accountability for the batterers through monitoring and behavior change.

In response to alarming rates of victimization and suicide of gay, lesbian, bisexual and transgender (GLBT) youth, the Department collaborates with the Governor's Commission on Gay and Lesbian Youth on the Supportive and Healthy Communities for Gay and Lesbian Youth project. This project funds community-based programs to provide a safe environment and leadership development for GLBT youth as well as education and technical assistance to school personnel and health and human service providers in order to help them address the needs of GLBT youth within their service delivery population.

HIV Services

Access to health care for HIV infected individuals has been expanded through the MassHealth HIV waiver, which provides antiretroviral treatment to residents of Massachusetts who would otherwise not have qualified for services; the HIV Drugs Assistance Program (HDAP); and the Enhanced Medical Management System, which provides comprehensive medical and allied support services to clients.

The HIV/AIDS Bureau provides funding and technical assistance for community based health care service organizations, primary care centers and specialty clinics to encourage development and implementation of integrated models of service provision. These models integrate clinical services with social services, specialized case management, mental health and housing services. It has also established an HIV-specific Service Coordination Collaborative model statewide to ensure referral support between primary, specialty secondary level and tertiary levels of care.

In addition to programs of the MDPH HIV/AIDS Bureau, in the Bureau of Family and Community Health, MassCARE provides HIV-related specialty medical care, care coordination and support services for women, infants, children and youth with HIV/AIDS in community-based health centers and pediatric practices, and regional perinatal centers

for HIV positive pregnant women. A program known as MassCARE also has formal and informal linkages and referrals among primary, specialty secondary, and tertiary level care.

2F1.3 Efforts to reduce disparities in health access and improve cultural acceptability

A listing of activities within the MDPH to address racial and ethnic disparities is attached at the end of this needs assessment as Appendix 2F.1.3.1. Several programs and initiatives are also highlighted below.

The Office of Multicultural Health

The Office of Multicultural Health (OMH) in the Center for Community Health is a Department-wide resource to assist in program and policy development to assure that the needs of racial, ethnic and linguistic minority communities are met. OMH develops partnerships internally and externally to ensure that health systems responsively address issues of access, capacity and service delivery for these communities. OMH focuses on health disparities, language access, materials development and infrastructure support. Below are a few of the initiatives in which OMH has collaborated.

- Developing MDPH-wide standards for collecting data by race and ethnicity for surveillance and programs based on the revised OMB 15²⁰ directive and including attention to specific Massachusetts populations. The standards are under review by the Department-wide Data Standards Committee.
- Collaborating on Commonwealth-level procurement management teams for media and interpreter and translator services. OMH participation has ensured that minority vendors are on the media contract list and that interpreters and translators in multiple languages and areas of the state are on the interpreters and translators contract list.
- Assuring quality, accessible and appropriate language interpretations and translation for persons who have limited English proficiency (LEP) who need MDPH services by: (1) coordinating interpreter services for LEP clients for certain Center programs and the Legal Department; (2) with the hospital licensing unit, assessing hospital-based interpreter services when a hospital or health technology service applies for permission to add a service or make substantial capital improvements through the Determination of Need Program (DoN) process, attaching interpreter services conditions to approvals and monitoring their implementation; (3) with the licensing division, monitoring compliance with the Emergency Room Interpreters Law (ERIL); and (4) working with the interpreting industry agents to improve training and interpreter services throughout the state.

OMH works closely with internal and external partners to educate about, identify and implement strategies to decrease health disparities. Significant among these strategies are: Boston Public Health Commission's (BPHC) Legislative Commission to Eliminate Racial and Ethnic Health Disparities, Critical MASS and the New England Minority Health Committee (NEMHC).

- In 2003 Boston's Mayor convened a city-wide Task Force to develop a comprehensive approach to reducing disparities. In June 2005 the Mayor's

Task Force released its blueprint for action with 22 recommendations to be implemented by the Boston Public Health Commission. A Work Group of hospital CEOs developed action steps and raised \$1 million to fund community based interventions.

- In FY 2004, the Legislature created a Commission to Eliminate Racial and Ethnic Health Disparities to work collaboratively to create state-level, coordinated responses to health disparities. The Commission was charged with making “recommendations for designing, implementing and improving programs and services, and proposing appropriate statutory and regulatory changes to reduce disparities in access to health care services and quality care, and the disparities in medical outcomes in the Commonwealth, and to address diversity in the health care workforce, including but not limited to, doctors, nurses and physician assistants.” A panel of experts, stakeholders and decision-makers were involved in workgroups and the Commission heard testimony statewide about disparities in their local areas. Both the Commissioner of Public Health and the Title V Director are active Commission members.
- Critical MASS is a statewide public-private effort with a mission of mobilizing communities to take action on health disparities. Critical MASS is focused on helping racial and ethnic communities gain the tools and skills to address the root causes of health disparities and not concentrate on diseases. Towards that end, Critical MASS has held regional and statewide planning meetings, developed a listserv to disseminate information specific to health disparity activities, begun to collect information on programs across the state targeting disparity to encourage sharing of information and successful practices, and has a draft of a Health Disparities Reduction toolkit to guide and inform local action. Information is available at www.enddisparities.org.
- Through the efforts of federal Region 1 OMH, the established state offices of Minority/Multicultural Health and community based organizations sponsor a biennial conference focused on eliminating health disparities and developing a health disparities state plan. In 2003 Massachusetts was the host state and OMH convened the 18-month planning committee. Attention was given to educating immigrant communities about health and more than one-third of participants in the state breakout session at the 2005 New England Minority Health Committee conference held in Maine represented immigrant communities.

In 2002 the DHHS Office of Minority Health issued the CLAS (Culturally and Linguistically Appropriate Services) standards²¹ to help their grantees address 14 critical elements related to health disparities and assure quality in the delivery of services to racial, ethnic and linguistic minority communities. The MDPH Office of Multicultural Health, in partnership with the Office of Healthy Communities, is convening a center-wide working group to develop and implement MDPH standards consistent with the CLAS Standards.

Perinatal Disparities Project

Through the MATRICHS project, a 9-month on-line course funded by the CDC and the Association of Maternal and Child Health Programs (AMCHP), MDPH staff received training to identify a critical policy issue and use state, local and national data to inform policy direction and program priorities. Massachusetts identified perinatal disparities as the policy issue to address through the MATRICHS process.

The extent to which perinatal health disparities are addressed at the state and local levels, collaboratively with stakeholders and community partners, has been selected as a new Massachusetts MCH measure. Title V has created a unique scale to measure this effort.

Through the Perinatal Disparities Project we are:

- 1) enhancing the capacity of community partners to address racial disparities in birth outcomes by collecting and analyzing state and local data to inform policy and identify program priorities and
- 2) establishing a formal communication network between Massachusetts communities to encourage information sharing, raise public awareness, and advocate for resources to eliminate institutional racism, or the differential access to goods, services and opportunities of society by race.

In the disparities project the MDPH is partnering with Boston Public Health Commission, Worcester Infant Mortality Reduction Task Force, and the Springfield MCH Commission (organized by City Department of Health and Human Services) to strengthen coordination, implement fetal-infant mortality reviews (FIMR) in each of these communities, and share information. FIMR activities are supported by grants given directly to each of the three communities.

In particular, the Project is building local capacity to address racial disparities in birth outcomes through partnering with Springfield MCH Commission to develop a strategic plan to address disparities in their community. MDPH is providing training and technical assistance in use of quantitative and qualitative data to underscore factors contributing to disparities in Springfield, and using these analyses to inform a strategic planning process using various process management tools such as Strengths-Weaknesses-Opportunities-Threats (SWOT), ecologic models and logic models. This process will lead to a curriculum that will be replicated in other Massachusetts communities.

Violence Prevention and Intervention Services

In FY 1995, through a combination of state and federal funding, the MDPH and the statewide network of rape crisis centers developed a statewide Spanish-language hotline; by FY 2002, survivors accessing services at rape crisis centers who identified as Hispanic increased from 8% to 15%. With limited funding, this hotline continues to operate as a part-time helpline 35 hours per week; however, the number of Hispanic survivors accessing rape crisis center declined to 9.6% in FY 2004.

Other MDPH strategies also try to address this population. The Collaborative for Abuse Prevention in Racial and Ethnic Minority (CARE) Communities Program is developing models for providing domestic and sexual violence services for specific cultural and linguistic populations. It is a CDC-supported demonstration project in its final year of funding to improve cultural competence and collaboration among domestic violence and sexual assault service providers. In CARE Communities, battered women's

programs, immigrant/refugee programs, rape crisis centers, batterer intervention programs and child witness to violence programs network to provide cross training and protocol development. They assure that there is an appropriately tailored community-wide response to violence against minority women that incorporates all service providers. Four CARE networks were established in the Commonwealth as part of the demonstration project: in the Latino community (Chelsea and Pittsfield), the Cambodian community (Lowell), the African American community (Boston), and the Latino community (Pittsfield).

The Refugee and Immigrant Safety and Empowerment (RISE) Program was supported through a state budget line FY 1999-FY 2003, and funding is being restored for FY 2006. This program funded 15 community-based providers across the state to develop and provide linguistically and culturally appropriate outreach and crisis services to immigrant victims of domestic and sexual violence. In FY 2003, these providers served over 1,452 immigrants who would otherwise not have been able to access help through “traditional” domestic and sexual violence programs. Based on knowledge gained through experience with these model community-based programs, with limited FY 2004 to 2005 funding, RISE continued to work, encouraging “mainstream” domestic violence providers to adapt their approaches and programs to meet the needs of newcomer communities in Massachusetts and will begin funding community-based programs again in FY 2006 .

Community Health Worker Activities

The Center, through its contracts with community-based organizations including CHCs, supports significant outreach and health promotion activities provided by community health workers (CHWs). CHWs are public health outreach professionals who apply their unique understanding of the experience, language and/or culture of the populations they serve in order to carry out at least one of the following roles: bridging/culturally mediating between individuals, communities and health and human services, including actively building individual and community capacity; providing culturally appropriate health education and information; assuring that people get the services they need; providing direct services, including informal counseling and social support; and advocating for individual and community needs.

Community health workers are the bridge between communities in need and vital health and human services. Their unique ability to build trust in the community enables them to increase access to and improve utilization of preventive primary care. Without their efforts, many residents might either go without health care and other vital services, or get care later when it is most costly. Community health workers decrease cost of care, and play a unique role in reducing health disparities.

For example, the HIV/AIDS Bureau provides outreach to out-of-school youth at risk of HIV/AIDS, most of whom are poor, minority, or both. They provide screening and improve referrals that help improve the acceptability of professional services. Similarly, the Early Intervention Partnership Program (EIPP) services to hard-to reach women promote cultural acceptability of professional services and reduce disparities. Almost 50% of EIPP clients have English as second language issues. Bilingual/bicultural outreach workers are part of each EIPP team, along with a nurse and social worker, helping to link this very difficult to reach population with long-term services.

Services for CSHCN

MDPH Care Coordinators are located in practices providing culturally and linguistically appropriate services in Spanish and Portuguese. Spanish transition planning groups are available for parents at two practice sites. By moving into community pediatric practices, MDPH Care Coordinators have seen an increase in their non-English speaking client population. The increase is due largely to the fact that several Care Coordinators are located in practices with large Spanish and Portuguese-speaking populations. As of FY 2004, 20% of clients were Hispanic. The need for assessment and outreach to African American families has been identified. In addition, there appear to be increasing numbers of unauthorized immigrant families with CSHCN who do not qualify for benefits, or who receive very limited benefits. The CSHCN program is continuing to work with the National Center on Cultural Competence and the MDPH OMH on these issues.

2F1.4 Shortages

Despite the relatively large number of physicians both trained and currently registered within the State, as well as the extensive system of safety net health providers, localized health professional shortages remain in some urban and rural communities and for specific populations facing financial, linguistic or cultural barriers. Some of these disparities in the distribution of physicians and other health professionals are the result of a critical imbalance in the ability of CHCs and other safety net providers within these underserved areas to recruit and retain physicians. These providers have difficulty in matching competitive salaries and benefits in this marketplace, particularly with those offered by hospitals and affiliated group practices. A recent report indicated that in 2002, nearly 50% of medical residents trained in Massachusetts moved away from the state following their training. Physicians in Massachusetts continue to be negatively impacted by a high cost of living and malpractice insurance premiums. As noted, malpractice insurance appears to be contributing to a loss of OB/GYN resources in Massachusetts.

As in other parts of the country, health care employers are experiencing a severe shortage of nursing personnel. This shortage is affecting all aspects of the health system including hospitals, nursing homes, community health centers, home health agencies and schools. Community-based agencies are, perhaps, the most affected because they are unable to compete with the salary and benefit packages offered by hospitals and managed care organizations. Additionally, there is a declining student body and an aging-out of nursing faculty and staff. The University of Massachusetts has a fast track nursing program for individuals shifting from non-health careers in order to address the shortage issues; however, the results of this program will not be seen for several years.

Within this environment, the Massachusetts Primary Care Office (PCO) plays an important role. Funded by the federal Bureau of Health Professions (BHP) as well as state funds, the goal of the PCO is maximizing and coordinating resources to address access, CHC and other primary care capacity, emerging workforce, and health disparity needs facing the primary care health care system in Massachusetts.

PCO activities include implementing state and local needs assessments and work force surveys and providing technical assistance, data support and back-up analyses to communities, community health centers and other safety-net providers. More

specifically, in order to address the recruitment and retention issues, the PCO has prioritized increasing the number of primary care (especially for the MCH child and adolescent populations), dental and mental health professional shortage designations (HPSAs) in the state. These designations are based on strict federal guidelines and formulas that look at a combination of variables such as provider FTEs, poverty levels, census tract and/or community population numbers, as well as distance to health providers. These and/or other federal designations known as Medically Underserved Areas (MUAs) are prerequisites for the development or expansion of federally qualified health centers (FQHCs).

These federally approved designations provide enriched Medicare reimbursement rates for health care providers within the designated area as well as increased opportunities for National Health Service Corps (NHSC), State Loan Repayment, and Conrad 30 J1-Visa waiver placements. These three programs are also coordinated out of the PCO and require close collaboration with our federal partners as well as with the state's Primary Care Association, the Massachusetts League of Community Health Centers (MLCHC), the Title V programs, and the Offices of Oral and Rural Health at the MDPH.

The Conrad 30 Program screens and approves foreign physician visa waivers and increases employment placements within primary care settings in underserved and designated professional shortage areas of the state. The Massachusetts State Loan Repayment Program (MSLRP) provides educational loan repayments with state and federal monies to medical practitioners, including physicians, nurses, dentists and social workers who agree to work in community health centers in order to improve access to care and reduce health care disparities. The National Health Service Corps (NHSC) is federal program that works closely with all PCOs nationwide in order to match primary care and other physicians who agree to work in very high need HPSA placements for a number of years in order to receive medical education loan forgiveness.

Currently in Massachusetts, there are 19 Primary Care HPSAs, 15 Dental HPSAs, 5 Mental Health HPSAs and 44 MUAs. FQHCs receive automatic HPSA status from the federal Designation Bureau. Within the last year alone, four applications for new HPSA designations have been submitted through the PCO and are awaiting federal review: 2 Primary Care, 1 Dental and 1 Mental Health.

In 2004/05, the PCO approved the placement of 30 Conrad Visa Waiver physicians at high need areas/settings within the state. These include: 11 Primary Care/Internal Medicine, 4 Anesthesiologists (2 with pediatric specialty), 3 Neurologists, 2 Primary Care/Psychiatrists, 2 Cytopathologists, 2 Radiologists, 1 Pediatrician, 1 Burn Surgeon, 1 Emergency Medicine/Ultrasonography, 1 Vascular Surgeon, 1 Hematologist, 1 Pediatric Hepatologist, and 2 Radiologists.

Attached in Figure 2F1.4.1 to 2F1.4.3 are maps that identify the communities that have been designated as Dental-Health, Mental-Health, and Primary Care (PC)-Health Professional Shortage Areas (HPSAs) by the federal Bureau of Shortage Designation at HRSA. Few Mental-HPSAs are designated. This is an area that the PCO has been discussing internally and will be further exploring given the strongly articulated need for mental health services among participants in the MCH needs assessment.

Services for Children with Special Health Care Needs

In programs for Children with Special Health Care Needs (CSHCN), families, care coordinators and other providers report that shortages of in-home providers of nursing and personal care attendant services result in uncovered hours so that families of CSHCN do not receive the level of supports and services needed to care for their child. From the perspective of the Medical Review Team, many families caring for CSHCN, particularly those with single parents, have inadequate supports to care for their child at home once the child reaches preadolescence, as the child grows and it becomes more physically difficult to care for him/her because of his/her size. Families of children with autism report long waits and shortages of neurologists willing to accept children for diagnosis.

Early Intervention

Early Intervention (EI) services in Massachusetts have experienced significant growth for more than a decade. While more short-lived staffing shortages occurred previously, the current lack of therapeutic and nursing personnel is the most severe that has occurred since the full implementation in Massachusetts of the Individuals with Disabilities Education Act in 1993. From 2001 to 2005 in EI, the number of Physical Therapists have experienced no growth, Occupational Therapists grew by 16%, Nurses declined by 26% and Speech and Language Therapists declined by over 38%. Conversely, Early Childhood Specialists grew by over 40%.²² Schools systems and health care settings are the primary competitors with EI providers for nursing and therapeutic personnel. Based upon a variety of often overlapping factors (economies of scale, larger institutions, collective bargaining contracts, and higher reimbursement rates), EI providers cannot consistently compete in the marketplace for these personnel. Salary levels, particularly for therapeutic personnel, are often thousands of dollars less in EI for individuals with similar levels of experience.

The MDPH, in partnership with provider organizations and other payers, will develop a process during FY 2006 that will culminate in a strategy to improve salary competitiveness for EI personnel beginning in FY 2007 and continuing thereafter as a multi-year effort. Significant activities in this process will include consideration of the Massachusetts Early Intervention Consortium Salary/Benefits Survey 2005, U.S. Department of Labor Statistics income reporting by therapeutic discipline, targeted local school department and hospital salary schedules. Analysis activities will coordinate with the Department of Public Health Budget Office, MassHealth, private insurers and the Massachusetts Division for Health Care Finance and Policy.

2F1.5 Emerging issues

Several issues have heightened visibility since the last five-year needs assessment, a number of which have been discussed in preceding sections. This section presents information about both need and capacity related to additional emerging issues, with an emphasis on issues that cross MCH population groups.

Mental Health

For the three MCH populations, mental health has emerged as a visible and pressing issue. Perinatal depression, mental health issues of very young children, and mental health of children and adolescents, whether viewed as children with special health needs or not, are major topics of concern in Massachusetts currently.

Perinatal Depression

National research suggests that depression is one of the most common complications of the prenatal and postpartum periods.²³ Data on the prevalence of perinatal depression specific to Massachusetts is limited, however information that has been collected indicates that perinatal depression is a serious health public health problem that should be addressed. In 2003, a paper prepared for the Massachusetts Division of Medical Assistance (DMA) reported that among women who were screened for depression during pregnancy by a MassHealth (Medicaid) provider, 83% screened positive and were counseled or referred.²⁴ The Boston Healthy Start Initiative found that out of a total of 718 black women screened for depression, 33.7% screened positive during pregnancy; 19% screened positive at 8 weeks post-partum; and 18% screened positive at one-year postpartum.²⁵ The Early Intervention Partnerships Program (EIPP) Maternal Child Health Team members report waiting lists up to four months depending on the area of the state for mental health services, even when screening indicates the need for immediate referral.

Depression is the leading cause of disease-related disability among women²⁶ and is linked to many adverse health problems. Depression during pregnancy has been correlated with higher rates of substance abuse, functional impairment, and poor pregnancy outcomes including preterm labor, preterm birth and low birth weight infants.^{27,28,29} Other serious consequences can occur as a result of perinatal depression, including, in the worst cases, suicide, infanticide, and non-accidental injury to the child. In 2003, suicide took the lives of 48 females ages 15 to 44 in Massachusetts.³⁰ An impressive knowledge base clearly delineates the link between maternal depression and a host of poor child health and developmental outcomes including cognitive and language delays,^{31,32} difficulties in emotional regulation and attachment,^{33,34,35} psychopathology³⁶ early onset of depression^{37,38} and behavioral and educational problems.^{39,40} Maternal mental health and family well being are inextricably linked.

In response to the need to address perinatal depression as a public health issue, the Center has initiated the Perinatal Connections Project, funded by the Maternal and Child Health Bureau. The Project aims to increase awareness and decrease stigma associated with perinatal depression and increase access to appropriate mental health services for women and their families. An innovative and community specific model is being developed and piloted in four Massachusetts communities. The model aims to systematize the detection and management of perinatal depression and strengthen the connections among community health centers, early intervention partnerships, and WIC programs.

Maternal mental health was also the key priority area addressed by the Healthy Mothers, Healthy Babies Coalition of Massachusetts, in which the Center is a key convener and collaborator, in addition to providing technical assistance. The Coalition, with support from the Harvard Pilgrim Health Care Foundation, and made possible through its affiliation with the National Healthy Mothers, Healthy Babies Coalition,

implemented the “Community-Based Model for Improving Maternal Mental Health” project. Through the provision of forums for skills building, information sharing, and resource development in several Massachusetts communities, the project was designed to expand the capacity of community-based direct care providers (community health workers and other community health center staff, WIC staff, faith-based workers, and volunteers). The project created a replicable model for additional current and future activities to address maternal mental health. The Coalition is a partnership of 18 public and private perinatal organizations dedicated to the goal of safe and healthy home environments for all children, in which families have access to and utilize optimal health care and support services.

Depression among Children and Adolescents

Based on the National Survey of Children’s Health, 9.8% of Massachusetts children ages 3 to 17 have moderate or severe difficulties in the area of emotions, concentration, behavior, or getting along with others, including about 30% of those who screen in as having special health care needs and 3% who do not.⁴¹ For children and adolescents, mental health and behavioral issues may be related and/or difficult to diagnose. One mother in a CSHCN focus group for this needs assessment had a child with autism spectrum syndrome (ASD) diagnosed with a mental illness until ninth grade when the child was enrolled in a clinical trial and given a full assessment. Another child had an as yet undiagnosed disorder that appeared neurological and manifested with mental/behavioral symptoms.

Of 29,384 children enrolled in EI in FY 2004, 7,840 (26.7%) had a social/emotional delay.⁴² A 2002 survey of parents of children with mental health issues conducted by the Parent-Professional Advocacy League (PAL) found that 48% of children reported with issues first began to show signs of a mental health problem by age 4; 76% of respondents said providers were not at all or only somewhat helpful at linking them to other resources about their child’s diagnosis.⁴³ A recent national study on expulsion of young children from preschool because of difficulties ranked Massachusetts ninth in the nation in preschool expulsions, with a rate of 11.1 expulsions per 1,000 enrolled.⁴⁴ In Massachusetts, 16% of teachers reported expelling at least one pre-kindergarten child over the past year. After a study indicating that 18% of children were at risk of expulsion in the Worcester area, the Health Foundation of Central Massachusetts initiated Together for Kids, in which MDPH participates, to train teachers and intervene with children. Together for Kids has demonstrated significant improvement in children’s behavior, self-help skills, and academic development.

Depression is a substantial issue among middle and high school students, with percentages even higher among youth with disabilities or who report that they are lesbian, gay, bisexual or questioning their sexual identity (“sexual minorities”). Almost 54% of sexual minority high school students in Massachusetts felt so sad and hopeless that they stopped doing important things; 31% seriously considered suicide, 16% actually attempted suicide and for 8.4% the suicide attempt resulted in medical treatment. Similarly, 56.7% of high school students with disabilities felt so sad and hopeless that they stopped doing important things; 27.3% seriously considered suicide; 11% actually attempted suicide and for 5.7% the suicide attempt resulted in medical treatment. BRFSS data from 1997-2002 also indicate poorer mental health and increased suicide ideation among young adults with disabilities aged 18-24. This suggests there is an important role

for physicians in coordinating care around issues related to depression and suicide. Figure 2D.4.4 in Section IIB: 2D.4 shows self-reported suicide ideation and attempts among these three groups.

School health nurses and school based health center nurse practitioners also report for this needs assessment that the major issue of concern to them was mental health. School nurses cite childhood depression, suicide ideation, eating disorders, behaviors such as “cutting” and other body mutilation. Mental health is the primary reason for visits to school based health centers (although initial presenting problems may differ). Nurses and nurse practitioners work with school psychologists and local sources of mental health care to ensure that the students are referred; however, this remains a challenge as services are limited. For those children able to obtain services, re-entry after treatment for suicide, substance abuse, and other mental and behavior difficulties is a major issue.

In the PAL survey, one-third of the parents reported that it took over a year for the child to receive treatment after the parent realized the need; an additional 9% said the child was still not getting the care needed. The primary reasons given for delays in getting care were that the services were full and they could not get an appointment (39%), the child did not have a diagnosis (35%), the family did not know how to find services (32%), the primary care provider did not think the problem required treatment (17%), insurance would not pay (13%), the services did not exist (11%), or the family did not realize the problem required treatment (10%). Almost half of the parents (48%) said their primary health care provider rarely or never asks about the child’s mental health.⁴⁵ Based on the National Survey of Children’s Health, 67.6% of Massachusetts children with current emotional, developmental, or behavioral problems received some type of mental health care during the year before the survey, compared to 58.7% nationally.⁴⁶

Transition from youth to adulthood is also an issue. The Department of Mental Health (DMH) follows federal guidelines, which are more stringent for adult than child eligibility. At age 18, youth may lose services, though some continue to age 22 through the schools. Guardianship may be a complicated an issue. Some adolescents do meet the DMH eligibility criteria but services may not exist geared to the needs of the young adult age group, since adult services have been oriented toward an older, chronic population. DMH is actively planning for the 16 to 25 year old population now.

In 2002, the Massachusetts Legislature created the Mental Health Commission for Children as a public-private partnership representing child-serving agencies, parents and professionals with expertise in children’s mental health. The Commission is in the process of finalizing recommendations to the Executive Office of Health and Human Services in keeping with the principles that include: appropriate care and treatment for all, including culturally competent care in the least restrictive, most socially appropriate setting; parity between mental and physical health; family-centered care; evidence-based practice and a continuous improvement model; universal and timely access to care; supporting healthy communities for prevention, health promotion and wellness, encouraging strength and resilience in families and children. Likely recommendations include, for example, supports for families and family organizations, that formal mental health screening be a part of every routine well child visit, and that all public and private insurers have adequate provider networks. The Commission included a special task force on “stuck kids,” who remained in hospitals or acute residential care longer than medically necessary, and at least one pilot program is already underway to address this issue.

MDPH has been an active participant and the Title V Director is a member on the Commission. It is expected that the Title V agency will work jointly with the Department of Mental Health and the other EOHHS agencies including Medicaid to address these recommendations.

Early Childhood System Consolidation

In the Summer of 2004, the Massachusetts Legislature created a new Department of Early Education and Care (DEEC), which formally began operations July 1, 2005. This act was crafted and the new agency designed to be responsible for the administration of all public and private early education and care programs and services in MA. The Department of Education Early Learning Services and the Office of Child Care Services officially transferred to the new entity on July 1. MDPH staff have been involved with the establishment of this new Department and expect to work in partnership to assure linkage and collaboration between birth to 5 services.

Factors that influenced the move toward consolidations were increased focus on preschool education, school readiness advocacy and research, and a commitment to integrate early education and care services.

An environmental scan was completed in 2003 and 2004 by the Massachusetts Early Childhood Comprehensive Systems (MECCS) project and key partners in order to determine service needs for young Massachusetts children and their families. This scan yielded a picture of a human and social services system with numerous resources, programs and services available to children and families, but so fragmented as to make the system all but impossible for families to navigate. Prior to July there were no less than 13 state and federal agencies delivering 47 programs for families and children five and under. Differing payers, eligibility criteria, paperwork, and a myriad of other obstacles make it difficult to locate the services needed. The fragmentation of the current service delivery system also raises the potential for limiting the knowledge and competency of early childhood professionals.

Two major collaborations contributed to the emerging system consolidation: Head to Toe and the Massachusetts Early Childhood Comprehensive Systems (MECCS) project. Head to Toe, or the Massachusetts School Readiness Indicators Project, is a partnership of 19 public and private agencies that have worked together for over three years around a shared vision of successful children and families. Head to Toe's goals are to identify school readiness indicators for Massachusetts and to make indicators data and school readiness information available to families, child care providers, funders, and policy makers. This work was initiated by the report of the Governor's Commission on School Readiness in 2001, which recommended a system of indicators to measure how well we prepare children for school, and a statewide strategy to communicate with families and service providers about school readiness. Head to Toe envisions a coordinated system of early education and family support that builds on an understanding of school readiness to provide what families and communities need to support the learning and healthy development of their children. These partners believe that using a common set of indicators to drive policy and funding decisions, in both the public and private sectors, will help make the service delivery system less fragmented and more efficient.

MECCS is a systems building project funded by MCHB. The grant's main goal is to integrate systems of care, health, and education for young children and their families. The MECCS grant focuses on the following five required areas: early care and education; medical homes and access to health insurance; social emotional development and mental health; family support; and parent education. MECCS is currently transitioning from a two-year planning grant to a 3-4 year implementation grant. Highlights from MECCS planning accomplishments and proposed activities are:

- Lead the Early Education and Care Council's Task Force on Core Competencies.
- Lead the New England Collaboration to plan and conduct distance-learning training for child-care health consultants and Head Start Health Managers.

Some selected implementation activities include:

- Collaborate with the new DEEC to circulate and gather feedback on draft core competencies for EI, child-care and early education professionals.
- Participate with the New England states to broaden the audience for the Health Consultant training to include child-care licensors, mental health consultants, and other key early childhood and education staff.
- Coordinate the Committee on Early Childhood Mental Health, a public-private partnership to build on recommendations developed by the Governor's Mental Health Commission for Children's Public Health Subcommittee.

Emergency and Disaster Preparedness

Responding to September 11, 2001 and subsequent anthrax attacks, Congress and the President authorized funding to state and local health departments to enhance bioterrorism preparedness. The MDPH has established the Center for Emergency Preparedness (CEP). The CEP is the administrative hub for all of MDPH's emergency preparedness activities, which include readiness assessments and hospital preparedness plans, to upgrade infectious disease surveillance and investigation, and to expand laboratory and communications capacity in the MDPH infrastructure as well as regional and local health systems. The CEP liaison for Special Populations activities collaborates with the Center for Community Health through CCH staff and an internal special populations workgroup that meets monthly to ensure that the needs of special populations are included in MDPH's Emergency Preparedness plans. Special populations have been identified as an issue in both the CDC and HRSA bioterrorism grants to states. The MDPH EMSC program is working to improve pre-hospital care for children. CSHCN and EMSC programs are helping families to connect with EMS providers in their communities and establishing family emergency plans. The Bureau of Substance Abuse Services is establishing emergency response plans at its residential sites as well as listing information on the MASSSUPPORT website.

The Special Populations Nursing Coordinator in the Center for Community Health provides information and technical assistance to organizations and groups which serve special populations with emphasis on individuals with special health care needs. In the event of disasters, the coordinator oversees the staff coverage for the toll-free TTY and voice lines, open to the public. She is also the liaison on disaster preparedness for special populations to other Centers within the Department. Community Health Centers and all acute care hospitals with emergency departments in Massachusetts receive

funding from MDPH (HRSA Hospital Preparedness Funding) to develop emergency preparedness plans. The hospitals also participate in the development of regional hospital plans. The following identifies the specific population needs MDPH is addressing.

Pregnant Women (and/or women of childbearing age) and infants

MDPH is preparing a fact sheet regarding preparedness and response for pregnant women's increased clinical needs for themselves and for the fetus, if exposed to chemical or biological agents in a disaster. The increased stressors of a disaster may create additional unsafe environmental factors for the fetus, necessitating specialty care. In FY 2006, planned workgroups will include OB/GYNs who practice in local Community Health Centers and hospitals, as well as those who work with special populations such as pregnant women with HIV/AIDS. The Special Populations Nursing Coordinator will work with MDPH programs serving pregnant women to ensure emergency and disaster plans are in place. HRSA-funded hospital preparedness plans include surge capacity for care of pregnant women, children and infants.

Children with Special Health Care Needs

Based on substantial consumer consultation, the MDPH Family Support Plan mandated by the Massachusetts Legislature has focused on disaster and emergency preparedness for families who have members with special needs. The Director of Family Initiatives of the Division for Perinatal, Early Childhood, and Special Health Needs has taken a lead role in the development and implementation of this plan. Focus groups were conducted in each of the 6 regions of the state through the Family TIES (Together in Enhancing Support) program. Most families attending were parents of children with complex medical needs, including children using oxygen, mechanical ventilation, feeding tubes and assistive technology for communication and mobility. Very few families were aware of community emergency resources such as the Disability 911 Indicator Program or the need to make contact with local emergency responders. Less than 5% of family members attending focus groups reported that they had written emergency plans. Even families with emergency plans expressed strong concerns about travel to and from educational programs that might be up to two hours away from home. There were concerns about shelter accessibility for children on the autism spectrum exhibiting significant behavioral challenges when introduced to unfamiliar environments. Families were concerned about the availability of life sustaining medications and durable medical equipment if their children were prevented from returning home at the end of the school day. Parents were unsure if school personnel would know what necessary life-sustaining medications and equipment would need to accompany children being evacuated from school buildings. Focus group participants strongly stated the need to "get to" their children with special health needs during emergencies.

A special chapter on disaster and emergency preparedness was added to the *Directions* manual distributed to parents of CSHCN through MDPH programs and insurers. MDPH has also established a toll-free, TTY line that will provide technical assistance and information about access to emergency health services for those individuals with communication needs. Most communities have an Enhanced Disability 911 Indicator Program, about which MDPH is helping to inform families. A directory of local emergency management directors, disability 911 indicator programs coordinators

and ADA coordinators has been developed for staff to refer individuals who call MDPH to the appropriate local entity.

MDPH Care Coordinators are preparing to work with the Special Populations Nursing Coordinator and the Medical Home practices to develop plans for families at highest risk during emergencies. Staff will work with the Massachusetts Chapter of the American Academy of Pediatrics (MCAAP) medical home committee to discuss adding emergency and disaster preparedness to the Medical Home trainings.

Children and Youth

School children and youth face particular challenges during a disaster. Not all families with children and youth have personal emergency plans in place, including directions to reunite or make contact. The *Growing Up Healthy* child health diary is adding information about disaster planning and readiness.

Each school facility must have an emergency evacuation plan as well as a lockdown plan. In the event of a large-scale emergency, many Massachusetts schools have been chosen as the site for dispensing of medications, vaccines or other needed supplies. School nurses may be the first to identify an infectious agent in the school setting. The MDPH school health program provides bioterrorism preparedness and smallpox certification training to school nurses. Of the 351 cities/towns, 25% have at least one school nurse educated with the Emergency Dispensing Site (EDS) Overview and Smallpox administration. Twenty-three percent have at least one school nurse certified to administer the smallpox vaccine. A total of 14% of school nurses have been educated with an EDS overview and smallpox administration training. There are 239 school nurses certified to administer smallpox vaccine. An additional 100 experienced school nurses attended a training on behavioral health emergency planning and rash surveillance. Nevertheless, school nurse training is mostly provided during the school's professional days. MDPH has made disaster/bioterrorism trainings available at the times and days most convenient for school nurses. There are 11 training dates scheduled for specific communities from June 2005 to April 2006. The School Health Institute will offer training to 100 school nurses on behavioral health emergency planning, emergency dispensing site planning, and smallpox vaccine administration certification training. Additionally, there is an online course in development to provide recertification to the nurses currently certified to administer smallpox vaccine. This is targeted for completion in the summer of 2005 with a pilot to be conducted in the fall. To assist families of school aged children, an emergency planning check off list is being developed to be included in the health assessment section of the updated school health manual.

Refugees and Immigrants across MCH populations

A particular need in this group is for informational materials in multiple languages, delivered in culturally competent ways to ensure comprehension, compliance and to avoid the risk of re-traumatization. Mental health professionals need ongoing training and support so that they can respond in a culturally competent fashion. All providers and responders need to understand the issues of re-traumatization of refugees and immigrants in disaster/bioterrorism settings.

The Special Populations Workgroup with the assistance of the Refugee and Immigrant Health Program, a member of the workgroup, has translated a glossary of bioterrorism/disaster, risk communication terminologies. To date, this glossary has been translated into Vietnamese and Somali. MDPH is taking the lead in offering

psychological first aid training to MDPH staff, and staffs of community based organizations. Proposed programs include CME training modules for primary care practitioners serving refugees and immigrants. MDPH plans to translate the glossary into additional languages, particularly those from low incidence languages in MA.

2F1.6 Evaluation of the Title V relationship with others in the state who address inadequate or poorly distributed health care resources.

Based on the reorganization within the Executive Office of Health and Human Services two years ago, the Title V program is actively involved with MassHealth programs and the Uncompensated Care Pool. In the reorganization, the Medicaid program was split into the Office of Medicaid, Acute and Ambulatory Care, and Long Term care which is located within the Executive Office of Elder Affairs. The operations functions were separated out and placed under the direction of the Under Secretary within the EOHHS. The Office of Health in the EOHHS includes MDPH, Health Care Finance and Policy, Acute and Ambulatory Care, and Mental Health. The current Assistant Secretary for the Office of Health is the Acting Commissioner of Public Health. This has assured that the Title V program and Center programs are at the table and involved in discussion and planning for addressing distribution of health care resources. Family Planning, for example, is involved in discussions with Medicaid concerning a family planning waiver. The Governor's proposed Safety Net program is being designed by the Office of Health. Over the past nine months, the key focus of the Office of Health has been on understanding the distribution of health care resources including financial access within the state and developing a plan to assure continued access. In addition, the Title V Director serves on a Policy Group that is looking at long-term care options not just for elders but for children and adults. The most critical need is for mental health services and the Title V Director is a member of the Mental Health Department Steering Committee. The major effort in this area is in integrating the state system with the Medicaid system, creating one behavioral health network of services. One effort has been to develop a pilot with four CHCs and four mental health providers, which will integrate services.

The Primary Care Cooperative Agreement, state loan repayment and Conrad 30 (J-1 Visa program) are all co-located with oral health, rural health, family planning, perinatal, pediatric and adolescent, Comprehensive Primary Care programs, adolescent pregnancy prevention, adolescent health, and school health. This assures that there is a strong collaboration between these programs and a focus on mothers, children, and families. Collaboration occurs across the programs and staff for HPSA designations, loan repayment, and Conrad 30 decisions.

Because CHCs are the major safety net providers in the state, Title V has a strong relationship both with the professional association and each health center. Working with the Massachusetts Hospital Association and the Office of Rural Health, the issues related to assuring hospital-based services within rural areas are addressed. The creation of the new and expanded Community Health Center sites has also increased the availability of services.

The Title V program is well-positioned and has long standing relationships with others outside as well as inside state government who address inadequate or poorly

distributed health care resources. The MDPH and Title V have been active participants in a number of collaborations to address disparities, as described above, including the Legislative Commission, rural health initiatives, and dental care initiatives. MDPH staff collaborated with Massachusetts ACOG to understand the effects of liability insurance on the supply and distribution of OB/GYNs in Massachusetts hospitals, and others. In addition, MDPH has relationships with most family advocacy organizations in the state as well as some national organizations.

2F2. Population-Based Services

The Center for Community Health directly manages certain population-based services such as newborn hearing screening. Whether managing the population-based services or not, the Center also coordinates with other agencies and organizations to insure that key population-based services occur. Selected population-based services are described in this section.

2F2.1 Pregnant Women, Mothers and Infants

Smoking Cessation

Massachusetts supports the Quitline that provides telephone counseling for smokers who wish to quit smoking. All women are screened for pregnancy status at intake. All pregnant women receive an immediate transfer to the “Great Start” national program designed to provide telephone counseling and cessation services to pregnant women.

Universal Newborn Hearing Screening

Massachusetts law requires that each child born in the Commonwealth receive a hearing screening at birth prior to discharge. After passage of the law, a multi-disciplinary Advisory Committee was established to assist in developing regulations and guidelines. This Advisory Committee has been active for over six years and continues to provide technical and clinical advice to the program. The state’s Universal Newborn Hearing Screening Program (UNHSP) systematically tracks and provides outreach and follow-up to the approximately 81,000 families with children born in the Commonwealth each year. Population of the data system begins with the electronic birth certificate system and it is then integrated with data from other early childhood programs in the Early Childhood Data System (ECDS). Additional information on diagnostic testing and family contact is collected in the Childhood Hearing Data System (CHDS), a sub-system of the ECDS. In addition, the state hospital licensure regulations have been amended to include a section on newborn hearing screening, and birth facility guidelines have been established. The UNHSP oversees birth facility protocols and also approves the audiological assessment/diagnostic centers to which hospitals refer children for follow-up testing. Site visits are performed at both birth facilities and audiological assessment/diagnostic centers. Although the site visits are held primarily to assure that protocols are being carried out, a strong emphasis is placed on data collection. Additional outreach is performed at a variety of settings, including the statewide Early Intervention Program and specialty programs that serve children who are deaf or hard of

hearing, college and university programs, and statewide and national conferences and trainings.

In addition to conducting site visits, the UNHSP provides three trainings per year for birth facility and audiological assessment/diagnostic center staff. UNHSP guidelines for approval require attendance at these trainings. The trainings include speakers who speak on a variety of topics such as the genetics of hearing loss, medical management of hearing loss and auditory dysynchrony. UNHSP staff also use this time to train audiologists about data collection requirements of the UNHSP and other emerging issues or topics.

With newborn metabolic screening, Massachusetts UNHSP staff have been meeting with representatives of other New England states and the state of New York as well as the MDPH Legal Office and Registry of Vital Records to begin to address the issue of “border babies” (children that are born in a state in which they do not reside, or reside in a state and are born in another state) to ensure that these families get connected to services.

Massachusetts is participating this summer in a workgroup that will bring together ten states to develop a plan to enhance Medicaid benefits for children with hearing loss: “Strategic Directions for Achieving National Objectives for Medicaid-Insured Children with Hearing Loss.” A meeting of this workgroup is being coordinated by the Maternal and Child Health Bureau, Maternal and Child Health Policy Research Center, and the National Center for Hearing Assessment and Management. Representatives from Massachusetts include the UNHSP Program Director as well as Barbara McMullen, RN, BSN, Assistant Director, Preventive Health Services and Early Periodic Screening, Diagnosis and Treatment (EPSDT).

Newborn Metabolic Screening

The statewide Newborn Screening Program is administered by the MDPH Bureau of Laboratory Sciences in conjunction with the New England Newborn Screening Program at the University of Massachusetts Medical School (NENSP). The NENSP is responsible for all program operations, including provision of services related to pre-test educational materials, training of hospital personnel, laboratory testing services, post-test reporting services including on-demand clinical consultation for clinicians, track-to-treatment and outcomes evaluation, conducting research to improve timeliness, quality, predictive values and scope of services, and conducting pilot studies as determined by the Massachusetts Commissioner of Department of Public Health. As described in Section 2E, virtually all newborns are screened for treatable disorders and diseases and most, as well, with parental consent, for cystic fibrosis and 19 other rare metabolic disorders.

Based on data from the past 6 years, the NENSP has calculated that about 1.5% of Massachusetts residents are born in (or transferred before screening to) another state. In addition, 475,876 births screened in Massachusetts in this time period, a minimum of 2.8% of Massachusetts occurrent births, were performed on babies born to residents of other states who gave birth in MA. The tracking of such “border babies,” to account for their being screened and offered appropriate services in their state residence is a challenge. Regional conference calls are underway to address some of these challenges, including two with New England states’ privacy officers. The calls are in “educational mode” as participants begin to understand the needs of the newborn screening

coordinators in each state, data system capabilities, and the variable interpretation of states' privacy laws.

The Newborn Screening Program has a standing advisory committee with representatives from pediatrics, neonatology, genetics, infectious disease as well as consumers, ethicists, and health care organizations. A 2005 meeting of the Committee is being scheduled and agenda items will include discussion of the ACMG proposal.

2F2.2 Children and Adolescents

School Vision, Hearing, and Height/Weight Screening

Chapter 71, section 57, of the Massachusetts General Laws requires annual vision screening and hearing screening as well as measurements of heights and weights for all school-age children except those for which the MDPH grants a waiver for certain grades. (The majority of the school districts do have a waiver.) In addition, the statute requires postural screening in grades 5 to 9. Through the ESHS, height and weight measurement are being promoted in four grades, and the updated proposed Massachusetts MCH state component measure for healthy weight includes monitoring of process in this area. WIC and SBHCs are also participating in this component of the measure to improve healthy weight.

The School Health Unit provides the following:

- Training in vision, hearing and postural screening through the School Health Institute. All new school nurses are required to participate in these trainings. They are presented in collaboration with the University of Massachusetts/Simmons College, Boston University School of Medicine (vision screening), Massachusetts Society of Eye Physicians and Surgeons, National Scoliosis Foundation, etc.
- Training in the new preschool vision screening protocols as required by an amendment to Chapter 71, s. 57. This amendment requires that all children entering kindergarten be screened within a year prior to entry. Screening includes stereopsis (identification of amblyopia) and acuity. During the FY 05 school year, the SHU collaborated with BU to train more than 600 primary care providers, their office staff and school nurses in these new protocols.
- ESHS Nurse Leaders have been trained in the correct techniques for measuring heights and weights. Their software then converts these into BMI's. While not required, the ESHS programs have been advised that if they measure a single grade, they should choose grade 4; for multiple grades, 1-4-7-10.

Childhood Immunization

The Center's Maternal and Child Health Immunization Program (MCH-IP) works with existing comprehensive, community-based systems of care to ensure accessible, affordable and appropriate pediatric immunization services for un- or under-insured children, with a particular focus on those who may be at greater risk due to socio-demographic factors. The program works in partnership with the Massachusetts Immunization Program (MIP) and Massachusetts WIC Program. The MCH-IP supports improved infant and child immunization rates through assessment and immunization

tracking, and integrates education, outreach, and referral mechanisms within these programs.

Population-based immunization activities including vaccine distribution and surveillance of vaccine-preventable diseases are the responsibility of the Massachusetts Immunization Program (MIP) within the MDPH Bureau of Communicable Disease Control. The MIP is funded by the federal Centers for Disease Control and Prevention National Immunization Program, with additional state funding primarily for the purchase and distribution of vaccines.

The MIP provides universal distribution of vaccine (free of charge) to all public and private providers for all childhood vaccines and limited distribution of certain adult vaccines. MDPH regulations require the age-appropriate vaccination, as recommended by the Advisory Committee on Immunization Practices (ACIP), for entry into licensed preschool/day care, schools, and post-secondary institutions. Childhood immunization activities include assuring that immunization status is checked and vaccinations delivered at every possible opportunity within the context of primary care.

The MIP conducts vaccine management audits and lot quality assurance (LQA) assessments of childhood immunization levels at public and private pediatric provider offices. These present an opportunity for both assessment of immunization coverage and of modifications the practice can make to improve its coverage. The MIP-supported MCH Immunization Program staff participate in these assessments at contracted primary care sites, and support practice changes to make improvements when appropriate.

The MIP funds, in full or in part, three positions within the Center related to training, monitoring, outreach and technical assistance at contracted primary care, home visiting, and WIC programs as part of its immunization improvement initiatives. The BFCH has closely collaborated with the MIP in multiple aspects of statewide immunization improvement efforts. Combined primary care, school health, WIC, and home visiting programs each have contract requirements for screening, education, and either provision or referral as appropriate. The MCH-IP works to assure that providers in these sites are provided the most up-to-date immunization protocols and provides technical assistance as needed. An MCH-IP Coordinator serves as a liaison with BFCH internal program staff and with contracting agencies. The MIP also funds an Immunization Specialist position within MCH-IP to help support these activities.

The MIP-funded WIC Immunization Coordinator provides training including continuing education credits, technical assistance and monitoring of all local WIC programs related to immunization. Local WIC program staff perform immunization assessments at all infant and child certification and re-certification visits until a child has completed the primary series of shots.

The MIP collaborates closely with the statewide health care delivery system in its immunization improvement efforts. MIP also funds an immunization program manager position within the Massachusetts Chapter of the AAP.

The MIP also has been actively working on the implementation of a statewide immunization registry. The Massachusetts Immunization System (MIIS) is a web-based immunization information management and vaccine management system that will support MDPH, providers, local boards of health and other health care providers in managing pediatric and adult immunizations, including forecasting and reminder-recall. In addition, the MIIS has a comprehensive vaccine management module that includes

vaccine ordering, reporting and recall management. The MIP began the development of this statewide immunization registry in 2004. An extended, field based, pilot program of the system will commence once the final production ready system has been completed in the summer of 2005.

Lead Screening

The Massachusetts Lead Law requires that all children in the Commonwealth of Massachusetts aged 9 to 36 months be screened annually for lead poisoning and, in high-risk communities, that children be screened at 48 months as well. The Commonwealth is recognized as a national leader in screening young children and working to provide lead-safe housing. Nevertheless, lead poisoning remains one of the greatest environmental health threats to children in the state. Massachusetts communities are identified as high risk when their adjusted 5-year incidence rate for blood lead level (BLL) equal or greater than 20 ug/dL is greater or equal to the state's comparable rate.

Nineteen communities were identified as high risk in 2004. From highest to lowest incidence rate, these communities were: New Bedford, Lawrence, Springfield, Fitchburg, Lynn, Holyoke, Chelsea, Boston, Pittsfield, Brockton, Worcester, Lowell, Somerville, Chicopee, Fall River, Haverhill, Taunton, Quincy, and Attleboro. Overall, in 2004, 73% of children ages 9 months to 48 months of age were screened; in high-risk communities, the screening rate was 81%.

Parent Resource for Early Child Health

MDPH has developed and is updating *Growing Up Healthy* (“the diary”), a child health diary originally developed in 1998 as a part of the Massachusetts Bright Futures Campaign to help parents of young children (birth to six) become more informed and empowered consumers of preventive health care for their children. Key goals of the diary are: to provide an easy to read/use resource for parents who may have difficulty accessing the health care system because of literacy issues, language barriers, or cultural/racial/ethnic differences; to increase the use of well-child care and ensure appropriate content of care; to improve parent and family knowledge of and involvement in well-child care; and to provide clinicians and health care plans with information and tools to provide quality well-child care. The diary, which has been translated into Spanish and Portuguese, includes content on growth and development; parenting skills; health and safety; resources for families; well-child visit records; and emergency preparedness. MDPH will print 85,000 copies, which will be distributed through the state’s 52 hospitals and birthing centers to families of all children born in the coming year. It will also be available on-line.

2F2.3 Cross-MCH Population

Poison Control

The Poison Control Center (PCC) is a regional center for Massachusetts and Rhode Island. It provides consultation in the diagnosis and management of poisoning cases to providers and lay consumers in Massachusetts and Rhode Island. The PCC maintains a 24-hour toll free telephone hotline service that offers immediate information and/or referrals related to poisonings. Frequent users of the hotline are parents of small

children, hospital emergency department clinicians and prehospital emergency care providers. In 2003, the PCC received 56,526 calls from Massachusetts providers and lay consumers. About 44,000 of these calls were for poison exposures; the rest were information calls. The PCC maintains a computerized poisoning reference database along with accompanying relevant databases, toxicology texts and journals.

Through an Advisory Committee, the PCC has developed innovative strategies and outreach initiatives to reduce unintentional and intentional poisonings and toxic exposures. Underserved populations, particularly mothers and children, have been prioritized, including urban residents and cultural and linguistic minorities. All outreach materials are translated into the two non-English languages most spoken by minority groups in a particular target area, most frequently Spanish and Portuguese.

Domestic Violence Screening

As a response to the high rates of domestic violence within the MCH population, VPIS developed the Domestic Violence Screening, Care, Information and Referral Project (DVSCRIP). The goal of this project is two-fold: develop a training curriculum for maternal and child health providers on issues of domestic violence as well as screening protocols to help identify and refer victims and develop standards for MCH providers to include screening protocols for domestic violence into their standard service delivery.

Injury Prevention and Control

The state's Injury Prevention and Control Program (IPCP) is one of the oldest in the nation. Several of its projects are described below:

Residential Fire Injury Prevention Project

The Residential Fire Injury Prevention Project is funded by a five-year grant from the CDC to increase the installation of smoke alarms and to provide in-home fire safety education for at-risk families and individuals in MA. The IPCP, in collaboration with the State Fire Marshal's Office, is working with local fire departments and other community agencies to install smoke alarms and provide fire safety education in low income, high risk households. Currently, fire departments are providing this service to low-income families and individuals, elderly and immigrant and refugee populations in MA.

Passenger Safety Program

The Passenger Safety Program provides training and education, technical assistance, coalition and task force leadership, program development (including local Child Safety Seat Checkpoints), and public information materials on a range of passenger safety issues with a specific focus on child passenger safety. IPCP maintains the *Car Safe Line*, a toll-free telephone line for Massachusetts residents who have questions about passenger safety and related Massachusetts laws, which receives many calls about child passenger safety.

Suicide Prevention Program

With the Massachusetts Suicide Prevention Coalition, the MDPH Suicide Prevention Program is implementing the statewide strategic plan for suicide prevention

across the lifespan. The major program activities of the Suicide Prevention Program include: outreach and education through trainings and conferences for school personnel, elder service providers, mental health clinicians, law enforcement officers, first responders and others; support of community-based prevention efforts; development of outreach and education materials such as the Massachusetts Suicide Prevention Resource Guide; and participation in collaborative efforts, such as the EOHHS Task Force on Suicide Prevention in Residential Facilities.

2F3. Infrastructure-Building Services

2F3.1 State capacity to Promote Comprehensive Systems of Services, Local Delivery Systems, Collaboration, and Coordination, and the State's Perspective on Local Systems

Because of its location within the Center for Community Health and the Department of Public Health, which is located within the Office of Health, Executive Office of Health and Human Services (EOHHS), the state Title V program has a tremendous capacity to promote comprehensive systems of service. One of the major goals of the state reorganization two years ago was to develop a system that promoted collaboration and coordination across all the programs within EOHHS. Through multiple work groups and advisory groups, the level of collaboration has increased dramatically. In addition, the reorganization with the MDPH created Centers that were charged with developing cross-communication and initiatives across both programs within the specific Center and across Centers. Within the Center for Community Health, Title V currently has increased cross-program initiatives with Health Promotion and Chronic Disease Prevention, Violence and Injury Prevention, Tobacco, HIV/AIDS, Multicultural Health, Healthy Communities, and Substance Abuse.

Within the EOHHS, reorganization has assured that the Title V program has been involved in the development of the new Medicaid MMIS system, the Medicaid waiver application, the Governor's Health Care Reform package, the creation of the new Department of Early Education and Care, the development of the new Autism division at the Department of Mental Retardation, development of new complex case management program for children receiving services from multiple state agencies, participation in the creation of new suicide and mental health protocols and guidelines for children in state residences, and more. At the state level, there is a commitment to creating a comprehensive system of services for mothers, children and families. While we have moved forward in many areas, much work to remains.

Beyond EOHHS, there has been increased involvement with the Department of Public Safety. Linkages with the Department of Education continue to be strong, and utilizing the Coordinated School Health Grant the level of collaboration has increased. The CSHCN program and Division of Health Promotion and Chronic Disease prevention have ties with transition programs, vocational rehabilitation, special education and developmental disabilities programs.

The capacity to work with, influence, and promote comprehensive provider-based service systems continues to include not just hospitals and community-based providers such as community health centers but the private providers, professional associations

such as AAP, ACOG, and the Massachusetts Medical Society, as well as payers and insurers, for example, the continued participation (described below) on the Massachusetts Health Quality Partners and the Alliance for Health Care Improvement.

The Department of Public Health CSHCN program collaborates with other state and federally funded agencies and organizations to address the needs of individuals with developmental disabilities. The Director of Family Initiatives represents the Department as a council member on the MDDC. In that role, she participates in the development of the Agency's 5-year plan focusing on the creating supports that enable individuals with developmental disabilities to live within their communities and access effective educational, employment and recreational opportunities. As a Council member, she provides information about MDPH resources, reviews grants and assists families to access Consumer Empowerment Funds. In addition, the Director of Family Initiatives sits on the Advisory Board of the Institute for Community Inclusion, one of Massachusetts' two University Centers for Excellence in Developmental Disabilities. ICI works across the lifespan to develop and disseminate programs and resources. The Director of Family Initiatives provides the public health and the family perspective on the need for and availability and efficacy of these programs, resources and community based supports for individuals with developmental disabilities.

It has also been critical to work with communities as they design their approach to addressing specific programs and multiple collaborations are currently in place. The Healthy Communities program and the 6 Regional Offices are key in providing both the on-going information related to issues, changes, and needs and connections to the key stakeholders within specific communities. The Rural Health Advisory Council has assisted us in assuring that services are designed and provided to meet the needs of these communities and to promote accessibility.

Without county health departments and minimal comprehensive city health departments, the Department has developed a network of health and human service providers along with local Boards of Health to create a network of services. The MDPH through the Office of Healthy Communities launched the statewide Community Health Network Areas (CHNA) Initiative in 1994. The CHNAs mission is convening youth, parents, schools, community coalitions, local boards of health, non-profit and for-profit organizations and institutions, and other local and state agencies to collaboratively identify, plan and effectively utilize public and private resources to improve the health of the Commonwealth's residents.

CHNA is a forum for mobilizing the communities around health issues impacting residents and promoting prevention efforts to address the identified health priorities. This initiative is designed to enhance access to care and create a client-centered, outcome-oriented health service delivery system in each community. CHNAs promote efficiency in service delivery by working to reduce duplication and by identifying service gaps. They work to increase prevention efforts that will reduce the demand for health care services.

In addition, each CHNA continues to build capacity within its local region through the services of the MDPH funded Regional Centers for Healthy Communities (RCHC). RCHC staff provide technical assistance to community-based coalitions (including CHNAs) and agencies in assessing local and regional needs. This support includes analysis and interpretation of data provided by MDPH through annual birth and

death data reports. Staff also provide assistance in the design, implementation and analysis of community needs assessments that identify assets and deficiencies of the service delivery system for the MCH population. For example, MDPH regional managers have worked with selected communities to determine the extent and underlying causes of racial and ethnic disparities in perinatal health outcomes and to make recommendations for system improvements. This has been accomplished by convening key community stakeholders and conducting focus groups with targeted racial and ethnic populations in some communities and in assisting coalitions in other communities in the preparation of grant applications for funding that support system capacity-building at the local level.

A further consolidation occurred creating 10 service areas that can be used in relation to bioterrorism and other emergencies. Key to creating, promoting and maintaining local service systems has been involvement with key stakeholders to assure the system meets the unique needs of the local communities.

These local and regional resources and the examples of infrastructure-building collaboration efforts in which Title V has major involvement described below, inform the Title V program's perspective on how local and regional delivery systems meet the MCH population's needs, a perspective documented throughout this needs assessment. The collaborations provide information about appropriate standards, how well they are implemented, whether the agencies providing services and the communities and individuals to be served consider them to be working, and whether the available data support these perceptions. As described in the section below on monitoring and evaluation, the Title V program is also actively involved in monitoring the delivery of services and evaluating their efficacy.

Substance Abuse Strategic Plan

In 2004, the Commonwealth under the MDPH, Bureau of Substance Abuse undertook an effort to develop a statewide Substance Abuse Strategic Plan. Input was solicited from a broad spectrum of human services providers, state and local law enforcement, advocacy groups and others. In total, representatives of more than 30 federal, state and local agencies as well as dozens of private sector stakeholders, clinical and research experts and consumers participated. The overall goal of the plan is to enhance the Commonwealth's collective ability to reduce the scope and consequences of a problem whose impact is felt throughout the human services, health care, judicial, corrections, public safety systems and every community of the Commonwealth.

Based on the plan, the Commonwealth will integrate prevention, interdiction, enforcement, screening, assessment, and treatment and support efforts. Efforts will be strategically directed to reduce health care costs, crime, homelessness, and deaths. Programs and services will be organized to empower people to live full and productive lives. In the past the focus has been on developing and funding services rather than strategies. This plan shifts the focus to strategies and increased coordination and collaboration. Adolescents, pregnant women and families have been identified as key populations who are considered at risk and will be targeted.

Statewide Coalitions for Asthma, Healthy Weight, and Chronic Conditions

MDPH has collaborative initiatives in place developing statewide community coalitions related to healthy weight, asthma, diabetes, cardiovascular health, and cancer. MDPH provides staffing and data support, generally with assistance from CDC grants. These coalitions each develop state plans and also coordinate with each others' plans, including sharing and contributing to common objectives. They address these interrelated issues across the lifespan, including work with all three MCH populations. Plans promote environmental changes (policy and systems changes) in multiple venues, including school, work, and the community.

The Massachusetts Asthma Planning Collaborative Initiative (MAPCI) is an example. It is beginning a collaborative with a goal to form a strong and diverse coalition, composed of interested stakeholders (healthcare providers, public health researchers, local coalition members, and representatives of the business community) who together design a state plan. The asthma state plan will become the means for the state to address asthma in MA.

MAPCI has already been working to expand the use of asthma action plans (AAP) in the state – an AAP is written medical instructions for the patient (and family) to manage asthma episodes and administer asthma medications. MAPCI is also working to improve physician education around asthma diagnosis and treatment.

The Massachusetts Partnership for Healthy Weight (PHW) has already developed a burden document and state plan, which it is implementing. Over 100 public and private organizations from public health, education, academia and industry and coalitions and other groups were involved in the development of the state plan. Partnership members implement initiatives that help meet the objectives outlined in the state plan. Key focus areas include improving policy and systems that support individual and family access to healthy foods and opportunities for physical activity. This is accomplished by implementing initiatives at the state, city and town, organization and individual level.

Examples of PHW collaborative efforts include: with Blue Cross and Blue Shield of Massachusetts to implement Healthy Choices, a nutrition and physical activity intervention designed to improve student knowledge and improve school policies to support healthy eating and physical activity among Massachusetts school children, in 116 middle schools in FY 2006; with Rails to Trails and the National Park Service to implement a neighborhood physical activity initiative; with the Progressive Providers Network to implement a pilot nutrition and physical activity education program for adults with disabilities and CYSHCN; and with YMCA Alliance and University of Massachusetts Boston to implement an after school nutrition and physical activity program for youth. Partner organizations also support local community nutrition and physical activity efforts. Communities that have community-wide initiatives include Attleboro, Boston, Cambridge, Somerville, Needham, Newton, Norwood, Springfield, and Waltham. MDPH has developed a database of physical activity resources on a community by community basis, which will be available on the Partnership for Healthy Weight website in the near future.

Nutrition and Physical Activity Infrastructure

Nutrition and physical activity capacity is critical in relation to all MCH populations and relates to promotion of healthy weight, prevention of chronic disease, and support for breastfeeding, all of which relate to healthy pregnancies, mothers, infants, children and adolescents. For children with special health care needs, nutrition and physical activity accommodations or specialized services may be required. Increasing capacity to promote healthy weight is an MCH priority in Massachusetts, with a new state-developed measure to monitor progress.

The Center has developed or supported capacity to address nutrition and physical activity, including:

- The Partnership for Healthy Weight, described in the preceding section.
- WIC, with a broad network of care and relatively stable funding that can serve all income-eligible women, infants and children to age 5 across the state. WIC nutrition and breastfeeding service providers come from multiple cultural and linguistic backgrounds, and materials are available in up to nine languages as needed.
- The Nutrition Division in the Center, which houses the WIC program. The Division and WIC have strong coordination for various projects with CHCs, other MCH programs (including, for example, targeted outreach and enrollment for homeless families), the Massachusetts Breastfeeding Coalition (to improve breastfeeding services and rates), MassHealth (for example, for integrated participant referrals and educational materials for pregnant women), the Massachusetts AAP (for example, for key health messages for pediatricians to prevent overweight in children) and others.
- The Essential School Health and School Based Health Center programs. Both have provided training in BMI monitoring and healthy weight promotion. They have incorporated nutrition and physical activity initiatives into the guidance that contracted programs follow. For example, school nurses and clinic nurse practitioners screen for healthy weight and make referrals.

WIC and programs located in schools also participate in the Partnership for Healthy Weight.

This capacity for nutrition and physical activity and promotion of healthy weight is not universally available across all populations, age groups, and geographic areas. One issue is the lack of consistency of messages between various community-based providers and medical practitioners about breastfeeding, feeding recommendations, healthy eating, and physical activity. Another is inconsistently available treatment for overweight and the lack of nationally recognized evidence-based programs, particularly for children. Nutritionists and lactation consultants are not as available at all hospitals and communities as needed. Within schools, healthy foods are not always readily available; vending machines provide unhealthy snacks. Center programs and the Partnership are engaged with schools in attempts to change the school environment to encourage healthy choices. For surveillance, surveys are in place, although they do not cover all age groups and subpopulations. Increasingly, BMIs are collected in schools, school based health centers, WIC programs, and other venues.

Injury Prevention and Control

The Injury Prevention and Control Program's (IPCP) primary work is through infrastructure building. IPCP staff provides leadership to an array of collaborative initiatives that inform policy development and enhance data collection and surveillance efforts to document the extent of the burden of unintentional injury and suggest areas of emerging programmatic need. In FY 2005, IPCP completed a draft of *Maximizing Our Efforts: The Massachusetts State Injury Prevention Plan*, a document which is intended to guide MDPH injury prevention activities over the coming five years. The plan outlines major priorities and next steps for this work, four key focal areas for prevention (motor vehicle occupant safety, elder falls, poisonings, and fire and burn-related injuries), and two overarching issues that must be integrated into prevention strategies – traumatic brain injury and the role of alcohol and other substances. As a result, MDPH has convened a Traumatic Brain Injury Task Force to respond to the significant incidence of TBI across the lifespan. This Task Force will be focusing on 5 major areas: Passenger Safety, Shaken Baby Syndrome, Suicide, Occupational Injuries, and Elder Falls. The Task Force has set itself a one-year timeframe to develop recommendations that will be presented to the Department.

IPCP's Emergency Medical Services for Children (EMSC) Program provides support and enhancement of emergency medical services for children, including training and curriculum development, comprehensive injury prevention initiatives, innovative planning and policy development, and the development of pediatric care standards and protocols.

Massachusetts Child Fatality Review

The Massachusetts Child Fatality Review is a process in which MDPH is an active participant and leader on the State Team. The Massachusetts Child Fatality Review law, passed by the state legislature in October 2000, established Local Teams within each of the 11 District Attorneys' offices and a State Team within the office of the Chief Medical Examiner. The Local Teams collect information on individual cases, discuss case information in team meetings, and advise the State Team by making recommendations for changes in law, policy and practice that will prevent child deaths. Local Teams also take action at the community level to enhance the safety of children. Through the review process, Child Fatality Review Teams promote collaboration among the agencies that respond to child deaths and/or provide services to families.

2F3.2 Standards of Care, Guidelines, Program Monitoring, and Evaluation

The Title V Program is involved in multiple areas related to standards of care, guidelines, program monitoring and evaluation. The following are a few key examples.

Perinatal Regulations

The Department of Public Health currently licenses 51 hospitals to provide maternal and newborn care plus one freestanding children's hospital providing newborn intensive care. For more than 18 months, the Department has been working with clinicians, hospitals, professional organizations, and consumers to revise hospital licensure regulations governing maternal and newborn services.

With the advice of these individuals, organizations, the Perinatal Regulation Revision Task Force and several working groups, the Department is proposing amendments to the regulations that are consistent with our goal to ensure mothers, newborns and their families have access to and receive quality care. Amendments include 1) standardization of the definitions and service requirements for the various levels of hospital maternal and newborn care 2) updating and improving hospital providers' credential requirements and 3) mandating reporting requirements on patient volume and quality of care. The amendments incorporate the principles of national recommendations to address the Healthy People 2010 Objectives, American College of Obstetricians and Gynecologists (ACOG) and the American Academy of Pediatrics (AAP) guidelines, modified to the Massachusetts health care system.

Within MDPH, the proposed amendments represent the collaborative efforts of the Department's Center for Community Health, and Center for Quality Assurance and Control with input from the Center for Health Information, Statistics, Research and Evaluation and the Center for Communicable Diseases.

MA Health Quality Partners

The Massachusetts Health Quality Partners (MHQP) is a broad-based coalition of physicians, hospitals, health plans, purchasers and government agencies first established in 1995 to promote improvement in the quality of health care services in MA. Member organizations include Blue Cross Blue Shield of MA, Fallon Community Health Plan, Harvard Pilgrim Health Care, Health New England, Tufts Health Plan, Massachusetts Hospital Association, Massachusetts Medical Society, Massachusetts Department of Public Health, MassHealth, MHQP Physician Council, two consumer representatives and one employer representative.

MA Health Quality Partners (MHQP) has issued Adult and Pediatric Routine Preventive Care Recommendations and Immunization Guidelines every two years since 2001. A collaborative working group of clinicians compiles a single set of preventive care and immunization recommendations to eliminate inconsistent guidelines and to support efforts to provide high quality, evidence-based care. The guidelines are based on recommendations from the U.S. Preventive Services Task Force (USPSTF), the U.S. Centers for Disease Control and Prevention (CDC), the Massachusetts Department of Public Health (MDPH), the American Academy of Pediatrics, and the American Academy of Family Physicians and other nationally recognized specialty societies. The guidelines are used by managed care organizations in the Commonwealth to help satisfy National Committee for Quality Assurance requirements.

Massachusetts Diabetes Prevention and Control Program

The Massachusetts Diabetes Prevention and Control Program (MDPCP) is in the process of developing guidelines for the management and care of gestational diabetes. These guidelines are expected to be released by summer of 2005 and will be followed by consumer information brochures.

Statewide Smoke-Free Workplace Bill

The statewide smoke-free workplace bill prohibits smoking in any worksite. Pregnant women are thus protected at work from second-hand smoke.

Violence Prevention

Violence prevention staff provide substantial leadership in the area of violence prevention at the community, state, regional, and national levels. In all of these venues, staff bring a public health, *prevention* perspective to the work that often compliments the criminal justice perspective or victim service perspective of many of our collaborative partners.

Staff serve on each of the seven committees of the Governor's Commission on Sexual and Domestic Violence, a body composed of leaders in state government, the battered women's movement, the criminal justice community, health care and human services. Additionally, staff from the Supportive and Healthy Communities for Gay and Lesbian Youth Project work closely with the Governor's Commission on Gay and Lesbian Youth to develop standards and programming that address the specific violence and suicide prevention needs for this population.

The Sexual Assault Prevention and Survivor Services (SAPSS) program plays a leadership role in the development of statewide policies and programs that respond to the needs of sexual assault victims. The SAPSS program fosters collaborations with other state and community organizations, such as Jane Doe, Inc: the Massachusetts Coalition Against Sexual Assault and Domestic Violence to maximize the effective use of resources and achieve program goals toward the elimination of sexual assault and has been a significant source for data collection and analysis on sexual assault. The Director of the SAPSS program chairs the Massachusetts Coalition for Sex Offender Management and was a leader in the founding of the Massachusetts Child Sex Abuse Prevention Partnership.

Staff has begun implementation of the *Youth Violence Prevention Initiative* through funding from the Centers for Disease Control and Prevention. Currently in the early stages of this work, the Initiative is developing a statewide, multidisciplinary Youth Violence Prevention Coalition whose intent is to gather information regarding resources and needs and to develop a statewide strategic plan for addressing youth violence prevention. The Coalition is currently pulling together and examining the existing data in order to prioritize those at greatest risk and consider protective factors that can be effectively employed in prevention initiatives. This Coalition puts the Department in partnership with a wide variety of other state agencies, community based providers, researchers, and activists all concerned with addressing youth violence from a comprehensive public health approach.

By state statute, the MDPH is required to develop certification specifications for batterer intervention programs and to monitor programs for their compliance. The MDPH has developed "*Guidelines and Standards for the Certification of Batterer Intervention Programs*" which are comprehensive and detailed in their requirements for these programs. Additionally, the program has developed pilot program specifications for working with adolescent perpetrators of dating and domestic violence as well as batterers in same sex relationships. These program specifications are the first statewide standards of their kind. Certified programs serve court-, DSS-, and self-referred perpetrators of domestic violence by offering education and holding these men accountable for their abusive behavior. These community-based programs are required to have working relationships with local domestic violence programs and rape crisis centers and to offer community education programs.

The Sexual Assault Nurse Examiner Program has developed what is considered the national gold standard kit and protocol for forensic evidence collection in sexual assault case. The protocol has changed the standard of care for adolescent and adult victims of sexual assault entering hospital emergency departments in this state – both those that are designated “SANE sites” and those that are not designated, but that have been influenced by this standard of care. Additionally, the SANE program has developed a pediatric sexual assault forensic evidence collection kit – the first of its kind in the country – as well as an accompanying protocol and curriculum to train specialized pediatric SANEs to provide services to victims under the age of twelve. Twenty-six pediatric providers have been trained. In state FY 2006, funding has been allocated by the Massachusetts State legislature to support initial implementation of pediatric SANE services. MDPH will pilot the developed protocol and pediatric kit during the first year and expand implementation into child advocacy centers in coming years. Implementation of pediatric SANE is a newly proposed state MCH measure.

School Health

The ESHS program sets requirements for the participating districts, many of which have influenced other districts through the consultation offered to school nurses. The program is in the process of revising its 800-page *Comprehensive School Health Manual*, with a plan to distribute it by CD to all schools in Massachusetts. Recently promulgated regulations include reporting of epinephrine (Epi pen) administrations for life-threatening allergies by all schools.

Child Care Health Consultants Development

Current Massachusetts state child-care regulations require a Child Care Health Consultant (CCHC) of record, but do not require CCHCs to visit programs. A recent study in the Boston area found that as many as 25% of ECE programs do not even have current contact information for their CCHC. Since 2002, the six New England states, as Healthy Child Care New England (HCCNE), have collaborated in training CCHCs. Each year, CCHC training reaches approximately 100 participants through jointly funded and produced multimedia-training activities, including on-line training.

The New England states have worked together to enhance the HCCNE’s sustainability and strategic impact. Title V Directors agreed to support efforts to continue HCCNE training including allocating a small amount of funding (\$2,000 per state). Currently, HCCNE is exploring other funding sources for long term sustainability, including working with regional insurance companies and foundations. Additionally, the Connecticut Nurses Association has agreed to serve as the HCCNE’s fiscal agent, as well as the source of Nursing Contact Hours for the training. The New England states have also agreed to develop a common assets-based MCH measure related to CCHCs.

To reduce HCCNE’s costs, enhance accessibility and expand the training audience, on-site training will be shortened and the online training component will be broadened. Online content will address the role of a CCHC, children’s social-emotional development, access to medical homes and health insurance, and injury prevention and playground safety. Massachusetts is exploring the possibility of making online training modules accessible to families and ECE providers.

To strengthen expectations and formalize roles for CCHC's across the state, MECCS is working with HCCNE, the National Training Institute for Child Care Health Consultants (NTI), and other national partners to support the development of a CCHC credential with required competencies, as well as standardized job descriptions, involving on-site consultation. The HCCNE training collaboration has been working closely with NTI, since both groups are planning similar revisions to their training format to include more on-line or distance learning segments.

For future activities, the HCCNE collaboration will widen the health consultant training audience to include mental health consultants, child care licensors, and other staff who consult to ECE programs. Often mental health consultants are clinicians who have limited knowledge and skills to work effectively within ECE settings and with diverse communities. The NTI curriculum addresses best practices in areas relevant to the expanded audience, including consultation skills, working with children with special needs, ECE quality issues, cultural competency, and policy development. The training closing activity is the development of Action Plans so trainees can practice applying their learning and knowledge of the CCHC's role.

By reaching licensors and other consultants, the NE training effort expects to boost its impact on young children's education and care services to more widely address health, mental health, and safety. Data from last year's training evaluation demonstrated the potency of including licensors in the training; one licensor's work potentially affects the lives of over 20,000 children each year. And, by bringing consultants, licensors and CCHCs together for training, HCCNE creates a new professional network with immense potential for collaboration across disciplines and within communities. To support that potential, MECCS will create a listserv and website bulletin boards and chat functions to support dialogue among the training participants.

Program Monitoring and Evaluation

Massachusetts uses a purchase of service system to provide most MCH services. While contract payments are regularly monitored, so is contractor performance with specific outcome measures identified, tracked and annually reported. The Center also performs program audits, including on-site visits and client record reviews. Vendor performance measures are weighed along with other criteria when new contracts are awarded. Statistics and Evaluation (S&E) staff within the Center for Community Health provide these measures, often developed from program data as reported by contractors.

S&E houses a total of 43 epidemiologists, research analysts, consultants and others, who support program staff engaged in logic model development, program monitoring and evaluation. Each program area has a plan for surveillance/needs assessment activities, evaluation and capacity for analyses to advise policy and program development. The Center leadership has affirmed as both a principle and an MCH priority that managers and staff use data and evaluation to prioritize issues, inform practice, support programs, and adapt to shifts in the continuum of care and nature of issues. A logic model provides a roadmap for the implementation of this principle by identifying all relevant factors for service success, including those not under the control of program staff. These relevant factors are measured and represented in the logic model by data set elements and statistics that are useful in performance monitoring.

A logic model also guides program evaluation by identifying outcome measures at various time intervals and by identifying the long-term service impacts expected. Having measures defined in this manner assists the evaluators by identifying which outcomes can be the evaluation's focus after a given time period. A properly specified statistical model using accurate and timely measures forms the basis of service evaluation studies. Qualitative as well as quantitative methods are used in evaluation studies. During FY 2006, S&E staff will be trained in the use of qualitative analytic software {Atlas TI}. Evaluation studies are planned for teen pregnancy prevention services, chronic disease statewide coalition development and youth services coordination. Newborn hearing screening and EI services studies have informed this needs assessment and will continue, including a cost study for EI in FY 2006.

2F3.3 Key MCH Data Systems Development and Linkage Efforts to Assure Comprehensive Systems of Care

MA is using and developing new data linkages to improve understanding of the relationship between perinatal and birth events and later child health outcomes, assisted by the MCH State Systems Development Initiative. The Title V Director is the Executive Sponsor for the Virtual Gateway/Electronic Services Management/Electronic Invoice Management (ESM/EIM) project, formerly called STEPS. It will provide the mechanism for integrating services and the service data, including client records related to intake, encounters, claims, and discharges across programs. It also provides supporting architecture that includes or will include over time interfaces to Medicaid, Food Stamps, programs at the Departments of Mental Health, Social Services and Mental Retardation, births, immunizations, and other health systems. Existing functionality for this system was integrated with the state's Health and Human Services (EOHHS) secretariat's Virtual Gateway project in 2004. The Virtual Gateway includes an internet-based common intake application to be used by hospitals and health and human service providers to obtain information about public programs, enroll in MassHealth (the state's Medicaid and other public insurance programs) and the uncompensated care pool and referral to other public programs such as WIC, child care and Food Stamps. This system will be expanded over the next year to allow for direct enrollment from the majority of public health programs and many other state programs. This expanded system known as ESM/EIM is currently undergoing testing and will include eligibility screening, enrollment, service tracking and invoicing. It is expected that in a later phase direct consumer access will be developed. The current system includes the functionality to identify eligible WIC clients based on their Food Stamp or MassHealth applications, query them as to whether they would like a referral and then make the referral to the WIC program. Over time all DPH programs and most of the child and family programs within other Health and Human service agencies will be integrated into the system.

Of major significance for data linkage projects, to facilitate the common intake and follow-up services, EOHHS developed regulations that enable data sharing across EOHHS client-service programs, within federal constraints.

The Pregnancy to Early Life Longitudinal database (PELL) is a public-private partnership between the MDPH, Boston University School of Public Health, and the CDC, which is also the funding agency. PELL links data in order to examine the impact of the prenatal environment and experience on postnatal child and maternal health. A

second goal of PELL is to evaluate public health strategies and programs. The core PELL database consists of birth certificates, fetal death records and birth-related hospital discharge data on both mothers and infants. Starting with 1998 data, PELL links data sets each year when the files become available. Linkage is beginning to 2003 birth data. The core has been linked to records from Early Intervention, birth defects surveillance, and other public health programs.

Linkage of PELL and EI data have provided a unique opportunity to use population-based data for Early Intervention program evaluation. Several aspects of EI program referral, assessment for eligibility, and enrollment in Massachusetts were evaluated using this data: the percentage of children born at high risk of developmental delay due to birth risk factors who are referred for services; time to EI referral among infants born < 1200 grams; and maternal socio-demographic characteristics associated with EI referral, evaluation, and enrollment. PELL linked files will be used for the newly proposed Massachusetts measure of interpregnancy interval less than 12 months.

WIC has been creating a monthly file for PELL since July of 2004. Agreements that enable the current PELL programmers to test the WIC files have been completed and testing will continue this grant year to assure that, when 2004-2005 birth data are available, the WIC files can be linked. WIC currently does not maintain histories for WIC participants needed for the proposed MCH analyses. Consequently, MDPH created this system to accept monthly files and create histories for them.

Interpregnancy interval (IPI) data are available from both the annual birth data (retrospectively) and longitudinally linked birth data in PELL (prospectively and retrospectively). Depending on the policy question each method has its utility in MCH to improve maternal health and improve birth outcomes. For the first time this year, IPIs were analyzed by age of the mother, correlated with birth outcomes, and released as part of the annual public press event. IPI will be included as an ongoing measure in the annual births release as well as to develop program initiatives to decrease the percent of women giving birth who have short IPIs.

A three-month pilot of the Pregnancy Risk Assessment Monitoring System (PRAMS) began April 1, 2005, and Massachusetts intends to submit for funding to CDC. For the pilot, Massachusetts obtained substantial input from CDC and other states; developed an internal working group and advisory board, selected questions, developed funding for printing the materials (including internal sources and the March of Dimes); created and printed materials to mail to the women selected for the survey; set up the CDC-required tracking system; obtained IRB and internal data use approvals; randomly selected the sample from birth records; prepared the mailing; and hired a contractor to conduct phone interviews of women who do not respond by mail.

2F3.4 Four Constructs of a Service System for CYSHCN:

The Maternal and Child Health Bureau has defined four constructs by which to assess the service system for CSHCN and state involvement with it. This capacity assessment responds to each of these four constructs in turn below.

1. Collaboration with other state agencies and private organizations

MDPH continues to collaborate with other state agencies and private organizations, either through specific initiatives that we oversee or in which we participate. Key among these collaborative efforts have been:

The Massachusetts Consortium for CSHCN

The Massachusetts Consortium for CSHCN is a working group of which MDPH is a key player. The Consortium offers a tremendous opportunity for collaboration. The Consortium, which was formed in 1999 to address continuing gaps in service and to promote improvement in the quality of the overall system of care for CYSHCN in MA, represents a broad array of over 180 members representing more than 70 organizations working on improving systems of care for CYSHCN in MA. Members include parents, direct care providers, parent organizations, state agencies (Departments of Mental Retardation, Mental Health, Education and Public Health; Division of Medical Assistance (MassHealth); Mass Rehabilitation Commission; and Mass Developmental Disabilities Council), health plans, academic institutions, hospitals and other health care settings. The CSHCN Director is a member of the Consortium Steering Committee, while other MDPH staff serve on other Consortium work groups. The Director of Family Initiatives co-chairs the Consortium's Family Participation Work Group, the Director of Care Coordination and Medical Home Initiatives is on the Medical Home Work Group, the Care Coordination Supervisor is on the Care Coordination Work Group, and the Director of Special Projects is on the Transition Work Group. Other MDPH staff also participate in the larger Consortium activities. MFT's Family-Professional Partnerships Institute, Transition Training, and medical home activities will be carried out through a contract between MDPH and the Consortium, and will include significant collaboration by the Massachusetts Chapter of the American Academy of Pediatrics Committee on Disabilities.

As an example of a Consortium project, in 2004-2005 the Consortium and MDPH conducted a pilot "Family Partners Initiative," which consisted of six pilot family-professional collaborations. Organizations such as health insurers, academic institutions and community-based practices were invited to apply to participate in the pilot, which was intended to model a variety of partnerships between families/consumers and professional organizations. The selected organizations were then partnered with a parent of a child with special health care needs to work with them on a particular project. The participants included three pediatric practice sites that wanted to develop Family Advisory Councils; one managed care organization interested in assessing need for and developing and implementing an orientation curriculum for its Member Services staff, aimed at helping the staff work more effectively with families of CSHCN; one school of public health's MCH department, that was interested in making its faculty more aware of the need to model family involvement within the MCH curriculum; and one school for students with disabilities that wanted to develop an orientation for school staff. These pilots helped the Consortium and MDPH further identify the needs of professional organizations and families in facilitating meaningful family-professional partnerships. MDPH and the Consortium are now in the process of developing a Family Professional Partners Institute, which will expand on this initial pilot.

The Consortium was involved in needs assessment focus groups and analysis of National Survey of Children with Special Health Care Needs data.

The Early Intervention Interagency Coordinating Committee

The Early Intervention Interagency Coordinating Committee (ICC) has promoted strong interagency collaboration for the 0 to 3 population generally. Parents recruited through the ICC were involved in the needs assessment.

The Federation for Children with Special Needs

The Federation for Children with Special Needs is the state's parent training and information center. MDPH works with the Federation to help ensure an informed and empowered family constituency. MDPH has several contracts with the Federation. The Federation was involved in the needs assessment through focus groups.

The Alliance for Health Care Improvement

The Alliance for Health Care Improvement is a collaboration of the Medical Directors of the five MA-based not-for-profit health plans. Representatives from member organizations were involved in the needs assessment through the MassHealth MCH Quality Improvement task force.

MDPH has collaborated with the non-profit health insurance plans of the Alliance for Health Care Improvement (Blue Cross Blue Shield of MA, Fallon Community Health Plan, Harvard Pilgrim Health Care, Neighborhood Health Plan, and Tufts Health Plan), New England SERVE, and the Massachusetts Consortium for CSHCN, to create *Directions: Resources for Your Child's Care*, a health education tool for families of CSHCN. The purpose of *Directions* is: 1) to help families organize health records and information; 2) to provide resources and specialized information about caring for a child with special health care needs; and 3) to improve communication among families, health care providers, and health insurance plans. Content includes forms for record-keeping; resource information and parent tips related to a child's medical team, everyday home care, health insurance, education planning, transition to adulthood, and connecting with other families; and a resource directory. 7,500 English and 2,500 Spanish copies were printed in 2005 and are being distributed to families and providers of CSHCN through a variety of methods, including physician practices and health plans. (Portuguese translation is currently underway.) Copies were sent to 1,800 members of the Massachusetts Chapter of the American Academy of Pediatrics.

Other MDPH Collaborations

Other MDPH collaborations that enhance capacity and support the state program's efforts include:

- Collaboration meetings with the MassHealth Community Case Management Program.
- Participation on an interagency working group, convened by the state Department of Mental Retardation, around state agencies' Family Support Plans.
- Participation in the Governor's Commission for Employment of People with Disabilities' Youth Leadership Forum for Students with Disabilities.

- Partnership in the New England Genetics and Newborn Screening Collaborative, which is engaged in efforts to enhance genetics literacy and newborn screening systems.
- Participation on the National Disability Mentoring Council, a project of Partners for Youth with Disabilities.
- The SSI/Public Benefits Specialist is an ex-officio member of the Statewide Special Education Advisory Council; a member of the Disability Determination Services Advisory Committee; and a participant in the SSI/Disability Coalition along with the Disability Law Center and statewide legal assistance programs.

2. State Support for Communities

State support for communities is provided through multiple programs, process and initiatives. Specific programs of the Division for Perinatal, Early Childhood and Special Health Needs address the special needs of children with disabilities at the community level. Initiatives in this area include intensive efforts to promote provision of Early Intervention services in natural environments (aimed not only at improved services for individual children but also at increased community understanding of and capacity to meet special needs); the MASSTART program which provides consultation to schools and families about safe school placement of very medically involved children; the Family TIES program, which provides information and referral to families of CSHCN and their providers, and also serves as the state Parent-to-Parent organization; the Flexible Family Support Fund and the Catastrophic Illness in Children Relief Fund, which provide financial support to eligible families with CSHCN; and practice-based MDPH care coordination in community-based medical practices, which helps increase the capacity to meet needs of CYSHCN at the community level.

In all meetings and focus groups with parents of CSHCN for this needs assessment, there was agreement when asked for the strengths of the Massachusetts system of care that the various forms of parent support and, in particular, parent-to-parent support came first. Education of parents to promote family participation and parent support occurs through the Family TIES program, the Massachusetts statewide information and referral network for families of CSHCN and their providers and the Parent-to-Parent Program; the Massachusetts Consortium for Children with Special Health Care Needs; the Federation for Children with Special Needs; Massachusetts Family Voices; and other family organizations such as those organized around specific conditions.

3. Coordination of health components of community-based systems:

Medicaid Managed Care

Medicaid managed care has enhanced opportunities for coordination of care at the community level in MA. Unlike states in which families experience Medicaid managed care as a de facto cut in benefits, Massachusetts has chosen to provide a choice for families between a traditional managed care and membership in Medicaid's own PCC gatekeeper manager care program. This shift has enhanced coordination for parents of CSHCN.

Care Coordination for CSHCN

The Division for Perinatal, Early Childhood and Special Health Needs' Care Coordination Program is designed to help families coordination among multiple specialties and levels of care and to reduce fragmentation of care. Thirteen Care Coordinators are located in MDPH regional offices as well as 14 community-based pediatric primary care practices statewide. Care Coordinators help families navigate the health care system to better manage the medical, educational and social aspects of their children's needs. They may conduct home visits, attend IEP meetings, or train parents to be better advocates. They connect parents of CSHCN to other families facing similar challenges. Care Coordinators also help providers understand existing entitlements, services and benefits available to families of CSHCN and how to access them, and assist practices in developing systems to help them provide medical homes to families of CSHCN. Staff were involved in the needs assessment.

Universal Newborn Hearing Screening Program

The Universal Newborn Hearing Screening Program (UNHSP) employs a Parent Outreach Specialist – who is also a parent – who contacts all families with infants and young children diagnosed with hearing loss and provides parent-to-parent support. Educational materials are provided to all families with newborns and a Parent Information Kit is given to all families when an infant or young child is diagnosed with hearing loss. During 2004 and 2005 the UNHSP developed family surveys to measure satisfaction. With 30% of surveys completed and returned at this time, analysis is beginning. Staff and a parent representative were involved in the needs assessment.

SSI/Public Benefits

The SSI/Public Benefits Specialist conducts statewide trainings for parent groups and organizations, state and local agencies serving families with CSHCN, and health care providers through community settings and hospitals serving CSHCN. Training and technical assistance is provided to help ensure CSHCN are aware of benefits available to them and that they have adequate health insurance. The SSI/Public Benefits Specialist also co-trains parents and providers serving “transitional youth” along with Disability Law Center staff on topics related to children, youth and transition to adulthood. Staff was involved in the needs assessment.

4. Coordination of Health Services with Other Services at the Community Level

MA Consortium for CSHCN

The collaborative relationships described above facilitate the coordination of health services with other services at the community level. Membership of and participation in the Massachusetts Consortium for CSHCN includes representatives from a variety of arenas, including early intervention, education, social services and family support services.

As part of a Champions for Progress grant awarded to New England SERVE and the Massachusetts Consortium for CSHCN, two pilot “regional affiliates” of the Consortium are being developed in western and central MA. This enhances capacity to

reach out to outlying parts of the state and develop greater linkages at the local and community level.

Care Coordination for CSHCN

As described above, the Division for Perinatal, Early Childhood and Special Health Needs' Care Coordination addresses a full range of services at the community level. Care Coordinators provide the 'glue,' in the form of information, advocacy and support, that can make systems that are not necessarily coordinated more coherent to families.

Community Support Line for CSHCN

The Division for Perinatal, Early Childhood and Special Health Needs' toll free Community Support Line provides families of CSHCN with information, referral and technical assistance. Assistance is available to families and providers statewide, including information on public benefits, family to family supports, flexible funds, and referrals to care coordination and other community resources.

Family TIES

The Family TIES program provides information and referral for families and providers as well as a parent-to-parent support network, which helps promote service coordination at the community level. Nevertheless, as noted in section 3.1.2.1, program staff have reported that lack of service coordination continues to be a barrier for families. In addition, Family TIES is acting on the need to do targeted outreach to culturally and linguistically diverse families of CSHCN. Of the nearly 1,300 calls received to date in FY 2005, 31 individuals have identified something other than English as their primary language, with 26 of these callers requesting Spanish. Family TIES has secured the part-time services of staff who speak Spanish and Portuguese. These individuals respond to messages left on the toll free line in either of these languages. In addition, the training Let's Get Organized has been translated into Spanish and offered twice. For FY 2006, Family TIES has identified as a primary goal expanding capacity to effectively outreach to under-served populations by building community-based relationships at organizations, recreational and educational sites and places of worship where diverse families typically come together. Family TIES convened a focus group for the needs assessment.

Moving Forward Together: Partnerships to enhance integrated community systems for children and youth with special health care needs in MA

MA was recently awarded an MCHB-funded state implementation grant for integrated community systems for CYSHCN. This project, *Moving Forward Together: Partnerships to enhance integrated community systems for children and youth with special health care needs in MA*, addresses all four constructs of a service system, and focuses on four of the six core outcomes for CYSHCN: medical home, family-professional partnerships, screening, and transition to adulthood. Planned activities over the next three years include developing a Family-Professional Partners Institute; Transition Training for care coordinators from a variety of settings statewide; creating linkages to ensure follow-up services for CSHCN identified through screening efforts; promoting medical home amongst pediatricians and physicians-in-training, in

collaboration with the Massachusetts Chapter of the American Academy of Pediatrics; and developing a Youth Advisory Council (in collaboration with Partners for Youth with Disabilities) to advise both MDPH and the Massachusetts Consortium for CSHCN. A key strategy of MFT is significant collaboration with the Massachusetts Consortium for CSHCN. In fact, one objective of the project is to strengthen the capacity of the Consortium. This grant provides the state Title V CSHCN program in particular, and the state in general, with an enormous opportunity for improving community systems for CYSHCN and their families in the state. MDPH recognizes that no single organization or agency, on its own, can build a comprehensive system of services for CYSHCN and their families. We plan to use the opportunity offered by this grant to build upon existing collaborations and relationships with community, family and agency partners to expand and enhance a system of care for CYSHCN.

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IIB: 2G. Selection of Priority Needs

The priority needs and the process for selecting them is described in section IIC below. In addition Appendix 2G.1 lists 17 priority needs that were strongly suggested by internal and external groups from which the final 10 were chosen through the consensus-building process. Appendix 2G2 provides a sample, for one priority, of one- to two-page documents staff prepared about each of the 17 proposed priorities to facilitate decision making. The priorities listed in Section IIC and the Massachusetts MCH Block Grant Application for FY 2006, Form 14. The factors that led to the selection of each are described in the State Narrative for 2006 Application, Part IV, Section B (“State Priorities”). The document *Relationships among Massachusetts Priority Needs, National Performance and Outcomes Measures, and New State Performance Measures*, attached to Part IV, Section B of the 2006 Application describes the relationships between population groups, groups, and national and state measures.

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IIC. Needs Assessment Summary

Massachusetts Five Year Needs Assessment involved a comprehensive review of the needs of each of the MCH populations and the capacity of the state to meet these needs. The review examined health status indicators for all of the MCH populations stratified by geographic area and population characteristics, as documented in the preceding sections.

The needs assessment, including the priority-setting process, formally began in September 2004 with meeting of program leaders within the Center for Community Health. Prior review of data had shown that, although many MCH indicators for maternal, infant, child and adolescent health were generally more favorable in Massachusetts than the nation, disparities were evident in access and outcomes in a number of areas. As a result, emphasis was placed on the theme of disparities. Consensus-building for the priorities involved an array of internal and external participants in meetings and focus groups.

Information related to state needs, capacity and priorities was collected at meetings and interviews held with various internal and external stakeholders, other state agencies and consumers, including 50 parents of children with special health care needs. Programs hosted statewide meetings to highlight needs, capacity and priorities. For example, meetings of WIC, school-based health centers and essential school health services drew over 60 nutritionists, 45 nurse practitioners and 120 school nurses, respectively. Smaller groups, such as the Rural Health Advisory Council, a Massachusetts Medicaid (MassHealth)-sponsored quality improvement insurer task force, and the Governor's Adolescent Health Council, contributed from their particular perspectives as well. MDPH regional managers solicited input from stakeholders in the geographic areas they cover. In collaboration with parent organizations, such as the Federation for Children with Special Needs and the Consortium for CSHCN, focus groups and surveys were conducted with parents from across the state. (The CSHCN organizations involved in the needs assessment are further identified and described in the Capacity Assessment in the section describing Constructs of a Service System for CSHCN in Massachusetts.) Additional focus groups involved 36 youth in the process of transitioning to adulthood. University researchers, funded by the Noonan Foundation, led studies done in collaboration with Title V to inform the needs assessment. Massachusetts General Hospital researchers analyzed NSCSHCN data in conjunction with families of CSHCN. A Boston University researcher interviewed additional families about their needs. The simultaneous assessment by the Commissioner of Public Health, called Public Health in the 21st Century, added input from many stakeholders in all regions of the state about priorities, for example, the framing of the data use priority below.

Given the expanded role of the Title V Director, it was important to take advantage of the opportunity the needs assessment presented to frame additional collaborations between more traditionally MCH-oriented Bureau of Family and Community Health and programs in these areas to benefit MCH populations. This represented a major change from the last Five-Year Needs Assessment process. Staff completed "SWOT" (strengths, weakness, opportunities, threats) analyses for the programs that focus on primary care, perinatal programs, adolescent programs, nutrition, and CSHCN to further identify needs, assess capacity, and recommend priorities for their respective areas. Internal staff seated within the central MDPH office and those more

directly engaged locally through the MDPH regional offices participated in meetings and then completed surveys to further brainstorm priorities. The process was particularly strong in establishing Center collaboration for MCH populations, involving HIV/AIDS, substance abuse, and tobacco-oriented groups previously more peripheral to Title V.

In the spring of 2005, 17 priorities strongly supported by various internal and/or external groups were summarized, by MCH population, into a working document (see Appendix 2G.1). To prepare for a retreat on April 22 where priorities would be chosen, staff developed one- to two-page documents about each proposed priority articulating responses to the following criteria: impact (scope and severity of the problem), intervention likelihood of success, and measurability for the priorities. (For a sample for youth transition for CYSHCN, see Appendix 2G.2.) Added to the list for discussion at the retreat were the five priority statements that emerged from the Commissioner's Public Health in the 21st Century statewide consensus-building process. The retreat was internal, attended by Center bureau, division, and relevant program leaders.

Retreat participants were asked to indicate their choice of MCH priorities as well as priorities for Center overall (including MCH). These choices were tabulated and then presented to the senior executive team of the Center for a final priority setting. Ten MCH priorities were selected, some which are also Center priorities. Along with the priorities, the Center executive team adopted six "overarching principles" that supplement the MCH national principles. An example is the disparities principle: Eliminate disparities in health access and health status, including disparities by race, ethnicity, language, income, education, insurance, health provider, disability, geographic area, age, gender, and sexual orientation.

Given the array of traditionally "non-MCH" programs now under the Title V Director, attention focused on strengthening internal collaborations and final priority setting internally. The Center will continue to further engage external partners who provided input in ongoing needs assessment and follow-up activities. In addition, through MCH participation in the Public Health in the 21st Century process, external collaborations long-established at the MCH level are now "owned" at the Commissioner level.

The nine priorities selected through the Massachusetts needs assessment process are presented below. They are all considered of equivalent priority:

1. Improve the health and well being of women in their childbearing years.
2. Improve adolescent health through coordinated youth development and risk reduction.
3. Improve supports for the successful transition of youth with special health needs to adulthood.
4. Integrate service systems and data, and use data to inform practice.
5. Increase capacity to promote healthy weight.
6. Develop and implement initiatives that address violence against women, children, and youth.
7. Increase the integration of unintentional injury prevention into relevant MCH programs.
8. Improve oral health.
9. Develop and implement public health programs, policies, and collaborations that promote positive mental health.

The factors that led to the choice of each of these priorities is given in the Part IV, Section B ("State Priorities") of the State Narrative, 2006 Application. Care was exercised to choose priorities related to each of the MCH populations, and six of the priorities address all three MCH populations. The document *Relationships among Massachusetts Priority Needs, National Performance and Outcomes Measures, and New State Performance Measures*, attached to Part IV, Section B ("State Priorities") of the State Narrative, 2006 Application, describes the relationships between population groups, groups, and national and state measures.

IID: Health Status Indicators

Please see Forms 20 and 21 in the Massachusetts 2006 Title V Block Grant Application for the most current information on all Health Status Indicators and Forms 17, 18, and 19 for all Health Systems Capacity Indicators. Also see Part III, Section F. in the Application Narrative for a discussion of the Health Systems Capacity Indicators and their relationships with Massachusetts Priority Needs (old and new) and our State Performance Measures (old and new).

Additional information about many of the Health Status Indicators and their implications is provided throughout the relevant sections of this Needs Assessment.

IIE: Outcome Measures

The relationships among the six National Outcome Measures and our new Priority Needs and new State Performance Measures are displayed visually in the chart that is the Attachment to Part IV, Section B. (Priorities) of our 2006 Application Narrative. Massachusetts has not chosen to add any State Outcome Measures. Additional discussions of the implications of the current outcome measure data for this Needs Assessment and for our programmatic activities and initiatives may be found in a number of places:

- The sections of the Needs Assessment related to the health status of pregnant women and infants (for Outcome Measures #01 - #05) and to the health status of children and adolescents (for Outcome Measure #06).
- Portions of the Capacity section of the Needs Assessment addressing perinatal health disparities, disparities in health access generally, injury prevention, violence prevention, and perinatal regulations, among others.
- Reporting in the Narrative portion of our 2006 Application on the activities (past, present, and planned) related to the following measures and Priorities
 - NPMs #08, 10, 15, 16, 17, and 18
 - Current SPMs #01 and 10
 - Current Priority Areas #1, 3, 4, 5, 7, 8, 9 (This material is located in the Attachment to Part IV, Section E in the Narrative.)

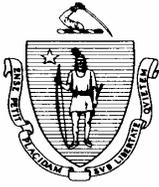
Improvements in all aspects of perinatal, infant, and child mortality, with a particular focus on reducing disparities among population groups or geographic areas, remain an overarching goal of the Massachusetts Title V program.

Needs Assessment Supporting Documents

Appendices

Figures

Tables



Adolescents and Young Adults

March 2005

Introduction

The proportion of people diagnosed with HIV infection in Massachusetts who are adolescents is lower than the national proportion. Within Massachusetts there is substantial variation in HIV infection among adolescents by gender, race/ethnicity and geography. Regarding gender, 10% of females diagnosed with HIV infection within 2001 to 2003 were between the ages of 13 and 24 years old compared to 6% of males. Among Hispanic individuals diagnosed with HIV infection during this time period, 9% were adolescents compared to 7% of black individuals and 6% of white individuals. Additionally, within certain Massachusetts communities the proportion of recent HIV infection diagnoses among adolescents is 2 or 3 times the statewide proportion of 7%. The following describes adolescents and young adults recently diagnosed with HIV infection and those living with HIV/AIDS in Massachusetts.

General Statistics:

- Within the three year period 2001 to 2003, 190 adolescents (age 13-24 years) were diagnosed with HIV infection, accounting for 7% of all diagnoses reported in Massachusetts.
- As of July 1, 2004, 263 (2%) people living with HIV/AIDS were 13-24 years old. Of people living with HIV/AIDS in Massachusetts, 1,397 (10%) were diagnosed with HIV infection at ages 13-24 years.

Regional Distribution:

Among Health Service Regions (HSRs), the Western and Boston HSRs have the largest proportions of adolescents among persons diagnosed with HIV infection within the years 2001 to 2003 at 9% and 8% of diagnoses, respectively.

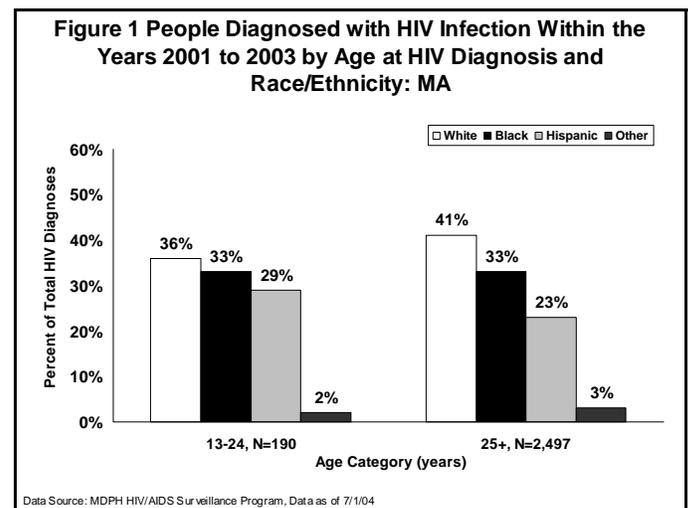
Within the years 2001 to 2003, the city of Boston had the largest number of people diagnosed with HIV infection at ages 13-24 years at 59 (7% of HIV infections diagnosed).

Among cities with over 20 people diagnosed with HIV infection within the three year period 2001 to 2003, the following have the highest proportions diagnosed during adolescence (N=number of adolescents diagnosed):

- Chelsea 18% (N=7)
- Holyoke 15% (N=7)
- Medford 15% (N=4)
- Lawrence 12% (N=6)
- Waltham 8% (N=3)

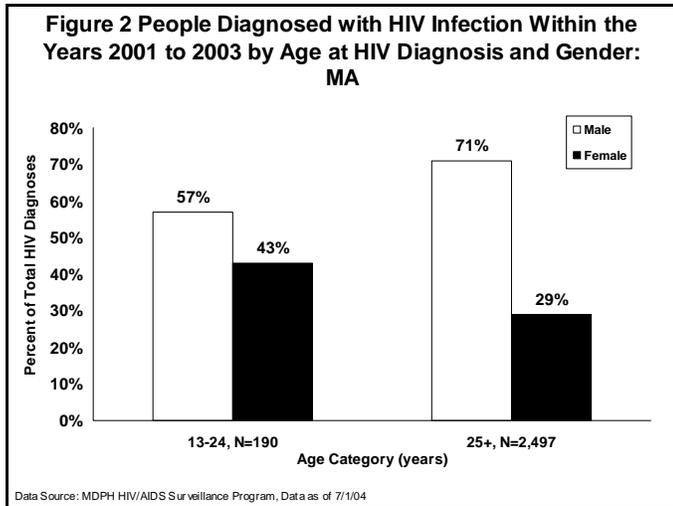
Race and Ethnicity:

- Among adolescents diagnosed with HIV infection within the years 2001 to 2003, 29% are Hispanic, compared to 23% of people diagnosed at age 25 years or above.
- Among adolescents living with HIV/AIDS as of 7/1/04, 35% are Hispanic, compared to 24% of people 25 years or older.



Gender:

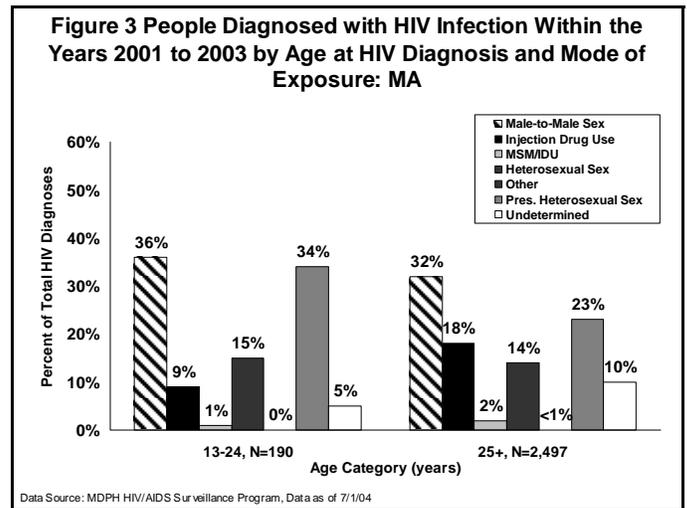
- Adolescents diagnosed with HIV infection within the years 2001 to 2003 were 57% male and 43% female. In contrast, 71% of people diagnosed with HIV infection at age 25 years or above are male and 29% are female.



- Among individuals living with HIV/AIDS who were ages 13-24 years on 7/1/04, 48% are female, compared to 28% of age 25 years and older.

Exposure Mode:

- A greater proportion of adolescents recently diagnosed with HIV infection were exposed through male-to-male sex, heterosexual sex or presumed heterosexual sex than people diagnosed at age 25 years or above. A smaller proportion were exposed through injection drug use.



- A higher proportion of adolescent males (age 13-24 years) diagnosed with HIV infection within the years 2001 to 2003 were exposed to HIV through male-to-male sex than men age 25 years and above (63% vs. 45%). Conversely, a lower proportion were exposed through injection drug use (10% among 13-24 year olds vs. 18% among 25+ year olds).
- A larger proportion of adolescent females (age 13-24 years) diagnosed with HIV infection within the years 2001 to 2003 were exposed to HIV through heterosexual sex with partners of unknown risk and HIV status (presumed heterosexual sex) than women age 25 years and above (57% vs. 40%). Conversely, a smaller proportion were exposed through injection drug use (9% among 13-24 year olds vs. 17% among 25+ year olds).

Adolescents Exposed to HIV Infection Perinatally:

- Among 257 children and young adults living with HIV/AIDS who were exposed to HIV perinatally and were enrolled in a statewide system that monitored perinatal HIV infection (the Pediatric Spectrum of Disease Study), 141 (55%) are currently age 13-24 years old.

Of these 141 individuals:

- Fifty-two percent are male and 48% are female
- Forty-five percent are black (non-Hispanic), 31% are Hispanic, and 22% are white (non-Hispanic).

Adolescents at Risk of HIV infection

Behavioral Risk Factors: According to school-based behavioral surveys, adolescents in Massachusetts are engaging in behaviors that put them at risk for HIV infection.

- Among 3,624 high school-aged respondents to the 2003 Massachusetts Youth Risk Behavior Survey (MYRBS), 47% reported ever using an illegal drug, 8% reported ever using cocaine, 3% reported ever using heroin and 2% reported ever using a needle to inject drugs.
- Among sexually active respondents to the 2003 MYRBS, 25% used alcohol or drugs before last intercourse, and 15% did not use any form of birth control or were not sure if any birth control method had been used when they last had sex.
- Fewer youth in 2003 than in 1993 reported the following: lifetime sexual intercourse (from 49% in 1993 to 41% in 2003), four or more lifetime sexual partners (from 15% in 1993 to 10% in 2003), and sexual intercourse before age 13 (from 8% in 1993 to 5% in 2003).
- Among sexually active respondents to the 2003 MYRBS, 57% used a condom at last intercourse – an increase from 52% in 1993.

State Funded HIV Counseling and Testing:

- Of 42,433 HIV tests performed in 2003, 30% (N=12,782) were among 13-24 year olds, of which 0.3% were positive.

Data Sources:

HIV/AIDS Case Data: MDPH HIV/AIDS Surveillance Program, Data as of July 1, 2004

Youth Risk Behavior Survey Data: Massachusetts Department of Education, Youth Risk Behavior Survey

HIV Counseling and Testing Data: MDPH HIV/AIDS Bureau, Office of Research and Evaluation

Additional References of Interest:

T Bingham, W McFarland, DA Shehan, M LaLota, DD Celentano, BA Koblin, LV Torian, DA MacKellar, GS Secura, GW Roberts Unrecognized HIV Infection, Risk Behaviors, and Perceptions of Risk Among Young Black Men Who Have Sex With Men --- Six U.S. Cities, 1994--1998. *MMWR*, CDC Aug 23, 2002; 51(33):733-736.

J Devieux, R Malow, JA Stein, TE Jennings, BA Lucenko, C Averhart, S Kalichman Impulsivity and HIV Risk Among Adjudicated Alcohol- and Other Drug-Abusing Adolescent Offenders. *AIDS Education & Prevention*. 2002;14(Supp. B):24-35

Civic D, Scholes D, Ichikawa L, Grothaus L, McBride CM, Yarnall KSH, Fish L. Ineffective Use of Condoms Among Young Women in Managed Care. *AIDS Care*. 2002;14:779-788.

Fuller CM, Vlahov D, Latin CA, Ompad DC, Celentano DD, Strathdee SA. Social Circumstances of Initiation of Injection Drug Use and Early Shooting Gallery Attendance: Implication for HIV Intervention Among Adolescent and Young Adult Injection Drug Users. *Journal of Acquired Immune Deficiency Syndrome*. 2002; 32;86-93

For more detailed information and a description of data limitations please see "HIV/AIDS in Massachusetts: An Epidemiologic Profile," available online at www.mass.gov/dph/aids

Center for Community Health Programs			
Bureau: Family & Community Health			
Division: Health Promotion and Disease Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
5 A Day for Better Health (Federal & private funds)	\$0	Works to increase public awareness of the importance of consuming 5 or more servings daily of fruit and vegetables, and to increase fruit and vegetable consumption by children, families and adults in Massachusetts.	In FY04, ~ 100,000 individuals received education and outreach
MA Asthma Planning Collaborative Initiative (Federal)	FY04 \$224K FY05 pending	Building a statewide infrastructure for asthma prevention and control. Documenting the burden of asthma. Facilitating the development of a statewide strategic plan for asthma prevention and control through a collaborative effort among external partners. Promoting pediatric asthma action plan. Developing an asthma action plan for adults.	In one year (3/1/04-2/28/05), 122,133 Massachusetts pediatric asthma action plans were distributed in English and 7 other languages.
Healthy Choices (Private funds)	\$640K	School-based overweight prevention program for middle school children. Works to improve the health of youth by changing policies and systems within schools to support healthier food choices and increased physical activity.	In FY05, ~ 120 middle schools accounting for ~ 1/2 of the middle school student population participated in the program
Massachusetts Obesity Prevention and Control Program (Federal)	\$1.3M	Program to address unhealthy weight and related chronic diseases; youth are the initial target group. Supports building a statewide infrastructure; state plan development; improved surveillance; and school-based prevention interventions.	In FY04, over 100 providers participated in efforts to develop a statewide plan
MassMoves (Federal)	\$0	Statewide public awareness campaign to increase physical activity. Emphasis is on populations that are sedentary and most at risk for the development of chronic diseases.	IN FY04, ~ 3,000 individuals were involved in program activities, and an additional 4,900 received education and outreach.
Office of Health Communication (Federal funds)		Coordinates development and dissemination of health messages for professional and public audiences across the Division of Health Promotion and Disease Prevention	In FY04 health messages pertaining to nutrition, physical activity and energy balance coordinated across the Division,

Appendix 2F1.2.1

Center for Community Health Programs			
Bureau: Family & Community Health			
Division: Health Promotion and Disease Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Office of Genetics/Genomics (Federal funds)		Will work to integrate issues related to genetics/genomics into public health initiatives throughout the Department. Will provide information to health care providers and the general public on genetics issues affecting children, families, and adults. Will work to ensure access to genetic services and consumer support programs, while protecting consumer control and privacy of personal genetic information.	Will be established in FY05
Office of Health and Disability (Federal funds)	\$387,000	Programs and activities to increase awareness and understanding of the health needs of persons of all ages with disabilities; to assure full access and inclusion of persons with disabilities in all public health and health care services; and to develop and implement health programs for people with disabilities. The Disability Access Project provides assistance and support to all MDPH vendors to achieve compliance with disability-related standards to ensure physical and programmatic accessibility for people with disabilities The Mammography Access Project (MAP) was developed to address accessibility issues at mammography facilities.	The MAP sent summary of findings from on site assessments to 183 mammography facilities. Ongoing TA provided to managers of mammography facilities. ADA training and TA provided to 8 DPH programs and 80 providers relative to DPH accessibility policies.
Women's Health Network (State & Federal)	\$2,918,099	Provides breast and cervical cancer screening for low income, uninsured women between the ages of 40-49, both breast and cervical cancers and cardiovascular risk factor screening to low income, uninsured women between the ages of 50-64.	In FY04, 13,000 women received breast and cervical cancer screening and diagnostic services; 2500 received cardiovascular services and 15,000 women and health care providers received education and training through the Community Training Institute

Center for Community Health Programs			
Bureau: Family & Community Health			
Division: Health Promotion and Disease Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Comprehensive Cancer Prevention and Control (Federal and State)	CC: \$310K (Fed) CRC: \$261K (Fed); \$185K State PROST: \$157K (Fed)	Provides education to the general public and health care professionals statewide regarding cancer prevention, screening, diagnosis treatment, survivorship and end of life care. Facilitates development of MDPH agenda and of statewide strategic plan for cancer prevention and control. Represents MDPH on statewide cancer coalition.	IN FY04 ~ 600,000 individuals and 15,000 professionals participated in conferences and educational offerings, or received cancer-related information
Diabetes Prevention and Control (Federal)	\$860,000	Provides public and professional education on the prevention and control of diabetes. Works to improve diabetes management and decrease related complications.	In FY04, more than 500,000 individuals received diabetes related outreach and education.
Heart Disease and Stroke Prevention (Federal and State)	HD: \$1.26M (Fed); \$300K (State) Stroke: \$885K (Fed)	Provides leadership for the Partnership for a Heart Healthy and Stroke Free Massachusetts, a statewide coalition that is working to reduce heart disease and stroke. Implements the Coverdell Acute Stroke Registry to improve the quality of care for stroke patients.	In FY004-05, recruited 60 agencies and organizations to implement the statewide plan and participate in the Partnership. Recruited approximately 50 Primary Stroke Service hospitals to participate in the Coverdell stroke registry.
Office of Elder Health (State, federal, & private funds)		Works to integrate elder health concerns into community-based health promotion and disease prevention efforts; fosters positive and healthy aging; educates elders about healthy behaviors; educates health professionals about the unique health needs of the elder population.	In FY04, more than 4,500 providers received education, and more than 150 elders received direct services.

Appendix 2F1.2.1

Center for Community Health Programs			
Bureau: Family & Community Health			
Division: Health Promotion and Disease Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Keep Moving Program (Federal and Private funds)	\$0	Keep Moving supports a statewide network of community-based walking clubs led by senior volunteers trained as peer leaders. The mission is to improve the lives of people overall social and emotional health of people over 50, through the promotion of physical activity	~ 3,000 adults participated through 183 walking clubs; an additional 800 seniors participated in 6 regional and statewide walk events. Two leader trainings were held. Twenty urban clubs and 3 new statewide clubs were organized..
Men's Health Initiative (State)	\$1M	Provides appropriate prostate cancer and cardiovascular outreach and education, risk factor screening, risk factor reduction counseling as well as access to primary care services for adult men. Emphasis is on African-American men and those who are at particular risk for these conditions.	Since the program's inception, over 53,000 uninsured, eligible males have received outreach and education and 7,600 have received clinical screening and risk-reduction counseling services.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Nutrition			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Folic Acid Campaign (Private funds)	Private funds	Statewide campaign to increase awareness about adequate folic acid intake, targeting all women to reduce the risk of certain birth defects, and the entire population to protect against heart disease and certain cancers.	Consumers of health services and educational materials from hospitals, community health centers, Early Intervention, Women's Health, WIC, Growth and Nutrition, and MA events.
Breastfeeding Initiative		Collaborates with BFCH programs to increase statewide breastfeeding initiation and duration rates. Provides promotional materials statewide, supports hospital breastfeeding regulations, monitors breastfeeding rates and trends, provides training to healthcare professionals and day care providers.	More than 81,000 infants born each year at 52 hospitals and birth centers in Massachusetts benefit from education and support to their mothers and families.
Growth and Nutrition Program (State)	\$723,570	Multidisciplinary outpatient evaluation and treatment for children birth to age 6 with nutritional growth delay (otherwise known as Failure to Thrive).	In FY04, 904 children participated in the program, 294 of them for the first time.
Office of Nutrition (State & Federal)	N/A	Serves as the liaison with health, education and human services programs responsible for the nutritional needs of Massachusetts residents across the lifespan. Develops and coordinates standards, policies and guidance for nutrition services and related activities within MDPH and for the Mass. DOE school meals program.	All residents of the Commonwealth of Massachusetts benefit, especially those served by other MDPH and MDOE programs.
WIC (Women, Infants, and Children) Nutrition Program (State & Federal)	State: \$12,859,601 Federal: \$68,984,929	Nutrition education and counseling and access to nutritious foods for low-to-moderate income pregnant and postpartum women, infants, and children up to age five, who are at risk of developing nutrition-related health problems. Access to healthcare and social services, immunization screening and referrals, and coupons for fresh produce at farmers' markets.	The number of women, infants, and children who have received WIC services has increased steadily since FY02; in FY05, WIC served 199,333, up from 199,164 in FY04.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Perinatal, Early Childhood Health and Special Health Needs			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Alcohol Screening Assessment in Pregnancy –2 (ASAP2) (Federal)	\$150,074	Demonstration project to increase provider screening and appropriate follow-up for alcohol and drug use during routine prenatal care. Provides systems development and clinician training and support.	In FY04, 75 health care providers received training, and 745 pregnant women were be provided screening, and appropriate referrals to substance abuse services
Early Intervention Regional Consultation (State, Federal, & ISAs – OCCS, DOE)	See EI	Provides consultation by specially selected providers to the EI service network, child care sites, and families concerning programming for inclusion of children with medically complex conditions in natural environments.	In FY04, 453 families benefited from consultation services.
Early Intervention Services (State, Federal, & ISAs – DOE, OCCS, EOHHHS)	\$30M	Comprehensive developmental evaluations, multidisciplinary therapeutic and education services for children ages 0-3 who are at established, biological or environmental risk for development delay. Provides support and education for parents caring for these children, including respite services for families of children enrolled in EI, especially those with complex medical needs.	In FY04, 28,635 children and their families received EI services
FIRSTLink (State & Federal)	See EI	Newborn screening and referral system to identify infants at risk for poor health or developmental outcomes and connect them with appropriate services and resources. Offers families of at-risk newborns a home visit that includes a family needs assessment, basic health and parenting information, and linkage with community-based services.	100% of Massachusetts newborns are screened annually utilizing the electronic birth certificate; in FY04, FIRST link staff outreached to 2,356 identified newborns and their families; 1,207 of those families were located and offered direct services. An additional 5,156 parents of newborns received health education and resource information.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Perinatal, Early Childhood Health and Special Health Needs			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Early Intervention Partnerships Program (EIPP) (ISA-DMA & Federal)	\$500,000	Coordinated by an existing Early Intervention Program, the Early Intervention Partnerships Program (EIPP) is a high-risk maternal and newborn screening, assessment and service system. Women with social and environmental risk factors such as homelessness, substance abuse or violence in the family, and adolescents who experience a second (or third) birth are eligible. Led by the EIPP MCH Nurse, EIPPs provide maternal and infant health assessment and monitoring, health education and guidance, and appropriate referrals.	In its first year (FY04), EIPPs outreached to 394 pregnant and postpartm women with 317 receiving services with an average of 5.5 home visits. 91% of families received a comprehensive health assessment with 87% receiving health education and counseling. Also, 177 newborns received a neonatal and development assessment and 991 referrals were made to social and health service providers including clothing (7%), oral health/dental care (6%) educational services (6%) and family planning (5%) bring the top four referral topic areas.
Early Intervention Services Specialized Training and Support Projects (State, Federal, & ISAs)	See EI	EI child and family services (see above) for children with low-incidence conditions, including children who are blind and those diagnosed with autism or pervasive developmental disorders.	
FOR Families Program (ISA- DTA)	\$1,484,363	Home visiting program for homeless families temporarily residing in shelters. Social workers and nurses provide needs assessment, follow-up referrals and support, and assist with transitions into permanent housing.	In FY04, a monthly average of 350 families are receiving services
Massachusetts Center for Sudden Infant Death Syndrome (SIDS) (Federal)	\$62,500	Counseling and information to families experiencing sudden infant death from SIDS and other causes; training professionals responding to a family with an infant death; toll-free 24-hour helpline.	In FY04, 167 families were served by the Center, and an additional 4,548 individuals received outreach and education. 877 calls were fielded by the SIDS hot line.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Perinatal, Early Childhood Health and Special Health Needs			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Maternal Mortality and Morbidity Review (Safe Motherhood) (Federal)		Systematic review of deaths of all women who die while pregnant or during the first year postpartum. An expert committee consults with Department staff to review cases and make recommendations.	In 2003, 15 women died of pregnancy-associated causes
MaxCare (Healthy Child Care America Project) (Federal)	\$71,259	Project to maximize the health and safety of children in out-of-home care. Promotes the use of national standards for health and safety in child care, and access to health consultants in child care settings.	In FY04, over 2,500 child care providers, licensers, and health care providers received training and technical assistance.
Perinatal Disparities Project		Project to enhance the capacity of communities to address perinatal disparities by using state and local data to inform policies and program priorities for reducing disparities in birth outcomes.	Coalition building, training
Perinatal Connections Project (Federal)	\$168,660	Program to increase public awareness of the scope of perinatal depression and related mental health problems in mothers and their families to decrease stigma and improve rates of pregnant and parenting women accessing mental health services. Provides training on perinatal depression and the impact on families. Enhances capacity of health professionals and community providers to detect and manage perinatal depression, through innovative, sustainable model projects in four communities. (Lowell, Somerville/Cambridge, Fitchburg and Springfield.)	Training, support for implementing pilot programs in four sites

Appendix 2F1.2.1

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Perinatal, Early Childhood Health and Special Health Needs			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Universal Newborn Hearing Screening & Follow Up (State & Federal)	\$83,060 State \$183,240 Federal	Oversight of newborn hearing screening programs at all hospitals and birth centers, including review and approval of hospital screening policies and procedures. Provides outreach and follow-up to parents and pediatricians to ensure prompt diagnosis and early EI enrollment of children with congenital hearing loss. Parent to parent support provided at diagnosis. Review and approval of audiological testing center protocols.	Approximately 80,000 newborns are screened annually for potential hearing loss
Catastrophic Illness in Children Relief Fund (State trust fund)	\$1.4M	Trust fund program established by state legislature to assist families with significant financial burdens resulting from the medical condition of a child under age 19.	In FY04, 303 children and their families received direct financial assistance, including 192 new applications approved for funding
Family and Community Support: Care Coordination for Children with Special Health Care Needs (CSHCN) (State & Federal)	\$1.7M	Comprehensive care coordination for families of children with special health care needs, including information, referral, and technical assistance to parents and providers. Care coordinators are located in selected pediatric primary care settings and in the 6 regional DPH offices.	In FY04, 1711 received direct services, and an additional 2295 families and providers received education and outreach.
Family TIES/Early Intervention Parent Leadership Project/Family Initiatives (Federal)		Statewide parent-to-parent support and information and referral network for families and providers involved in the care of children with special needs; toll free in-state phone line. Central directory for Early Intervention services; website links parents and providers with up-to-date information. In addition, a variety of parent-driven projects offer opportunities for family members to participate in the development and monitoring of program policies, procedures and practices	In FY04, 3,135 received information, education and support. 240,100 web hits occurred.

Center for Community Health Programs

Bureau: Family and Community Health

Division: Perinatal, Early Childhood Health and Special Health Needs

Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
<p>Moving Forward Together – State Implementation Grant for Integrated Community Systems for CYSHCN <i>(NEW as of May, 2005)</i></p> <p style="text-align: center;">(Federal)</p>	0	<p>Federally funded project to enhance integrated community systems for CYSHCN in MA. Addresses medical home, family-professional partnerships, early and continuous screening, and transition to adulthood. Activities include developing Family-Professional Partners Institute; Transition Training for care coordinators/case managers from a variety of agencies/organizations statewide; creating linkages to ensure follow-up services for CSHCN identified through screening efforts; promoting medical home amongst pediatricians and physicians-in-training, in collaboration with the MA Chapter of the American Academy of Pediatrics; and developing a Youth Advisory Council. A key strategy of the project is significant collaboration with the MA Consortium for CSHCN.</p>	
<p>MassCARE (Massachusetts Community AIDS Resource Enhancement)</p> <p style="text-align: center;">(Federal)</p>	\$888,693	<p>Outreach to pregnant women and obstetrical providers to ensure early identification and enrollment in care of women with HIV, to enhance care for women and prevent HIV transmission from mothers to infants. Provision of HIV-related medical care and care coordination services for children and adolescents with HIV/AIDS in community based health centers. Outreach and support to perinatally-infected, newly-diagnosed and at-risk adolescents through teen groups and community education.</p>	<p>In FY04 622 individuals received direct services, and an additional 5,000 received education and outreach. 371 health providers received training in HIV care.</p>

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Perinatal, Early Childhood Health and Special Health Needs			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
MASSTART (Massachusetts Technology Assistance Resource Team) (Federal)	\$115,000	Specialized nurse consultation to parents and schools to ensure safe placement of technology-assisted children and other children with complex medical needs in school settings.	In FY04, ~ 72 individuals, providers and schools received direct services; an additional 659 providers, health professionals and school personnel received education and technical assistance
Medical Review Team (Federal)		Multidisciplinary team that screens all children for whom placement is sought in a pediatric nursing home in Massachusetts, to assure they meet strict medical and cognitive criteria.	In FY04, 65 children were screened
Special Medical Fund for CSHCN (State, Federal, & ISA – DMA)	\$100K	Payor of last resort for families with children with special health care needs for services, respite, equipment, medical supplies or other needs related to their child's diagnosis; includes payment for hearing aids, special foods and formulas for children and adults with a diagnosis of PKU or other related metabolic disorders; and epilepsy medications.	In FY04, 617 infants, children and adults were assistance form the Fund.
CSHN Community Support Program/Community Support Line (State & Federal)		Statewide tollfree community support line for families of children with special health needs. Information, referral and technical assistance provided to families and health and social service providers. Public benefits information, family-to-family supports, funding and referrals to care coordination, other BFCH programs and other agencies and community resources are provided.	In FY04 (4 th quarter data only; new program in 04) 413 technical assistance calls provided to families and providers
SSI and Public Benefits Training and Technical Assistance (State)		Information, referrals, and training programs regarding public benefit and health care financing programs, eligibility criteria, and application / appeals processes. Statewide toll-free number.	In FY04, 20 trainings provided with 421 attendees. 298 direct technical assistance calls/emails and 550 bulk mailings provided to families and providers.

Center for Community Health Programs

**Bureau: Family and Community Health
Division: Primary Care and Health Access**

Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Abstinence Education Project (Federal)	\$739,000	Abstinence only classroom education initiative.	In FY04, ~ 6,000 individuals, 8,000 families, and 10,000 providers received educational materials, a social marketing campaign and/or targeted technical assistance.
Coordinated School Health Program (CDC funded project with DOE) (ISA- DOE)	\$88,949	Collaborative effort to improve the overall health and well being of K-12 students. Infrastructure building, coordination of and support for comprehensive school health education covering the nine areas of the CSHP model: health education, physical education, health services, nutrition services, counseling, psychological and social services, healthy school environment, health promotion for staff, family and community involvement, and family and consumer sciences education. Focus on preventing chronic disease risk behaviors related to physical inactivity, poor nutrition, and tobacco use among school-age populations.	In FY04, the program reached ~ 10,000 health providers and educators
Essential School Health Services (State)	\$9,377,278	Funding to school districts to enhance school health service programs, coordinated with comprehensive school health education programs, using a nurse-managed model. Goals include strengthening infrastructure; ensuring comprehensive tobacco control and health education programs; establishing linkages with community providers and health insurance for all students; and implementing data systems.	In FY04, 103 school districts received funds for enhanced school health services; 10 of these provided consultation and support to 74 additional districts. In addition, 274 non-public/charter schools were served. In total, the schools have enrollments of over 565,000.

Appendix 2F1.2.1

Center for Community Health Programs

Bureau: Family and Community Health
Division: Primary Care and Health Access

Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Science-based Teen Pregnancy Prevention Programs (State)	\$990,000 with \$500,000 earmarked	Primary teen pregnancy prevention services in targeted communities with high teen birth rates to prevent teen pregnancy, sexually transmitted infections (STIs) including HIV/AIDS, and too-early sexual activity among youth ages 10-19. Programs are culturally competent, science based, medically accurate, and are designed to prevent teen pregnancy through comprehensive programming delivered through a public health approach. There are also two earmarked rural teen pregnancy prevention coalitions and two school districts receiving funds to implement science based programs and strategies to prevent teen pregnancy.	In FY04, approximately 1,000 youth and 500 families will receive services through this account

Center for Community Health Programs			
Bureau: Family & Community Health			
Division: Primary Care & Health Access			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
CenterCare (State)	\$2,654,975	Contracts with community health centers to provide primary, preventive health services within a managed care model to low-income uninsured adults who do not qualify for MassHealth, (with exception of MassHealth Limited)	In FY05, ~ 7,300 individuals were provided direct medical services with an average monthly caseload of ~ 4,920.
MCH Immunization Program (Federal)	\$74,113	In partnership with the Massachusetts Immunization Program, supports MCH programs to improve childhood immunization rates through assessment, education, tracking and follow-up. Works in coordination with the WIC program, other Bureau programs and Boston immunization program.	In FY04, 116 Bureau staff received immunization-related training and immunization assessments were conducted at 33 contracted agencies.
Combined Primary Care Programs (Perinatal, Pediatric, and Adolescent) (State & Federal)	\$450,000 from state	Comprehensive primary care for pregnant women, infants and children through age 18 in community health centers and primary care sites. Funding supports nutrition & social services, health education, outreach and case management.	In FY04, ~ 200,000 pregnant women infants and children were served through this program
Community Health Center Support and Enhancement (State)	\$4,637,366	Funding to Community Health Centers, which provide comprehensive health services for low-income, uninsured and under-insured individuals and families. Supports delivery of urgent, community-based, primary health care needs, in addition to capacity building, infrastructure, wrap-around health and social services, and other special initiatives. Manages the State Loan Repayment Program, which provides funding for educational loan repayment for health professionals working in community health centers.	In FY 04, 54 sites are funded to provide targeted health services, not supported by other funding sources.

Center for Community Health Programs

Bureau: Family & Community Health
Division: Primary Care & Health Access

Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Family Planning Services (State & Federal)	\$4,161,481	Comprehensive clinical care (including screening for cervical cancer and sexually transmitted diseases), health education and counseling, provision of contraceptives, and community education, training, and outreach for low-income women, men, and adolescents.	In FY04, 31,991, including 12,008 teens, received direct services.
Office of Oral Health (State, Federal, and private funds)	\$1,556,150 State \$74,112 Federal	Enhancement of oral health in Massachusetts through the development and support of organized systems of dental disease prevention, treatment, research, education and access to care.	In FY04, 135 cities and towns received support, with 44 clinics. 95 screening programs and over 50 sealant programs served pre-school and school-aged children, and ~ 32,000 children received fluoride treatment.
Office of Rural Health (Federal)	\$443,040	With a statewide network of rural providers, local officials, and community groups, provides direct technical assistance; coordinates resources and activities; manages the Massachusetts Rural Hospital Program and the Small Hospital Improvement Programs; strengthens local, state, and federal partnerships; and collects and disseminates information on rural health programs and policy.	In recent years, ~ 60 health care providers and others participated in coordination and network development activities; another 1,500 individuals received education, outreach and technical assistance, and three rural hospitals were designated as Critical Access Hospitals (CAHs).

Center for Community Health Programs

Bureau: Family & Community Health
Division: Primary Care & Health Access

Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
<p>Primary Care Office</p> <ul style="list-style-type: none"> • J-1 Visa Program • State Loan Repayment Program (SLRP) • National Health Service Corps Liaison (NHSC) • Health Professional Shortage Area Designations <p style="text-align: right;">(Federal)</p>	<p>\$112,200</p>	<p>Programs and activities designed to promote the availability of affordable, primary health care by assuring that there is a viable distribution of health care providers throughout the delivery system. Implements strategies to address health professional workforce supply and distribution issues. Manages the State Loan Repayment Program (funding for educational loan repayment for health professionals working in community health centers), the Conrad-30 Visa Waiver Program, and Shortage Area Designation activities and technical assistance. Liaison for National Health Service Corps.</p>	<p>In the past 2 years, facilitated the retention of 137 health care providers and increased access to qualified providers in underserved areas of the State</p>

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Violence and Injury Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Adolescent Sexual Assault Prevention Program (Federal)		Funding to five rape crisis centers for provision of teen dating violence/sexual assault prevention programming.	
Batterer Intervention Program Services (State & ISA - DOR)	\$727,700	Development of guidelines and standards for the certification of batterer intervention programs that promote cessation of dating and domestic violence, batterer accountability, and victim safety. Monitoring of certified programs for compliance with the standards and funding for programs to serve indigent, non-English speaking and DSS referred batterers, as well as adolescent perpetrators of dating or family violence.	In FY04 ~ 2000 individuals participated in batterer intervention groups; ~ 1400 women received safety and referral information for themselves and their children
Collaborative for Abuse Prevention in Racial and Ethnic Minority (CARE) Communities Project (Federal)	\$460,000	Pilot program to develop culturally competent and collaborative models of responses to violence against women, incorporating all service providers in four target communities (two Latino, one Cambodian, and one African-American). (Funding to end in FFY06)	From FY00 – FY05 20 direct service programs in 4 communities have collaborated to increase outreach, education, and coordination of services related to intimate partner violence
Domestic Violence Screening, Care, Referral and Information Program (DVSCRIP) (Federal)	-0-	Development of protocols and a comprehensive curriculum for maternal and child health providers to improve screening, care and referrals for domestic and sexual violence.	In FY04 the draft curriculum was completed and EIPP providers were trained. In FY05 all WIC providers were trained and 4 pilot sites have begun screening.
Emergency Medical Services for Children (EMSC) Partnership Project (Federal)	\$100,000	Provides support and enhancement of emergency medical services for children, including training and curriculum development, comprehensive injury prevention initiatives, innovative planning and policy development, and the development of pediatric care standards and protocols. Work with the Center for Emergency Preparedness, Committee on Special Populations, to develop guidelines for incorporating the needs of children with chronic illness into disaster planning at the community level.	In FY04 a needs assessment was completed. In FY05, injury prevention grants were awarded to 9 EMS agencies.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Violence and Injury Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Fire Injury Prevention for Immigrants and Refugees Everywhere (FIRE) (Federal)	\$145,139	Statewide program to decrease injuries due to residential fires in at-risk homes, including families with young children, the elderly, and immigrant and refugee households. Supports collaborations between local fire departments and community-based agencies serving the at-risk populations. Local programs provide free smoke alarms.	In FY05, partnerships have been developed between community-based agencies and local fire departments in 69 communities to provide smoke alarms
Injury Prevention and Control Program (Federal)	-0-	Promotes increased knowledge of injury prevention and reduction strategies across the lifespan; includes data collection and surveillance, program and coalition development, public information, provider training, policy development and evaluation. Also provides leadership and coordination of MDPH participation in county-based and statewide Child Fatality Review Team system.	In FY04, ~ 6000 individuals and 1,000 service providers received outreach and education.
Passenger Safety Program (Federal)	-0-	Provides training and education, technical assistance, coalition and task force leadership, program development, and public information materials; works to increase awareness of passenger safety issues and reduce motor-vehicle related injuries. Also maintains the Car-Safe Line, a statewide toll-free phone line for questions about passenger safety and related Massachusetts laws.	In FY04, there were 405 calls to the Car-Safe Line.
Regional Center for Poison Control and Prevention – serving Massachusetts and Rhode Island (Federal)	\$520,440	A 24-hour hotline providing assistance and expertise in the medical diagnosis and management of poisoning emergencies to medical professionals and the public. Provides professional education and develops innovative strategies to prevent poisoning and toxic exposure injuries. Serves both Massachusetts and Rhode Island through a jointly funded single program.	In FY03, ~ 45,000 Massachusetts residents were served through the Center, and an additional 12,000 received education and outreach education.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Violence and Injury Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Rural Domestic Violence and Child Victimization Project (Federal)	\$449,850	Provides advocacy and services to children who witness domestic violence and their mothers in rural communities in Western Massachusetts. Provides education and training to professionals and service providers, and works to increase community awareness of domestic violence and child victimization.	In FY05, 126 children and 170 adults received direct services, and additional 3,025 rural professionals, providers and community groups received education and outreach. 22 domestic violence products including posters, handbooks and news updates were developed and over 11,000 of these products were disseminated to rural communities throughout the Commonwealth.
SANE (Sexual Assault Nurse Examiner) Program (State & ISAs - EOPS)	\$733,409	Development of protocols and standard of care for treatment of sexual assault victims in designated emergency rooms/urgent care centers; specialized training and certification of Sexual Assault Nurse Examiners; forensic evidence collection and compassionate medical care for sexual assault patients in designated hospital ERs. Collaboration with rape crisis centers, police, district attorneys, crime labs; expert testimony at trial.	In FY04, over 800 victims of sexual assault age 12 and over received services in 23 designated sites across the Commonwealth. (Pending state funding, protocols for children under 12 are expected to be implemented in FY06.)
Pediatric SANE (Sexual Assault Nurse Examiner) Program (new in FY06) (State)	0	Protocols and standard of care for treatment of pediatric sexual assault victims. Planned implementation of pediatric services in FY06 within children's advocacy services. (<i>See SANE Program also.</i>)	
Sexual Assault Prevention and Survivor Services (State & Federal)	~\$2.95 M	Statewide network of rape crisis centers provides comprehensive sexual assault prevention and survivor services. Each center provides a 24 hour crisis hotline, counseling, and accompaniment of victims through legal and medical processes. Centers also provide professional training and consultation, outreach, and community education on sexual assault prevention and intervention.	In FY04, rape crisis centers responded to 11,059 hotline calls, and provided counseling services to 1,944 clients. An additional 44,674 individuals and providers received prevention education, training and outreach.

Center for Community Health Programs			
Bureau: Family and Community Health			
Division: Violence and Injury Prevention			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Llamanos: Statewide Spanish Language Sexual Assault Helpline (State & Federal)	\$136,213	Provides crisis intervention and referral to Spanish-speaking adults and adolescent survivors of sexual assault. Also provides training and technical assistance to providers to increase outreach, sensitivity and services for survivors of sexual assault and their families in the Massachusetts' Latino communities.	In FY04, 86 individuals and 38 providers received direct services; an additional 140 individuals received education and outreach.
Sexual Assault Prevention Coalition and Capacity Building (State, Federal,)	\$230,00	Supports Jane Doe, Inc: Massachusetts Coalition against Sexual Assault and Domestic Violence; provides curriculum and educational materials development and dissemination, training, conferences, and consultation to rape crisis centers.	In FY04, ~730 providers and community residents participated in training and outreach programs.
Suicide Prevention Program (State)	\$250,000	Works closely and collaboratively with the Massachusetts Suicide Prevention Coalition to address issues of suicide across the lifespan through implementation of the statewide strategic plan for suicide prevention. Supports a variety of activities including surveillance and training as well as the coordination of an annual Suicide Prevention conference.	In FY05, more than 500 school and community-based professionals and activists will attend the statewide conference on suicide prevention. More than 600 professionals have been reached through a speakers bureau; 65 educators have been trained in a school-based curriculum; 5 additional specialized trainings reaching approximately 250 professionals are scheduled in FY05.
Supportive and Healthy Communities for Gay and Lesbian Youth (State)	\$250,000	Provision of school- and community-based violence and suicide prevention activities focusing on the needs of gay, lesbian, bisexual, and transgender youth.	In FY04, more than 900 youth, teachers, guidance counselors, and health and human service providers received education, training and outreach regarding violence and suicide prevention for GLBT youth. In addition, more than 250 youth were served directly through community-based organization.

Center for Community Health Programs

Bureau: Family and Community Health
Division: Violence and Injury Prevention

Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and Number of Individuals
Domestic Violence Outreach to Faith Communities (State)	\$50,000	Supports the Safe Havens Interfaith Partnership to provide domestic violence outreach to faith communities in Suffolk and Middlesex Counties, including information and support for appropriate referral of victims and perpetrators to violence intervention services. Also provides a training curriculum to assist faith community leaders to provide effective support to victims of domestic violence.	In FY04, the program trained 6 congregations and their clergy, reaching more than 3,200 individuals
Domestic Violence Outreach and Education to the Gay Male Community (State)	\$120,000	Supports the Gay Men’s Domestic Violence Project to provide domestic violence outreach and community education within in the gay male community. Works to increase awareness and utilization of domestic violence services in this population.	In FY 04, 22,546 individuals received education and outreach information resulting in 371 new client calls and more than 700,000 website “hits”.
Refugee and Immigrant Access Program (State)	-0-	Works with community-based programs to provide technical assistance, information and support in addressing violence against women in immigrant and refugee communities. Based on knowledge gained through experience with model programs, the project is now working to encourage “mainstream” providers to adapt their approaches and programs to meet the needs of newcomer communities in Massachusetts. In	In FY03 funding for community based providers was eliminated. FY06 the Refugee and Immigrant Safety and Empowerment (RISE) Program will again begin funding community-based agencies to provide domestic and sexual assault services in 10-15 immigrant/refugee communities across to Commonwealth.

Center for Community Health Programs			
Bureau: HIV/AIDS			
Program Category	FY05 \$ Amt.	Description	Clients Served/Contacts made (program tracks client contacts, not individual contacts)
Prevention & Education	\$3.7M	Provides science-based and culturally sensitive HIV/AIDS prevention education and services to populations at-risk for HIV.	531,956 Contacts made
Needle Exchange Programs	\$2.5M	Provides sterile syringes, referrals/access to drug treatment, HIV C&T, primary care, case management, HIV prevention & education and other services; provides TB and HEP C screening	4,362 Clients served
Counseling & Testing	\$2.4M	Provides otherwise non-reimbursable multi-session sexual and drug risk assessment, HIV testing decision-making support, partner counseling assistance, and risk reduction counseling in anonymous and confidential environments for individuals seeking to learn status of HIV.	45,810 Contacts made
Client Services	\$5.0M	Provides non-medical support services such as case management, transportation, peer support, group support and volunteer programs, critical to supporting treatment adherence and community-based living arrangements for people with HIV.	7,614 Clients served
Jails Client Services and Transitional Integration Program (TIP)	\$6.3M	Provides HIV prevention education, case management, medical support and discharge planning, and transitional assistance to inmates of the County Houses of Correction.	788 Clients served (TIP) 656 Clients served
Home Health	\$.4M	Provides otherwise non-reimbursable VNA nurse visits and homemaker services to individuals who are homebound with the intent of keeping individuals out of more expensive residential treatment.	335 Clients Served

Center for Community Health Programs			
Bureau: HIV/AIDS			
Program Category	FY05 \$ Amt.	Description	Clients Served/Contacts made (program tracks client contacts, not individual contacts)
Housing Program	\$4.3M	Provides a range of services such as case management, mental health services to individuals who are homeless or at risk of becoming homeless; support of housing facilities, housing information, and rental assistance for persons living with HIV/AIDS statewide.	525 Clients Served
HIV Clinical Care	\$2.8M	Provides otherwise non-reimbursable clinical case management, treatment adherence support, and psychological and behavioral support not and other-wise non-reimbursable mental health services, and capitated primary care payments for uninsured individuals.	6,500 Clients Served
HDAP	\$6.6M	Provides payment for life saving medications or insurance for individuals living with HIV/AIDS who meet eligibility criteria.	3,953 Clients served (as of Dec. 04)

Center for Community Health Programs			
Bureau: Office of Tobacco Control			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and number of individuals
Massachusetts Tobacco Control Program	\$3.75 M state \$1.77M federal	Program to improve the public health in Massachusetts by reducing death and disability from tobacco use. Program involves four main components: preventing youth from starting to use tobacco products; protecting the public from exposure to secondhand smoke; persuading and helping youth and adult tobacco users to quit; and identifying and eliminating tobacco related disparities.	For the first six months of FY05, 6,266 compliance checks were conducted, resulting in 760 sales of tobacco to minors for a sales rate of 12.1%. Funded programs inspected 1203 stores to insure that proper signage regarding laws prohibiting sales to minors was displayed. Funded programs conducted second-hand smoking inspections in approximately 1740 establishments and responded to 266 complaints regarding smoking in the workplace. 968 self-referred smokers called the Quitline in the first six months of FY05, and 465 healthcare providers referred an additional 1481 patients to the Quitline for telephone cessation counseling. 20 hospitals and 3 community health centers adopted . Six focus groups among racial and ethnic minorities have been conducted to assess cultural attitudes about smoking, cessation, and smoke-free homes.

Center for Community Health Programs			
Bureau: Substance Abuse Services (BSAS)			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and number of individuals*
Prevention		Prevention Services include programs that target all residents in the community, programs that focus on particular groups of individuals who are at high-risk in a community, and coalitions that work with multiple systems in a community.	Regional Center's provided 11,074 service hours. Prevention programs provided 56, 679 hours contacting 244, 357 individuals
Acute Treatment Services (ATS)		ATS programs are medically monitored detoxification services. Programs provide 24-hour nursing care, under the consultation of a medical director, to monitor an individual's withdrawal from alcohol and other drugs and alleviate symptoms.	19,910 individuals
Transitional Support Services (TSS)		TSS are short-term residential, support services for clients who need a safe and structured environment to support their recovery process after detoxification. These programs are designed to help those who need services between acute treatment and residential rehabilitation, outpatient or other aftercare.	3,684 individuals
Residential Treatment Over 30 days		Residential Treatment over 30 days are services for individuals who have recently stopped using alcohol and/or other drugs, have been stabilized medically and are able to participate in a structured residential treatment program. Residential Treatment Over 30 Days include Recovery Homes, Social Model Homes, Therapeutic Communities, Family Substance Abuse Treatment Programs, and Youth Residential Programs.	5,612 individuals in adult residential 355 in Youth Residential \$81 in Specialized Residential for Women

Center for Community Health Programs			
Bureau: Substance Abuse Services (BSAS)			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and number of individuals*
Ambulatory Services		Ambulatory Services are provided in community-based settings and involve attending scheduled appointments for counseling and treatment. These include outpatient counseling services, day treatment/intensive outpatient services, acupuncture for recovery maintenance, compulsive gambling treatment, and opioid treatment.	19,755 served in outpatient counseling 3,571 individuals served in Day Treatment, 87 in Compulsive Gambling and 6,208 in Opioid Treatment
Aftercare and Recovery		Aftercare/ Recovery Support Services provide case management services to help link individuals and families to community supports such as self-help, housing, educational/vocational services and employment.	635 individuals served specifically in case management. All individuals present at time of discharge are counseled on community support options.
Homeless Services		Homeless Services provide substance abuse services to homeless individuals with alcohol and other drug problems. Most of these services are provided within the homeless shelter system.	7,396 homeless individuals served
Driving Under the Influence		BSAS oversees the provision of substance abuse education and treatment alternative sentencing programs for those convicted of first or second offenses of driving under the influence. These programs include First Offender Driver Alcohol Education, Second Offender Driving Under the Influence Residential Programs, and Second Offender Aftercare.	10,113 individuals served in Driver Alcohol Education 2,082 individuals served in 2 nd Offender Residential 1,849 individuals served in 2 nd Offender aftercare

Appendix 2F1.2.1

Center for Community Health Programs			
Bureau: Substance Abuse Services (BSAS)			
Program Name and Sources and Level of Funding	FY05 \$ Amt.	Description	Services Provided and number of individuals*
Statewide Support Services		Statewide Support Services support the Bureau of Substance Abuse Services funded system of prevention and treatment programs statewide with technical assistance, project coordination, and training on a range of topics. In addition, the Bureau funds Substance Abuse Information and Referral Helpline and a Revolving Loan Fund for Alcohol and Drug Free Housing.	NA

* BSAS Prevention statistics are based on SFY 2003 data. All other treatment statistics are based on SFY 2004 data.

**Appendix 2F1.3.1 Massachusetts Department of Public Health
Programs addressing racial and ethnic health disparities 5/05**

Program name	Program goal description	Target population	Geographic area	Funding source
<i>SENSOR: Work-Related Asthma</i>	Improve case ascertainment of work-related asthma among low-income, minority and immigrant workers by collaborating with a community health center and improving their capacity to identify and report work-related asthma.	Low-income, minority and immigrant workers receiving receive medical care at Chelsea Health Center. Among adult asthma patient population 40% are Latino.	Chelsea	National Institute for Occupational Safety and Health (NIOSH) at the Centers for Disease Control and Prevention (CDC)
<i>Fatality Assessment Circumstance Evaluation (FACE) Program</i>	Conduct in-depth research evaluations of select fatalities to evaluate underlying causes. The FACE program investigates, as a state priority, traumatic deaths among immigrants and minorities.	Immigrants and minorities at risk of traumatic fatality and serious injury	Statewide	NIOSH
<i>Core Program of the Occupational Health Surveillance: data analysis for work-related injuries by race and ethnicity</i>	Identify populations at high risk of occupational injury by race and ethnicity. Found disproportionate number (30%) of work-related amputations and burns were among non-white workers	Individuals with work related injuries	Statewide	NIOSH
<i>Occupational Exposures to Bloodborne Pathogens in the Home Care Setting</i>	Evaluate the risks of exposure to bloodborne pathogens in home health care workers by: estimating the incidence of occupational exposures to bloodborne pathogens, evaluating risk factors, and assessing the use of medical safety devices.	Home health care workers, among whom are African American and Hispanic aides	Worcester area and Eastern Massachusetts	NIOSH
<i>Minority Health Surveillance Program</i>	-Develop a public health surveillance capacity to identify disparities by producing special reports and research: Hispanic, Asian, and Black perinatal; minority health chart book with race-specific health status indicator risk ratios on the Web; Native American fact sheet (planned), multivariate	Race and Ethnic groups	States, region, county, CHNA, city or town, neighborhood	No designated funding

Appendix 2F1.3.1 MDPH Programs to address health disparities

	analyses of basic descriptive reports tobacco research on Chinese restaurant workers; targeted survey BRFSS Hispanic analyses			
<i>Data Standards for Race and Ethnicity</i>	Determine race and ethnicity data collection standards for MDPH. (Dialogue with Federal government about implementation of the revised OMB standards for race-ethnicity data collection moving towards focus on ETHNICITY in addition to race.)	Race and Ethnic groups	States, region, county, CHNA, city or town, neighborhood	No designated funding
<i>General Surveillance System</i>	Develop a public health surveillance program by using ongoing surveillance data (race/ethnicity and other demographics) and incorporate these into annual reports, tracking HP 2010, LHI reports, MassCHIP instant topics and custom queries.	Race and Ethnic groups	States, region, county, CHNA, city or town, neighborhood	No designated funding
<i>General Support</i>	-Provide general support to examine health disparities issues: collaborate with the MDPH Office of Multicultural Health, other Bureaus, - Represent MDPH on race-ethnicity data collection and tabulation issues -Work with community on these issues -Provide data to the community, and respond to data requests.	Race and Ethnic groups	States, region, county, CHNA, city or town, neighborhood	No designated funding
<i>Race-Ethnicity Population Estimates</i>	Work with the State Data Center, other state agencies and the U.S. Census Bureau to develop accurate population estimates for race-ethnic groups to be used in denominators of critical health indicators (rates).	Race and Ethnic groups	States, region, county, CHNA, city or town	No designated funding
<i>Determination of Need assessment of Hospital Based Interpreter Services</i>	-Ensure access to hospital based services for limited English proficient and non-English speaking patients -Monitor compliance with Emergency Room Interpreters Law	Linguistically isolated populations	Statewide	No designated funding

Appendix 2F1.3.1 MDPH Programs to address health disparities

<i>Gandara Center</i>	Address the mental health and substance abuse treatment needs	Latino	Springfield and Holyoke	State BSAS appropriation Federal SAMSHA-Substance Abuse Prevention & Treatment Block Grant
<i>Northern Educational Services</i>	Address the substance use and social service needs of the African American community	African American	Springfield-Mason Square	Same
<i>Concilio Hispano</i>	Provide driver alcohol education (DAE Program)	Spanish speaking clients	Cambridge/Somerville	Same
<i>MAPS – Massachusetts Alliance of Portuguese Speakers</i>	-Provide driver alcohol education (DAE Program) -Provide outpatient substance abuse services	Portuguese speakers	Cambridge, Somerville, Greater Boston	Same
<i>Casa Esperanza</i>	Provide BSAS Residential Services-Recovery Home	Latino Men	Boston	Same
<i>Latinas Y Ninos</i>	Provide BSAS Residential Services-Recovery Home	Latino Women & Children	Boston	Same
<i>Entre Familia</i>	Provide BSAS Residential Services/Therapeutic Community	Latino Women & Children	Boston	Same
<i>First Askia</i>	Provide BSAS Residential Services /TC	African American Males	Boston	Same
<i>Women’s Circle</i>	Provide BSAS Residential Services/TC	African American Women	Boston	Same
<i>Griffin House</i>	Provide BSAS Residential Services/TC	African American Women & Children	Boston	Same
<i>Hispanic Academy</i>	Provide BSAS Residential Services/TC	Latino Men	Boston	Same
<i>Nueva Vida Casa Esperanza</i>	Provide BSAS Supportive Case Management Services	Latino Men	Boston	Same
<i>La Alianza Hispana</i>	Provide substance use /outpatient counseling services	Latino Men & Women	Boston	Same
<i>John Flower/Dimock</i>	Provide BSAS Residential Services-Recovery Home	African American Men	Boston	Same

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<i>Brookside Comm. Health Center/ Brigham&Women's Hospital</i>	Provide substance use /outpatient counseling services	Latino Latino Men & Women	Boston	Same
<i>Martha Eliot Health Center/Children's Hospital</i>	Provide substance use /outpatient counseling services	African American, Latino American Men & Women	Boston	Same
<i>MOM's Project/Boston Public Health Comm.</i>	Provide substance use /outpatient counseling services		Boston	Same
<i>BSAS Interpreter Services</i>	-Ensure access to the continuum of substance abuse services licensed by BSAS for non-English and limited-English speaking individuals. Accomplished through a partnership with providers, BSAS, and MDPH's Office of Multicultural Health (OMH). OMH and BSAS developed and disseminated comprehensive clinical guidelines to enhance treatment provided with the use of language interpreters	Individuals who are non-English speaking (NEP) or limited-English speaking (LEP) who present in need of treatment for substance use disorders.	Statewide	Federal Substance Abuse Prevention & Treatment Block Grant.
<i>HIV Counseling and Testing Program</i>	Increase the number of persons at risk to know their HIV status and enter care	All persons at HIV risk, in particular: members of African American, Latino, sub-Saharan African, and Haitian communities	Statewide	U.S. Centers for Disease Control and Prevention; state AIDS account
<i>AIDS Prevention and Education Program</i>	Reduce the number of new HIV infections, build awareness of HIV risk, and seek HIV testing services	Men who have sex with men, injection drug users, high risk heterosexuals; in particular members of African American, Latino, sub-Saharan African, Asian/Pacific Islander, and Haitian communities	Statewide	U.S. Centers for Disease Control and Prevention; state AIDS account
<i>HIV Drug Assistance Program (HDAP)</i>	Ensure access to life-sustaining anti-HIV medications for uninsured or underinsured individuals	HIV positive individuals; in particular members of African American, Latino, sub-Saharan African, and Haitian communities	Statewide	Health Resources and Services Administration; state AIDS account
<i>HIV Client Services Program</i>	Ensure access to medical care and support services for individuals infected with or affected by HIV	HIV positive individuals and their families; in particular members of African American, Latino, sub-Saharan African, and Haitian communities	Statewide	Health Resources and Services Administration; state AIDS account

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<i>ACT-Now Program (AIDS Care and Treatment Now)</i>	Provide high-quality medical care for HIV infected individuals who are uninsured or underinsured	HIV positive individuals and their families; in particular members of African American, Latino, sub-Saharan African, and Haitian communities	Statewide	Health Resources and Services Administration; state AIDS account
<i>Collaborative for Abuse Prevention in Racial and Ethnic Minority (CARE) Communities</i>	Increase collaboration and cultural competence amongst service providers of intimate partner violence intervention services (domestic violence programs, rape crisis centers, batterer intervention programs, child witness to violence programs, and immigrant/refugee service providers) to increase accessibility to services in the targeted communities	Latino; African American and Cambodian Communities	Berkshire County and Chelsea; Boston; Lowell	Federal (CDC)
<i>Youth Violence Prevention Planning and Coalition Development</i>	Develop a multidisciplinary, statewide coalition to address youth violence prevention, including shared risk and protective factors, and initiate a statewide, prioritized strategic plan	Youth age 0-20 with a focus on those at greatest risk	Statewide	Federal CDC
<i>Llamanos: Statewide Spanish Language Sexual Assault Helpline</i>	Provide a resource for Spanish-speaking victims of sexual assault and offer technical assistance to the statewide network of rape crisis centers to improve their response to the Latino community (prior to FY04, this was a Hotline: 24/7 coverage)	Latino community	Statewide	State Federal CDC
<i>Supportive & Healthy Communities for Gay & Lesbian Youth; Youth of Color Coalition</i>	Support specific work with youth of color within the gay and lesbian community in order to reduce violence and suicide and address access issues to more traditional programming	GLBT Youth of Color	Statewide with heavy emphasis on Boston	State
<i>Batterer Intervention for specific cultural communities</i>	Support of certified batterer intervention programs to develop specialized services for cultural/linguistic minority communities	Cultural/linguistic minority communities	Statewide	State

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<i>Fire Safety for Immigrants and Refugees Everywhere (FIRE) Program</i>	Increase the installation and use of smoke detectors in immigrant and refugee households in order to reduce injury and death resulting from home fires	Immigrant and refugee communities	Statewide	Federal CDC
<i>Essential School Health Service Programs</i>	<ul style="list-style-type: none"> -Improve administrative infrastructure of the school health service program (staffing, data collection, policies, health assessments, emergency care) -Coordinate health screening, identify children at risk and target interventions for suicide, tobacco, substance use and other risk taking behaviors -Link school health service program with local health agencies, health providers, community-based activities, and public health insurance programs -Develop management information systems -Link children with primary care provider and MassHealth/CMSP 	School health providers Parents through education and outreach	Statewide	State school health
<i>School Based Health Centers</i>	-Ensure access to and provision of comprehensive high- quality primary care services to children and youth, particularly those at risk for health problems and with poor access to or utilization of primary health care	All children in school with special focus on those: <ul style="list-style-type: none"> -Eligible for free or reduced school lunches -Who are non-English speaking -With high absenteeism and at risk for drop-out before graduation 	Priority to SBHC in areas with: <ul style="list-style-type: none"> -Documented limited access to primary health care. -Higher rates of poverty measured by the % of children <18 living below 200% of the FPL 	State school health Third party reimbursement
<i>Oral Health</i>	Improve oral health outcomes through improved access to oral health care services	Head Start; Children with Special Health Care Needs; Low-income, Cultural and Ethnic Minorities; Elders	Statewide with concentrated programs in identified rural and urban areas	MassHealth Federal grants -Oral Health Foundation - Health Foundation of Central Mass

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<p><i>Family Planning Program</i></p>	<ul style="list-style-type: none"> -Prevent unintended pregnancies in populations at highest risk; -Prevent early initiation of sexual activity; -Improve reproductive health of these populations, -Reduce rates of sexually transmitted diseases, cervical cancer and HIV infection; -Improve the health status of infants, --Reduce infant mortality through planned pregnancies and increased spacing of births; -Reduce repeat pregnancies in adolescents; -Reduce the need for abortions 	<ul style="list-style-type: none"> -Uninsured women, men and adolescents; -Adolescents: male and female, with poor access to confidential contraceptive services, sexually active with high-risk histories including STDs, abnormal Paps, anal sex, previous births, abortions, intimate partner violence, or substance abuse; -Ethnic, racial, cultural and linguistic minority populations, including new and emerging refugee and immigrant populations with limited or poor access to culturally and linguistically appropriate care; -Women, men and adolescents living in rural towns with significant poverty levels and limited access to services; -Women and adolescents at risk of short interpregnancy intervals (12 months or less); -Victims of intimate partner violence; -Adult men and women with a history of substance abuse; and -Gay/ lesbian/ bisexual/ transgender populations. 	<p>Statewide with focus on 46 high priority communities</p>	<p>State Family Planning</p>
<p><i>Science-based Teen Pregnancy Prevention</i></p>	<ul style="list-style-type: none"> -Reduce incidence of teen pregnancies, births and STIs in select communities -Increase youth access to science-based teen pregnancy prevention -Increase protective factors for high risk youth in targeted communities 	<p>Youth ages 10-19 in 17 identified communities with a focus on teens at risk for poor academic, social and/or health outcomes</p>	<p>Cities with highest teen birth rates: Brockton, Chelsea, Holyoke, Lynn Springfield, Berkshires, North Quabbin</p>	<p>State Teen Pregnancy network</p>

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<p><i>Abstinence Education Project</i></p>	<p>Reduce the number of youth who engage in sexual activity before marriage. Objectives: 1) Increased self-esteem, pride and a sense of future self-sufficiency in pre-adolescents; 2) Increased support for families to instill positive values and set clear limits and behavioral expectations for their children; 3) Increased education of youth about the impact of alcohol and other substances in relation to sexual assault and the ability to remain abstinent; and 4) Increased awareness regarding the dangers of peer pressure, unhealthy and abusive relationships for youth.</p>	<p>Youth ages 10-18 and their families with emphasis on youth in African American and Latino communities with high rates of birth</p>	<p>Statewide</p>	<p>Federal Administration for Children and Families (ACF)</p>
<p><i>Heart Disease and Stroke Prevention and Control Program</i></p>	<p>-Facilitate development of statewide strategic plan with the Partnership for a Heart Healthy and Stroke Free Massachusetts -Increase public awareness of the prevalence of heart disease and stroke -Improve the quality of stroke care in hospitals -Increase recognition of the signs and symptoms of stroke</p>	<p>Fall River, New Bedford, Springfield, Lowell and Lawrence</p>	<p>Statewide with emphasis on Fall River, New Bedford, Springfield, Lowell and Lawrence</p>	<p>Cardiovascular Health Branch of CDC</p>
<p><i>MA Diabetes Prevention and Control</i></p>	<p>-Design, implement and evaluate improved strategies for prevention and control of diabetes -Increase public awareness of prevalence of diabetes and related complications -Improve quality of care -Facilitate development of statewide strategic plan</p>	<p>-High risk and underserved populations -Ethnic and culturally diverse populations</p>	<p>Statewide</p>	<p>CDC</p>
<p><i>Men's Health Partnerships</i></p>	<p>-Provide gender appropriate outreach and education with priority on high-risk populations -Provide access to, screening, risk factor reduction, counseling and primary care services for eligible men, with linkage to specialty care as needed.</p>	<p>-For prostate cancer screening: uninsured/underinsured men -50 and over -African American men age 40 or over -Men with family history of prostate cancer age 40 or over -For cardiovascular: men 18 and older who are un-/underinsured</p>	<p>Statewide</p>	<p>State Prostate Cancer Education</p>

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<i>Early Intervention (EI)</i>	<ul style="list-style-type: none"> -Improve and sustain children’s functional capabilities -Identify eligible children and their families -Provide comprehensive, integrated services to children at risk of developmental delay 	<ul style="list-style-type: none"> -Children 0-3 at birth or environmental risk for developmental delay 	Statewide	State: EI Services, EI retained Revenue, EI Project Focus Federal: program for infants/Toddlers w/ disabilities
<i>EI Partnerships/FirstLink</i>	<ul style="list-style-type: none"> -Maternal and newborn screening and assessment and referral for services -Reduce infant mortality and morbidity -Firstlink identifies high-risk infants and families at birth and links to appropriate health care and social services 	<ul style="list-style-type: none"> -Women with social and environmental risk factors Not eligible for other services -Adolescents who experience second pregnancies 	Communities with high rates of infant mortality	MassHealth Federal MCHB
<i>MA Center for Sudden Infant Death Syndrome (SIDS)</i>	<ul style="list-style-type: none"> -Reduce incidence of SIDS -Promote the long term mental health of family survivors -Provide culturally appropriate bereavement care -Train hospital and other providers -Develop culturally appropriate education material 	<ul style="list-style-type: none"> -Families who have experienced a SIDS death -Providers with focus on African American, Latino, Haitian, Cape Verdean 	Statewide	Federal MCHB
<i>MA community AIDS Resource Enhancement</i>	<ul style="list-style-type: none"> -Improve health status of participants by providing direct medical services and support for adherence to medication regimes -Increase number of clients screened for and educated about promising clinical trials -Support families infected and affected by HIV 	<ul style="list-style-type: none"> -Children living with HIV/AIDS -Infected pregnant women -Families and siblings of children with HIV 	Chelsea, New Bedford Holyoke Springfield Brockton, Lowell Revere Lawrence	Federal Ryan White Title IV
<i>Massachusetts WIC</i>	<ul style="list-style-type: none"> -Improve the nutritional and overall health of pregnant women, infants and children at or below 185% FPL -Influence lifetime nutrition and health behaviors -Provide nutrition education and counseling, checks for free specific nutritious foods, and referrals to health care Provide immunization screening and referral -Distribute coupons for fresh produce redeemable at Farmers’ Markets - Coordinate with and referrals to healthcare, 	<ul style="list-style-type: none"> -Low-to-moderate income pregnant women, infants and children under five with—or at risk of developing—nutrition related health problems -High-risk and minority populations (32% Hispanic, 20% Black, 6% Asian/Pacific, and < 1% Native American; 42% White) 	Statewide	State WIC Program Federal USDA

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	<p>health insurance</p> <ul style="list-style-type: none"> -Targeted initiatives to decrease disparities: Community Coordination and Outreach; Overweight/Obesity Prevention and Treatment; Cultural Perspectives on Childhood Obesity, Touching Hearts & Minds: Using Emotion-Based Messages to Promote Healthy Behaviors; Targeted Education Materials: Folic Acid Awareness Campaign -Monitoring Disparities through the Pediatric Nutrition Surveillance System (PEDNSS) and Prenatal Nutrition Surveillance System (PNSS) Data 			
<i>CenterCare</i>	<ul style="list-style-type: none"> -Provide coverage to low-income, adult MA residents who are uninsured 	Uninsured low income young adults, adults and elders in need of comprehensive care at or below 200% FPL	Statewide	State Managed Care at Community Health Centers
<i>Combined Primary Care</i>	<ul style="list-style-type: none"> -Improve access to and use of primary and preventive health care services -Improve birth and perinatal outcomes -Improve immunization status -Increase access to nutrition services -Decrease health risk behaviors among adolescents -Increase referrals for mental health services 	<ul style="list-style-type: none"> -Low income and high-risk pregnant women -High risk adolescents and children -Special focus on ethnic/linguistic minority populations 	Communities with elevated rates of LBW infants, infant mortality, teen pregnancy, inadequate prenatal care	State Family Health Services, Administration Federal MCHB
<i>Community Health Center Support and Enhancement</i>	<ul style="list-style-type: none"> -Reduce barriers to access and use of preventive and primary health services -Ensure provision of services to identified under and uninsured populations -Decrease cost of providing urgent or ED care 	--Support CHCs to provide primary and preventive care by funding essential services not funded by other sources, including interpreter services	Statewide	State Community Health Centers
<i>Community Health Worker (CHW) Initiative</i>	<ul style="list-style-type: none"> -Strengthen capacity of CHWs to deliver services and to educate other providers in areas of cultural competence -Assess and develop policy and program recommendations on status of CHWs statewide -Increase public perception regarding role of CHW as public health practitioners 	-Community Health Workers who work with populations that may be underserved	Statewide	Federal MCHB

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<i>MA State Loan Repayment</i>	<ul style="list-style-type: none"> -Reduce health professional shortages among under served populations -Improve recruitment and retention of health care providers in CHC -Assist in the recruitment of all qualified health professionals to work in underserved areas at CHCs 	<ul style="list-style-type: none"> -Low income populations -Linguistic minority populations 	Statewide in underserved areas	State Managed Care at CHC State Trust Fund Primary Care Loan Repayment Federal State Loan Repayment Program
<i>Primary Care Office</i>	<ul style="list-style-type: none"> -Reduce health care access shortage among underserved populations -Provide culturally competent, high quality, primary and preventive health care -Reduce health disparities by providing access to primary and preventive health care -Administer the J! Visa Program -Identify Health Professions Shortage Areas 	<ul style="list-style-type: none"> -Cultural and linguistic minorities -Underserved populations -Low income populations 	Underserved areas of the state	Federal Primary Care Cooperative Agreement
<i>Safe Motherhood</i>	<ul style="list-style-type: none"> -Review all deaths of women who die during or within one year of the end of pregnancy -Develop surveillance systems to monitor the incidence and severity of maternal morbidity and deaths -Develop recommendations to improve health of mothers 	<ul style="list-style-type: none"> -Women of childbearing age -Populations who suffer maternal deaths disproportionately -Providers of care to these women 	Statewide	Federal MCHB
<i>Perinatal Disparities Project</i>	<p>Enhance capacity of community partners to address perinatal disparities by:</p> <ul style="list-style-type: none"> -Training on the use of state and local data to map a community profile and a variety of analytic tools including focus groups, Perinatal Periods of Risk (PPOR) and Population Attributable Risk (PAR); -Conducting and analyzing results of focus groups, PPOR and PAR; and -Assisting communities to use a logic model to undertake strategic planning to address racial disparities in perinatal outcomes 	<ul style="list-style-type: none"> -Community coalitions in areas of the state with high rates of infant mortality -Special focus on ethnic minorities 	Statewide	Federal CDC and Association of Maternal and Child Health Programs

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<p><i>Perinatal Connections – State Grant for Perinatal Depression and Related Mental Health Problems in Mothers and their Families</i></p>	<ul style="list-style-type: none"> -Increase public awareness about perinatal depression and related mental health problems in mothers and their families -Decrease stigma of and improve rates of pregnant and parenting women accessing mental health services -Train and enhance the capacity of obstetric and pediatric health professionals and community providers to detect and manage perinatal depression -Develop an innovative community specific and sustainable model for screening and treating perinatal depression -Strengthen community capacity to provide mental health services to pregnant women -Demonstrate the effective expansion and increased capacity of existing community based maternal and child health services in addressing perinatal depression. 	<p>-Pregnant and parenting women who are depressed or have symptoms of depression</p>	<p>Lowell, Fitchburg, Somerville Cambridge and Springfield</p>	
<p><i>Refugee and Immigrant Health Program (RHIP) African Refugee Women’s Health Improvement Project</i></p>	<ul style="list-style-type: none"> -Reduce TB case rates among Liberian, Somali and Somali Bantu women -Identify high risk women with Latent TB Infection -Provide culturally and linguistically responsive support during treatment --improve capacity of the TB services network to deliver care to these women 	<p>Newly arrived refugee women from Liberia and Somalia</p>	<p>Metro Boston, Lynn, Worcester, Springfield</p>	<p>CDC, National Center for HIV, STD & TB Prevention, Office of Health Disparities</p>
<p><i>RHIP Perinatal Hepatitis B Prevention</i></p>	<p>Reduce hepatitis B through identification of pregnant women, testing for hepatitis B virus, vaccination of newborns, screening and vaccination of household contacts</p>	<p>Southeast Asian (Cambodian, Laotian, Vietnamese) women and their families</p>	<p>Statewide</p>	<p>Preventive Health and Health Services Block Grant</p>

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<i>Refugee and Immigrant Health Program</i>	-Reduce communicable diseases among new arrivals -Link individuals with care	Newly arrived refugees, asylees, victims of a severe form of trafficking	Statewide	Federal Office of Refugee Resettlement Refugee Medical Assistance through ISA with MORI
<i>Hepatitis C: General Education</i>	To encourage self assessment of risk for hepatitis C and testing for those at risk To provide support and referral through the Hepatitis C Hotline	General and at risk population (injection drug users, sexual partners of people living with hepatitis C Linguistic minorities-provision of materials in Spanish and Portuguese and fact sheets in 5 additional languages Hotline capacity in Portuguese and Spanish	Statewide	Primarily state budget with additional funds from the CDC
<i>Hepatitis C: Education for People Living with Hepatitis C</i>	To educate people recently diagnosed and facilitate appropriate medical management and other referrals	Recently diagnosed individual Spanish speakers recently diagnosed --Materials developed in Spanish and English	Statewide	State budget
<i>Lyme disease Prevention Begins with You Campaign '01-'04</i>	To implement a comprehensive community-based program to reduce the incidence Lyme disease and its complications	Primary: homeowners, tourists, schools and physicians and outdoor workers Targeted Brazilian population of seasonal laborers working outdoors	Martha's Vineyard	3 year federal CDC
<i>Tularemia Surveillance and Education</i>	To track locally acquired cases to determine high risk geographic areas	Outdoor laborers especially landscapers Portuguese speaking community	Cape Cod Vineyard Nantucket	State laboratory
<i>Arbovirus Surveillance and Education</i>	To target mosquito control and public health education efforts by identifying locally acquired cases of aboviral infection	General population with materials translated into Spanish and Portuguese	Statewide	Federal CDC
<i>Multilingual Flu Promotion Campaign</i>	To increase influenza vaccination rates among ethnic minority populations	Linguistic communities: Spanish, Portuguese, Haitian, Chinese, Vietnamese and Khmer	Statewide	Federal

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Past Initiatives

<i>Name</i>	Program description	Termination date and reason
<p><i>Community Health Center Project</i></p> <p><i>Identifying work-related injuries and illnesses among low-income, minority and immigrant workers</i></p>	<p>Use waiting room surveys at several community health centers serving low-income, minority and immigrant workers to identify the work experience of patients, as well as illnesses, injuries and hazards related to work. This data supplements analyses of large databases that may exclude minority and immigrant workers.</p>	<p>Funding ended. Reports to health centers and to NIOSH are being completed.</p>
<p><i>Translation of educational materials</i></p>	<p>Ensure dissemination of educational materials to communities who speak other languages. Among products translated:</p> <ul style="list-style-type: none"> -Burn poster in Spanish, Portuguese -Workers Compensation brochures in Spanish, Portuguese -Teen forklift sticker-Bilingual, English Spanish -Teen and parent child labor brochures-Portuguese -OSHA fact sheets Bilingual, English-Vietnamese, English-Khmer -Fall brochures -Spanish, Portuguese, Haitian Creole 	<p>Translation of new materials will continue, as needed</p>
<p><i>Community Presentations of Health Status Indicators by Race-Ethnicity</i></p>	<p>Inform community leaders and advocates about the health status of local community groups</p>	<p>2002 (appx.) Due to time and budget constraints.</p>
<p><i>Training in Data Access Methods</i></p>	<p>Educate communities how to access relevant indicators for their race-ethnic populations.</p>	<p>2001 (appx.) Due to time and budget constraints.</p>
<p><i>Series of Special Birth Report on Race-Ethnic groups</i></p>	<p>Produce special reports by detailed ethnicity data on perinatal outcomes. We produced the first reports in the series: a Hispanic, Asian, and Black perinatal reports, however, planned report on Portuguese speaking mothers has not proceeded, although it is still planned.</p>	<p>2003 (appx.) Due to time and budget constraints</p>

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<i>HDAP outreach program</i>	Increase participation in state HDAP by HIV positive sub-Saharan and Asian/Pacific Islander residents	March 1, 2004 End of campaign linked to federal (HRSA) fiscal year
<i>Get Tested, Get Care, Get Support</i>	Increase counseling and testing among African American and Latino residents	December 31, 2003 End of campaign linked to federal (CDC) fiscal year
<i>Face the Truth</i>	Increase awareness of HIV risk among sub-Saharan, African American, Latino, Haitian, disabled, and elder persons at high HIV risk	December 31, 2003 Linked to December 1 World AIDS Day and federal (CDC) fiscal year
<i>Refugee and Immigrant Safety and Empowerment (RISE) Program</i>	Develop programs to provide domestic violence direct service and outreach to immigrant and refugee communities across the state	7/1/03 – this program was funded through the state budget and funding was terminated in FY04.
<i>AMCHP Disparities Action Learning Lab (ALL)</i>	Develop statewide strategy to address perinatal disparities in Massachusetts	The intent of the support was short-term planning only. AMCHP and CDC through the University of Rochester have continued the work started with the AMCHP-ALL through the Perinatal Disparities Project/MATRICHS that is supported.
<i>Responding to the Needs of HIV-positive Refugees and Asylees</i>	Identify needs of HIV positive new arrivals	Office of Refugee Resettlement. One-time 17-month project funding
<i>SABAI (Southeast Asian Birthing and Infancy Project)</i>	-Develop culturally appropriate program for Southeast Asian pregnant women	MCHB SPRANS 1989-1995. Specific project ended with end of federal funding.
<i>Amerasian/Vietnamese Health Project</i>	Identify needs of Amerasian Vietnamese new arrivals	MCHB SPRANS 1992-1995. Specific project ended with end of federal funding.

Appendix 2G.1

MCH Needs Assessment Suggested Priorities with Strong Support Internal and External Groups

Note: Priorities are organized by population group. See the category “all populations” before assuming priorities missing, since most cut across the groups.

1. Pregnant women, mothers, and infants

- 1.1. Improve pregnancy outcomes, in particular, focusing on disparities by race and ethnicity
- 1.2. Improve the health and well-being of women in their childbearing years, including pre- and inter-conceptual health.

2. Children and adolescents (to age 22)—which also includes children with special health care needs

- 2.1. Increase capacity and linkage across Public Health programs for adolescent risk assessment, development of risk reduction plans, and service coordination which have a youth development base focusing on adolescent resiliency and environ interventions.
Possible variants: Change “Center for Community Health” to “public health” or omit. Add “and development of adolescent resiliency” and/or “environmental interventions.”
- 2.3. Improve policies and procedures to implement EPSDT, Bright Futures, AAP, MHQP and other approved measures and guidelines for quality primary care.

3. Children with special health care needs—focusing particularly on CSHCN although not exclusively.

- 3.1. Monitor and develop interventions for childhood conditions that are increasing in prevalence including asthma, diabetes, autism, and fetal alcohol spectrum disorders.
- 3.2. Develop collaborations and resources for healthy and successful youth transition to adulthood.

4. Priorities across all MCH Population Groups

- 4.1. Improve access to oral health, particularly for women, children and youth depending on publicly funded oral health coverage and children with special health care needs.
- 4.2. Improve and integrate systems, manual and electronic, for screening and risk identification, information, intake, referral, follow-up, and service provision for infants and children, with family involvement in design, implementation, and evaluation.
- 4.3. Develop cross-program, internal and external, initiative to promote healthy weight.
Increase capacity to promote healthy weight including nutrition and physical activity.
Variant: substitute “system” for “capacity.”
- 4.4. Monitor and assess the impact on MCH populations of MCH programs and broader environmental, health care delivery, insurance, and related policy and systems changes, enhancing data systems and technologies as needed or these purposes.
- 4.5. Develop and implement initiatives that address violence against women, children, and youth.

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- 4.6. Develop and implement public health programs and policies that promote positive mental health for women, children and youth, and collaborate to improve access to appropriate mental health and behavioral health services.
- 4.7. Increase cultural competency and reduce disparities in health access and health status for racial, ethnic and linguistic minorities.
- 4.8. Improve service availability in rural areas.
- 4.9. Increase public knowledge about MCH services.
- 4.10. Increase the integration of unintentional injury prevention into all relevant MCH programs.
- 4.11. Improve emergency and disaster preparedness for MCH populations

State Measures

In addition to current measures we are reviewing, several new measures have been proposed already and revisions to old ones have been proposed. The following is a partial list:

- Nutrition measure to be updated to align with nutrition priority
- Adolescent risk assessment measure to align with adolescent priority
- Violence measure to be updated to account for screening protocols already in place
- Measure to assess progress on planning and implementation of a better integrated continuum of screenings, services and family supports for CSHCN (related to priority 4.2 and a national MCH measure)
- HRSA Region 1-wide “assets-based” measure, probably choosing from one of the school readiness measures

Appendix 2G.2: Sample Priority Statement

Priority 3.2: Develop collaborations and resources for healthy and successful youth transition to adulthood.

Criterion #1: Impact

- Based on the National Survey of Children with Special Health Care Needs (NSCSHCN) survey percentages applied to the 2000 Census, approximately 61,482 youth aged 14 to 17 in MA may need transition supports. The percentage 13-17 year olds with special health needs (SHCN) in MA (19.8%) is higher than the national figure (15.6%).
- Compared with other NSCSHCN-measured outcomes, transition stands out as a deficit (only 3%-6% of youth receive services that meet the national measure).
- The MA BRFSS suggests that over 39,400 18-21 year olds have a disability.
- BRFSS data indicate that adults with disabilities in MA are significantly less educated, less likely to be employed, and more likely to have lower average household incomes than those without disabilities. According to the NSCSHCN, only 20% of MA youth with SHCN were receiving training for an adult job.
- MA residents with disabilities have more health risks and worse health status than those without. Among those with disabilities, blacks and Hispanics report significantly lower levels of education, lower incomes, more health risks, less adequate insurance, and worse health status than whites (BRFSS).
- Similar higher levels of risk behavior for youth with disabilities compared to youth without are documented for proposed priority 2.1. (Massachusetts Youth Health Survey 2004)
- Families and providers report that young adults with disabilities and childhood-onset conditions continue to receive care from their pediatrician and pediatric subspecialists well into adulthood, resulting in a concern that adult medical needs are not properly addressed. Families report that young adults in their 20's and 30's still receive care at Children's Hospital, with equipment (beds, oxygen masks, etc) too small for them.

Criterion #2: Intervention likelihood of success

- The Office on Health and Disability includes activities related to youth transition in its workplan.
- DPH just received a new 3-year MCHB CSHCN State Implementation Grant. The grant provides resources or a systems-wide approach to youth transition. Funding will support training of parent-professionals and care coordinators/case managers in managed health care plans, state agencies, hospitals, and primary care practices; incorporation of transition plans into DPH Care Coordination; and a Youth Advisory Council.
- Grant infrastructure has been established including collaborative relationships with the MA Consortium for CSHCN and its Transition Task Force. The Consortium provides connections to transition and CSHCN initiatives and access to a multi-disciplinary network. New England SERVE will develop and implement the transition training. Partners for Youth with Disabilities will support the Youth Advisory Council.
- Health and medical transition are the main grant focus and strength, but other areas addressed include post-secondary education; employment; socialization, community participation, and independent living.
- Many pilot projects related to transition have taken place in MA and elsewhere. Best practices are still being identified. Evaluation plans must be developed.
- Level of external demand for intervention is very high, as documented by parents and the Consortium Background Brief. Substantial challenges exist for youth with extremely complex conditions as well as for those who require fewer or only periodic supports. Preparation for transition is complex because it is as varied and unique as the youth themselves. The adult health and human service system is ill equipped to "take on" young people with SHCN; and, unlike Title V, there is no mandate for a system of care for adults with SHCN and disabilities.

Criterion #3: Measurability

- The NSCSHCN partially measures youth transition every 4 years, as an MCH national measure
- 3-5 years: Number of youth with special health care needs over age 14 who receive DPH Care Coordination services who receive transition planning services. Number of care coordinators/case managers and parent-professionals trained on transition services.
- Risk behaviors and health status among youth (and adults) with disabilities can be measured (MYHS).

Figure 2B.1

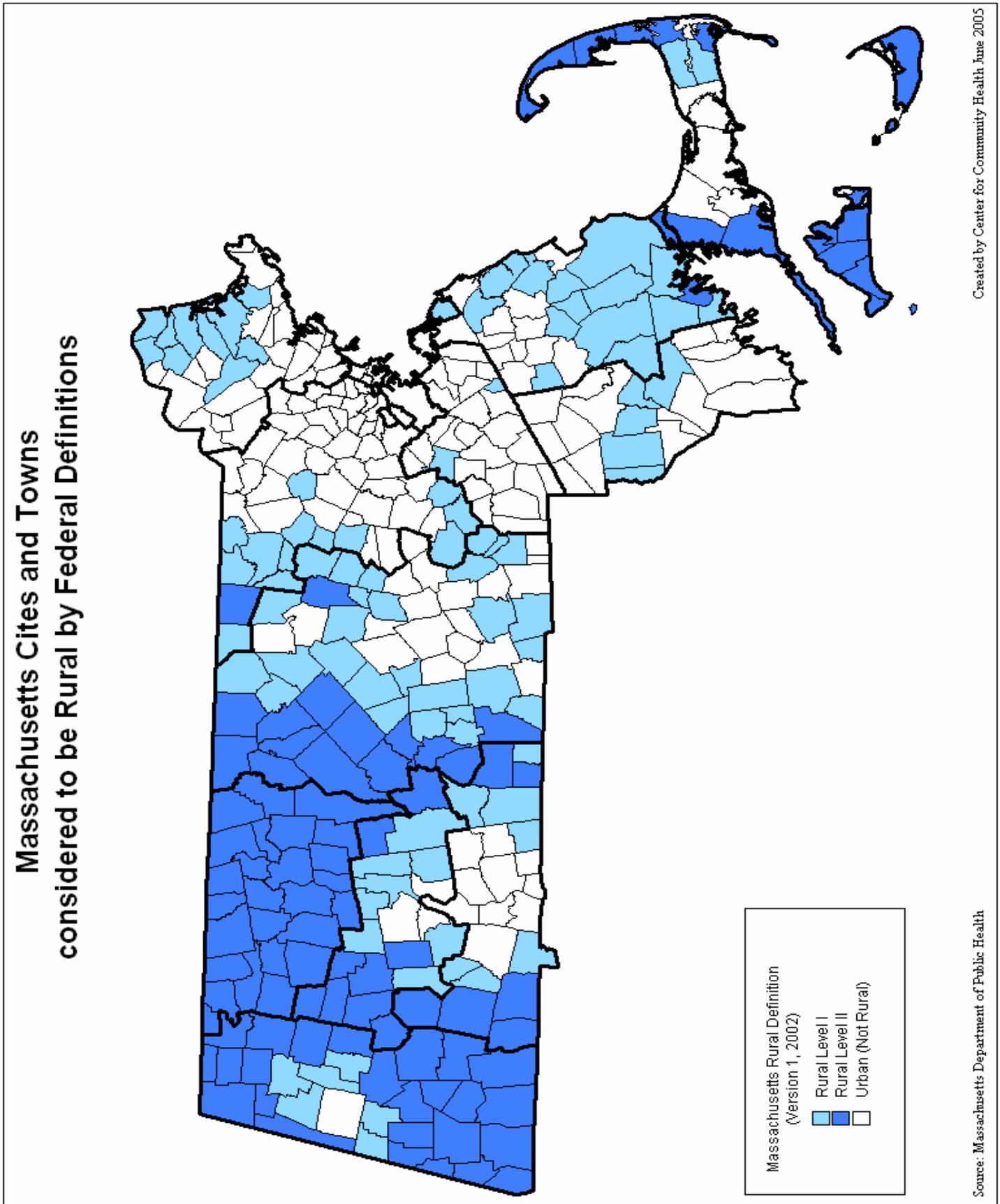


Figure 2B.1

Figure 2D.1.1

Map of Percentages of Students for whom their First Language is Not English (FLNE) by Town in Massachusetts Public Schools* During the 2002 - 2003 School Year

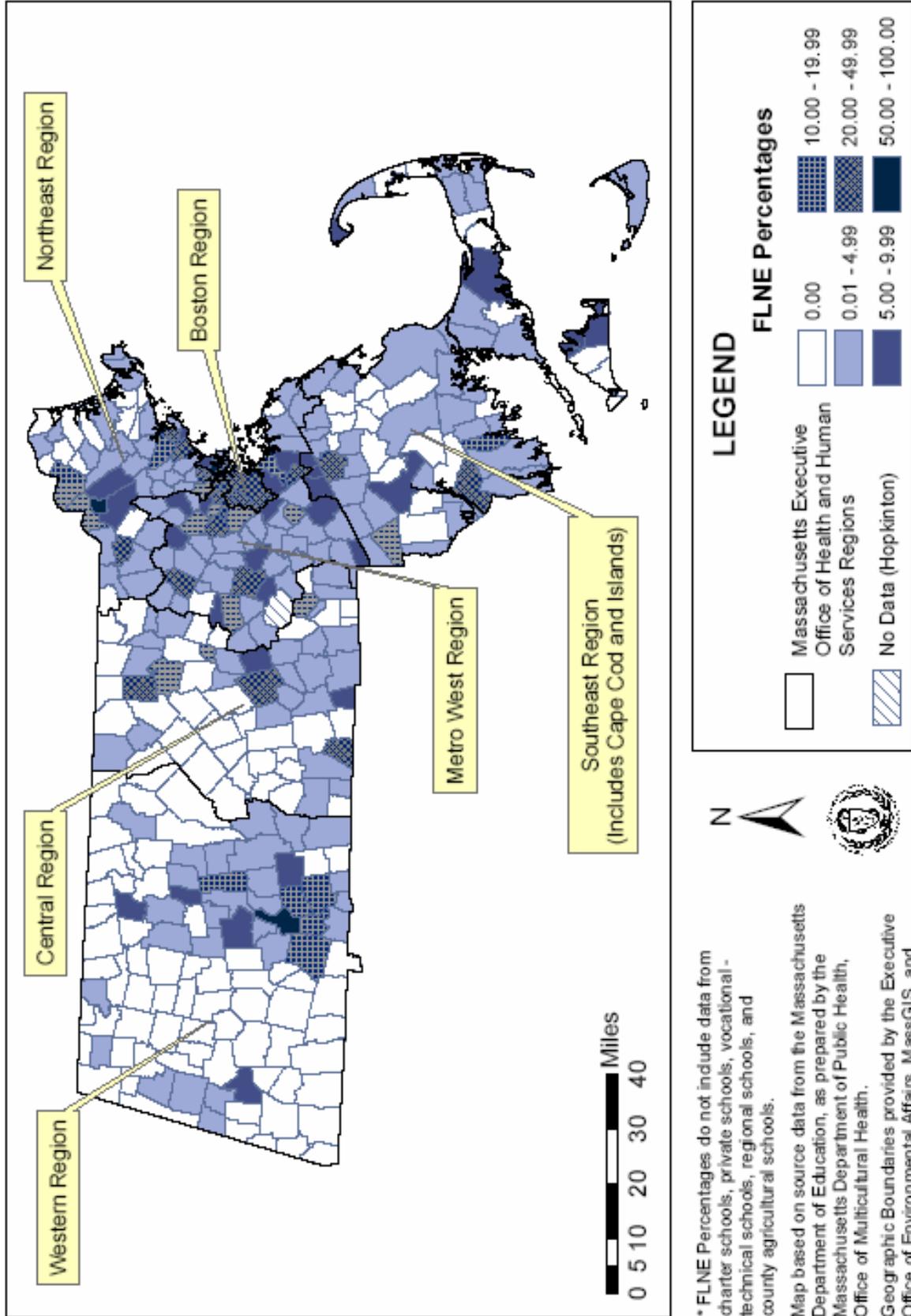


Figure 2D.1.1

Figure 2F1.2.1

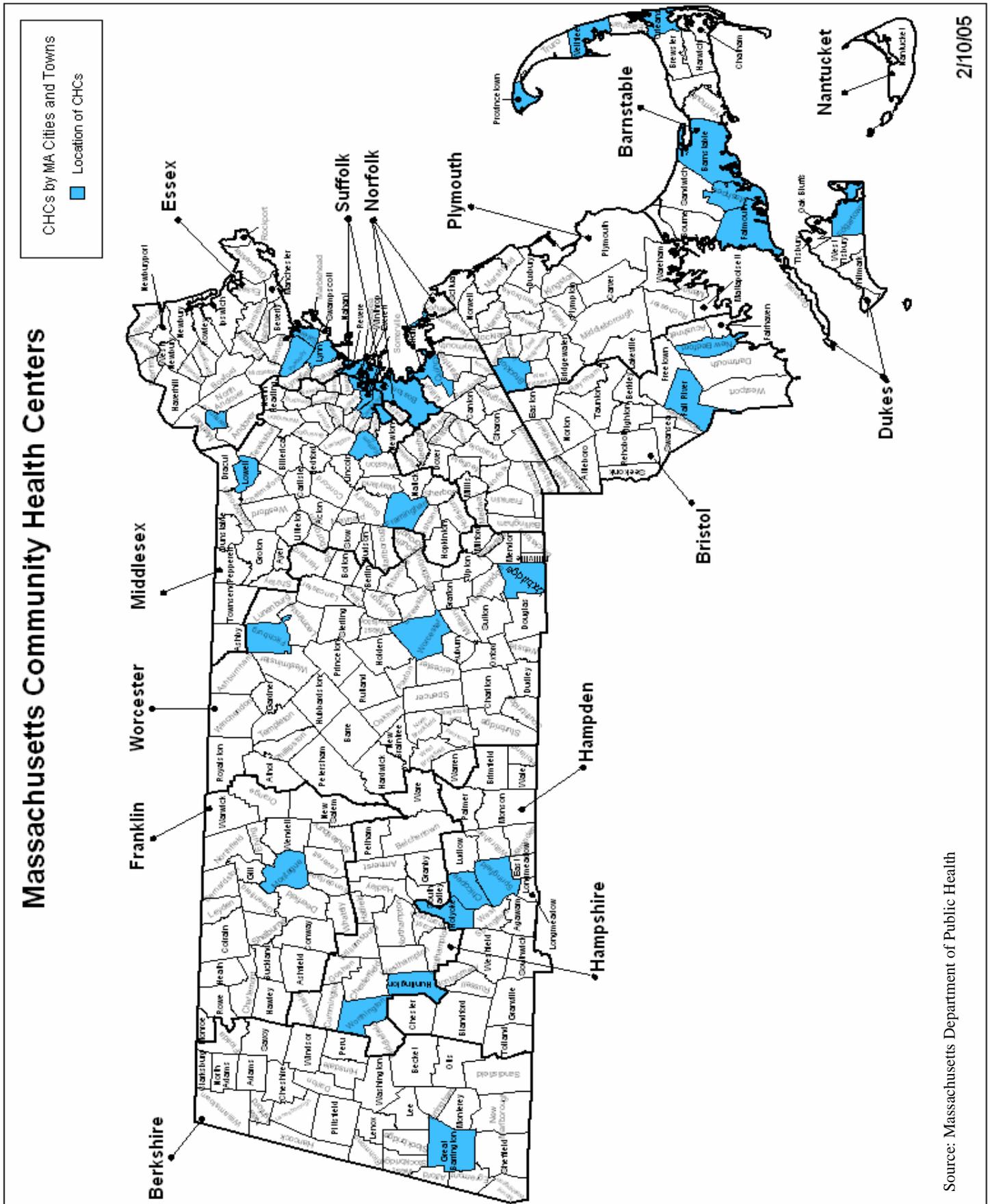
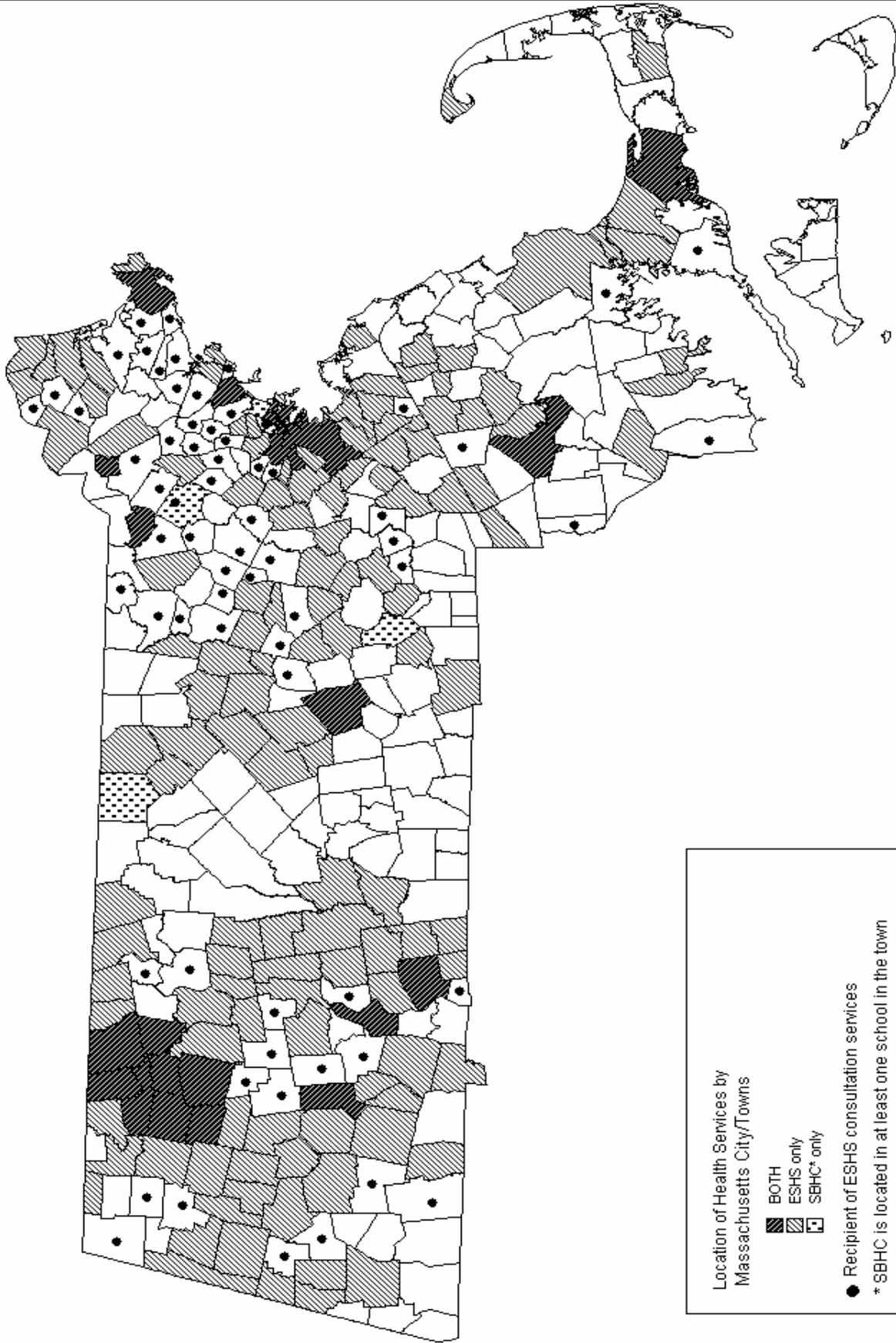


Figure 2F1.2.1

Figure 2F1.2.2

**Massachusetts Communities with Essential School Health Services
and School Based Health Centers (2004-2005 School Year)**



Created by Center for Community Health June 2005

Source: Massachusetts Department of Public Health

Figure 2F1.2.2

2005 Private and Mass Health Dentists' Locations

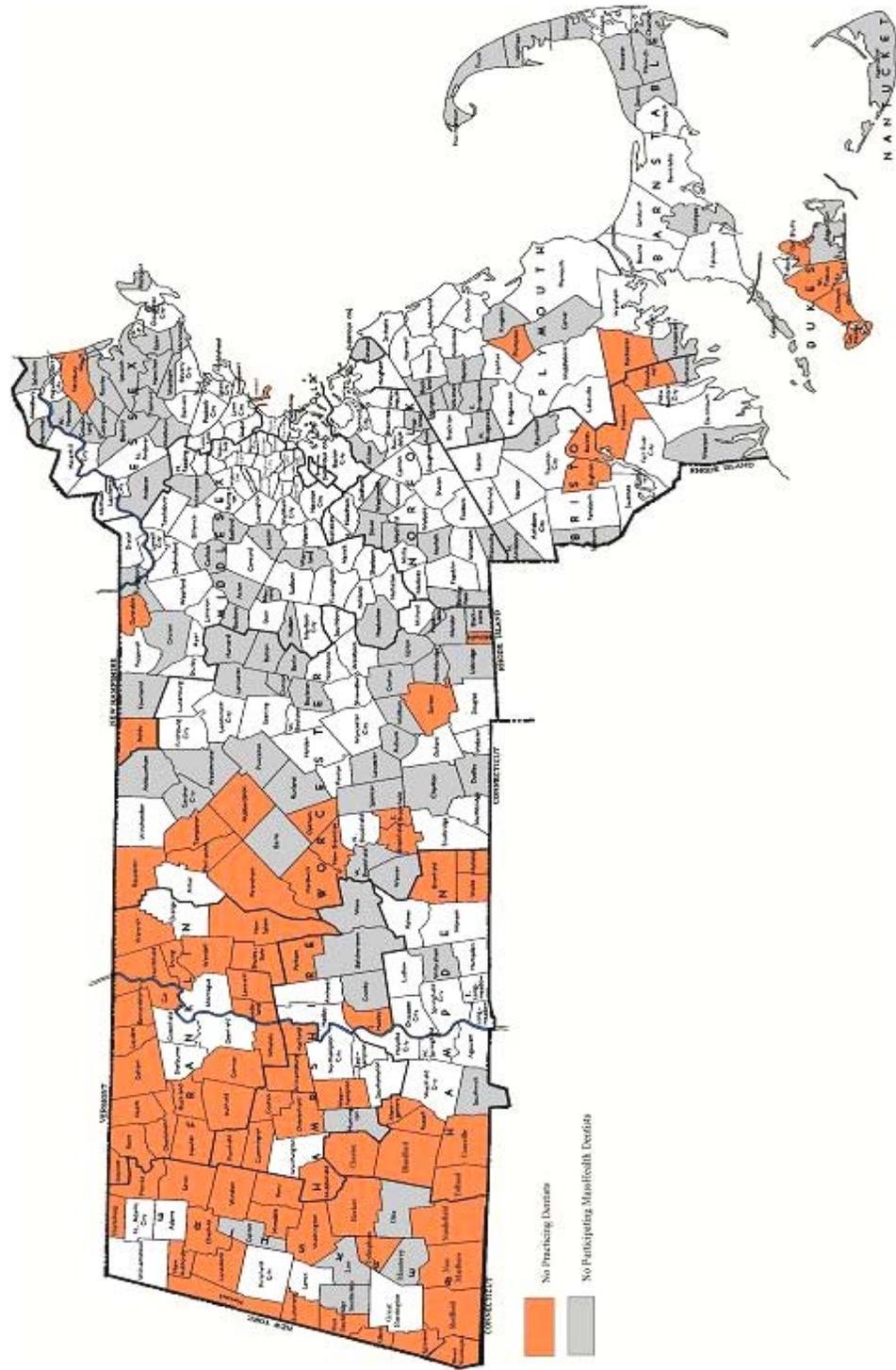


Figure 2F1.2.3

Created by Center for Community Health June 2005

Source: Massachusetts Department of Public Health

Figure 2F1.2.3

Table 2C.2.1 Health care access, health risks, behaviors, and conditions, and quality of life¹ among women ages 18-44, By Race/ethnicity, BRFSS 1998-2003, age standardized to 2000 US Census

	Overall ²		White		Black		Hispanic	
	N=12,394 ³		N = 9580		N = 986		N =1,828	
	%	95% CI	%	95% CI	%	95% CI	%	95% CI
Health Care Access								
No insurance	5.9	(5.4-6.5)	5.0	(4.4-5.6)	8.8	(6.3-11.4)	9.8	(7.8-11.8)
Inadequate insurance	18.4	(17.1-19.7)	16.5	(15.1-18.0)	20.8	(15.7-25.9)	31.0	(26.5-35.5)
Regular MD	88.4	(87.5-89.4)	91.1	(90.1-92)	85.1	(80.7-89.4)	75.9	(71.8-80.0)
Health Risks								
Overweight	34.6	(33.5-35.7)	32.1	(30.9-33.3)	56.6	(52.3-61.0)	52.2	(48.6-55.8)
Obese	12.1	(11.4-12.9)	10.8	(10-11.6)	24.7	(21.0-28.3)	20.3	(17.7-22.9)
No physical activity	21.9	(20.9-22.9)	16.8	(15.8-17.8)	33.9	(29.5-38.3)	50.3	(46.5-54.1)
Current Smoking	23.5	(22.6-24.5)	25.3	(24.2-26.4)	20.8	(17.2-24.3)	17.1	(14.8-19.4)
Binge drinking	15.6	(14.7-16.6)	17.6	(16.5-18.8)	7.8	(5.3-10.3)	8.8	(6.6-11.0)
Heavy drinking	6.7	(6.0-7.3)	7.5	(6.7-8.3)	5.0	(2.7-7.4)	2.7	(1.5-3.9)
< 5 fruits/vegetables per day	68.6	(67.3-69.9)	68.2	(66.7-69.6)	69.0	(63.9-74.1)	72.0	(67.5-76.5)
High blood pressure	8.7	(7.7-9.7)	7.8	(6.7-8.9)	16.1	(11.3-20.9)	12.9	(9.8-16.0)
Cholesterol check w/i 5 yrs	77.5	(76.2-78.8)	78.7	(77.3-80.1)	72.8	(67.7-77.8)	72.2	(68.4-76.0)
High cholesterol	18.2	(17.0-19.4)	18.5	(17.1-19.9)	16.4	(12.2-20.6)	18.0	(14.5-21.5)
Health Conditions								
Diabetes	1.5	(1.2-1.7)	1.3	(1.0-1.6)	3.8	(2.0-5.6)	2.0	(1.1-2.9)
Asthma	16.5	(15.6-17.5)	17.0	(15.9-18.1)	15.1	(11.5-18.7)	16.0	(13.6-18.4)
Disability	13.3	(12.3-14.2)	13.0	(12-14.1)	15.6	(11.6-19.5)	15.4	(12.6-18.2)
Preventive Care/screening								
HIV test ever	56.8	(55.7-57.9)	54.8	(53.6-56.1)	71.9	(68-75.9)	69.5	(66.4-72.6)
Pap smear past 3 years	91.5	(90.7-92.3)	92.7	(91.8-93.6)	93.4	(90.9-96)	88.6	(85.8-91.4)
Quality of life								
Fair/poor health	7.2	(6.6-7.8)	5.6	(4.9-6.2)	9.4	(7.0-11.9)	19.3	(16.8-21.8)
Poor health	1.3	(1.0-1.5)	1.2	(0.9-1.5)	1.2	(0.5-1.8)	1.9	(1.2-2.6)
Dissatisfied w/life	4.9	(4.2-5.5)	4.3	(3.6-5.0)	10.1	(7.2-13)	7.2	(5.1-9.3)
Sad 15+ days in past month	7.4	(6.8-8.0)	6.6	(5.9-7.2)	11.8	(8.8-14.7)	12.3	(10.2-14.4)

Tables 2C.2.1 to 2C.2.5 ¹See end notes for variable definitions ²Sample size for some variables are smaller than noted. *** sample size too small

Table 2C.2.2. Health care access, health risks, behaviors, conditions, and quality of life¹ among women ages 18-44, by income, BRFSS 1998-2003, age standardized to 2000 US Census

	Low income (approximately < 200% poverty level and below) N=3414 ²		Moderate/high income (approximately 200% poverty level and higher) N=7212	
	%	95% CI	%	95% CI
Health Care Access				
No insurance	10.4	(8.9-11.8)	3.2	(2.7-3.7)
Inadequate insurance	28.8	(25.8-31.8)	12.8	(11.2-14.3)
Regular MD	83.9	(81.5-86.3)	92.2	(91.1-93.2)
Health Risks				
Overweight	45.9	(43.6-48.2)	31.9	(30.4-33.3)
Obese	18.3	(16.5-20)	10.2	(9.3-11.1)
No physical activity	35.6	(33.3-37.9)	14.2	(13.1-15.3)
Current smoking	36.5	(34.3-38.7)	20.3	(19.1-21.5)
Binge drinking	15.4	(13.3-17.5)	17.9	(16.6-19.3)
Heavy drinking	5.7	(4.2-7.2)	7.7	(6.7-8.6)
< 5 fruits/vegetables/day	72.4	(69.8-74.9)	67.3	(65.5-69.1)
High blood pressure	12.0	(9.8-14.2)	7.1	(5.9-8.2)
Cholesterol check w/i 5 yrs	71.2	(68.3-74.0)	81.0	(79.3-82.6)
High cholesterol	20.1	(17.5-22.8)	17.4	(15.7-19.0)
Conditions				
Diabetes	2.5	(1.8-3.2)	1.2	(0.9-1.6)
Asthma	20.3	(18.2-22.4)	16.0	(14.7-17.2)
Disability	19.6	(17.4-21.7)	11.1	(9.9-12.3)
Preventive Care/screening				
HIV test ever	64.3	(62.1-66.5)	55.6	(54.1-57.1)
Pap smear past 3 years	90.2	(88.5-92.0)	94.3	(93.4-95.3)
Quality of life				
Fair/poor health	14.3	(12.7-15.9)	3.8	(3.1-4.5)
Dissatisfied w/life	8.6	(7.0-10.2)	2.8	(2.2-3.4)
Sad 15+ days in past month	12.8	(11.3-14.3)	5.3	(4.5-6.1)

Tables 2C.2.1 to 2C.2.5 ¹See end notes for variable definitions ²Sample size for some variables are smaller than noted. *** sample size too small

Table 2C.2.3. Health care access, health risks, conditions, and behaviors, and quality of life¹ among women ages 18-44, by Race/ethnicity and income, BRFSS 1998-2003, age standardized to 2000 US Census

	Low income (approximately 200% of poverty level and below)						Moderate/high income (Approximately > 200% of poverty level)					
	White N=1978 ²		Black N=448		Hispanic N=955		White N=6398		Black N=387		Hispanic N=385	
	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI
Health Care Access												
No insurance	10.2	(8.4-12.0)	9.8	(5.6-14.0)	11.1	(8.2-14.0)	2.9	(2.4-3.4)	4.7	(2.1-7.3)	7.2	(3.8-10.6)
Inadequate insurance	28.0	(24.4-31.6)	23.9	(16.1-31.7)	34.8	(28.2-41.4)	12.8	(11.1-14.5)	9.8	(4.0-15.6)	14.9	(8.6-21.2)
Regular MD	87.5	(84.8-90.2)	84.1	(77.2-91.0)	75.3	(69.8-80.8)	92.5	(91.4-93.6)	90.9	(86.3-95.5)	87.5	(81.9-93.1)
Health Risks												
Overweight	40.0	(37.2-42.8)	57.1	(50.5-63.7)	60.2	(55.7-64.7)	30.7	(29.2-32.2)	53.4	(47.1-59.7)	41.2	(33.3-49.1)
Obese	15.4	(13.3-17.5)	23.3	(18.2-28.4)	25.2	(21.4-29.0)	9.6	(8.6-10.6)	26.2	(20.3-32.1)	11.7	(7.5-15.9)
No physical activity	28.7	(25.9-31.5)	39.4	(32.7-46.1)	54.5	(49.8-59.2)	13.2	(12.1-14.3)	26.3	(19.7-32.9)	28.3	(21.1-35.5)
Current smoking	43.6	(40.8-46.4)	26.3	(20.4-32.2)	18.5	(15.3-21.7)	20.8	(19.5-22.1)	16.2	(11.5-20.9)	14.5	(9.5-19.5)
Binge drinking	18.8	(16.0-21.6)	6.0	(3.3-8.7)	9.7	(6.2-13.2)	18.4	(16.9-19.9)	12.0	(6.9-17.1)	14.5	(9.2-19.8)
Heavy drinking	7.3	(5.2-9.4)	5.1	(2.5-7.7)	1.5	(0.2-2.8)	7.6	(6.6-8.6)	6.3	(1.7-10.9)	7.8	(3.4-12.2)
< 5 fruits/veg./day	71.0	(67.8-74.2)	69.4	(62.1-76.7)	77.6	(72.8-82.4)	67.1	(65.2-69.0)	72.0	(64.5-79.5)	65.6	(54.2-77.0)
High BP	10.5	(7.8-13.2)	13.8	(7.5-20.1)	15.2	(10.8-19.6)	6.4	(5.2-7.6)	19.3	(10.6-28.0)	11.0	(4.7-17.3)
Chol check w/i 5 yrs	69.4	(65.7-73.1)	74.1	(66.8-81.4)	75.0	(70.0-80.0)	81.3	(79.6-83.0)	73.1	(65.6-80.6)	77.7	(70.8-84.6)
High cholesterol	21.2	(17.8-24.6)	17.9	(10.5-25.3)	18.0	(13.2-22.8)	17.6	(15.9-19.3)	16.4	(10.3-22.5)	14.9	(9.0-20.8)
Health Conditions												
Diabetes	2.2	(1.4-3.0)	4.5	(1.3-7.7)	2.8	(1.4-4.2)	1.2	(0.8-1.6)	3.0	(0.7-5.3)	1.6	(0-3.7)
Asthma	22.1	(19.3-24.9)	18.3	(12.2-24.4)	16.4	(13.3-19.5)	16.1	(14.8-17.4)	12.8	(8.1-17.5)	18.3	(12.4-24.2)
Disability	20.4	(17.7-23.1)	19.7	(13.3-26.1)	17.1	(13.2-21.0)	11.2	(9.9-12.5)	9.8	(4.5-15.1)	9.8	(5.0-14.6)
Preventive Care/screening												
HIV test ever	60.7	(57.9-63.5)	76.2	(70.4-82.0)	70.8	(66.5-75.1)	54.3	(52.7-55.9)	71.7	(65.7-77.7)	70.0	(63.8-76.2)
Pap smear past 3 yrs	90.1	(87.9-92.3)	91.7	(87.5-95.9)	89.6	(85.8-93.4)	94.1	(93.1-95.1)	98.3	(96.8-99.8)	96.1	(93.7-98.5)
Quality of life												
Fair/poor health	11.9	(10.0-13.8)	13.2	(8.7-17.7)	22.4	(18.8-26.0)	3.7	(3.0-4.4)	3	(1.2-4.8)	6.3	(2.9-9.7)
Poor health	2.6	(1.7-3.5)	2.2	(0.8-3.6)	2.4	(1.3-3.5)	0.8	(0.4-1.2)	0.4	(0-0.8)	0.7	(-0.1-1.5)
Dissatisfied w/life	8.3	(6.2-10.4)	11.8	(7.6-16.0)	8.2	(5.4-11.0)	2.7	(2.1-3.3)	8.1	(3.2-13)	2.3	(0.1-4.5)
Sad 15+ days past mo	12.5	(10.6-14.4)	13.3	(9.2-17.4)	13.8	(10.9-16.7)	5.0	(4.2-5.8)	10.3	(5.3-15.3)	7.6	(3.5-11.7)

Tables 2C.2.1 to 2C.2.5 ¹See end notes for variable definitions ²Sample size for some variables are smaller than noted. *** sample size too small

Table 2C.2.4. Health care access, health risks, conditions, and behaviors, and quality of life¹ among women ages 18-44, by insurance status, BRFSS 1998-2003, age standardized to 2000 US Census

	No insurance N=731 ²		Govt insurance N=2316		Comm. Insurance N=8986	
	%	95% CI	%	95% CI	%	95% CI
Health Care Access						
No insurance	100		0		0	
Inadequate insurance	100		24.4 (20.6-28.2)		11.5 (10.2-12.8)	
Regular MD	51.5 (45-58)		89.1 (86.8-91.4)		92.6 (91.6-93.6)	
Health Risks						
Overweight	37.0 (32.1-41.9)		51.6 (48.7-54.5)		32.5 (31.2-33.8)	
Obese	13.3 (10.1-16.5)		23.9 (21.3-26.5)		10.6 (9.8-11.4)	
No physical activity	28.6 (23.7-33.5)		43.7 (40.7-46.7)		16.5 (15.5-17.5)	
Current smoking	37.5 (32.6-42.4)		37.8 (35.0-40.6)		20.9 (19.8-22)	
Binge drinking	19.1 (14.1-24.1)		10.9 (8.9-12.9)		17.0 (15.8-18.2)	
Heavy drinking	10.8 (6.4-15.2)		3.8 (2.5-5.1)		7.1 (6.2-8.0)	
< 5 fruits/vegetables per day	73.5 (68.2-78.6)		73.1 (69.9-76.3)		68.0 (66.4-69.6)	
High blood pressure	13.0 (7.6-18.4)		13.6 (10.6-16.6)		7.5 (6.4-8.6)	
Cholesterol check ever	62.9 (56.5-69.3)		67.2 (63.6-70.8)		81.3 (79.8-82.8)	
High cholesterol	18.9 (13.3-24.5)		21.8 (18.5-25.1)		17.8 (16.3-19.3)	
Conditions						
Diabetes	1.6 (0.6-2.6)		3.9 (2.6-5.2)		1.2 (0.9-1.5)	
Asthma	18.2 (13.3-23.1)		23.3 (20.5-26.1)		15.3 (14.2-16.4)	
Disable	15.7 (11.4-20.0)		34.4 (30.9-37.9)		10.2 (9.2-11.2)	
Preventive Care/screening						
HIV test ever	43.6 (31.1-56.1)		68.2 (60.9-75.5)		75.6 (73-78.2)	
Pap smear past 3 years	78.4 (72.7-84.1)		90.7 (88.4-93.0)		94.0 (93.2-94.8)	
Quality of life						
Fair/poor health	12.1 (8.6-15.6)		23.8 (21.4-26.2)		3.9 (3.3-4.5)	
Poor health	1.2 (0.4-2.0)		5.1 (3.7-6.5)		0.6 (0.3-0.9)	
Dissatisfied w/life	11.7 (7.6-15.8)		14.5 (11.8-17.2)		2.9 (2.3-3.5)	
Sad 15+ days in past month	12.2 (9.0-15.4)		19.0 (16.7-21.3)		5.3 (4.7-5.9)	

Tables 2C.2.1 to 2C.2.5 ¹See end notes for variable definitions ²Sample size for some variables are smaller than noted. *** sample size too small

Table 2C.2.5. Health care access, health risks, behaviors, and conditions, and quality of life¹ among women ages 18-44, by Race/ethnicity and insurance status BRFSS 1998-2003, age standardized to 2000 US Census

	No insurance			Government insurance (Medicaid, Medicare, VA, etc)		
	White N=498 ²	Black N=70	Hispanic N=159	White N=968	Black N=310	Hispanic N=838
	%	95% CI	%	95% CI	%	95% CI
Health Care Access						
No insurance	100		100		0	
Inadequate insurance	100		**	100	17.3 (12.7-21.9)	16.6 (7.1-26.0)
Regular MD	61.3 (53.7-68.8)	**	29.6 (18.6-40.6)	93.1 (90.4-95.8)	90.8 (85.4-96.1)	82.8 (78.1-87.5)
Health Risks						
Overweight	32.1 (26.5-37.8)	50.6 (34.5-66.8)	50.5 (39.1-61.9)	44.7 (40.6-48.9)	61.9 (53.9-69.8)	60.3 (55.7-64.9)
Obese	10.2 (6.9-13.5)	20.1 (8.4-31.7)	22.6 (13.4-31.8)	19.1 (15.5-22.7)	30.8 (23.9-37.7)	30.2 (25.8-34.6)
No physical activity	20.4 (15.2-25.5)	45.3 (29.5-61.1)	53.0 (40.8-65.2)	34.5 (30.5-38.5)	39.6 (31.6-47.5)	59.4 (54.5-64.3)
Current Smoking	43.7 (37.9-49.5)	13.2 (5.8-20.6)	23.0 (13.7-32.3)	49.5 (45.5-53.5)	30.5 (23.1-37.9)	19.9 (16.5-23.3)
Binge drinking	22.4 (16.2-28.6)	**	12.7 (3.3-22.1)	14.7 (11.6-17.9)	7.8 (3.7-11.8)	6.2 (3.4-9.0)
Heavy drinking	12.1 (6.4-17.7)	**	8.4 (1.0-15.8)	5.4 (3.2-7.6)	5.2 (1.8-8.6)	1.0 (0-2.3)
< 5 fruits/veg/day	74.0 (68.0-80.0)	78.4 (63.1-93.6)	70.2 (57.8-82.6)	72.4 (68.0-76.8)	66.8 (57.4-76.1)	76.0 (70.8-81.2)
High BP	9.8 (4.3-15.3)	**	22.6 (6.9-38.3)	12.6 (8.2-17.1)	16.3 (9.3-23.3)	14.6 (10.1-19.1)
Chol check w/i 5 yrs	60.5 (53.0-68.1)	**	69.1 (55.1-83.1)	63.6 (58.5-68.8)	70.1 (60.9-79.2)	71.6 (66.3-776.9)
High cholesterol	18.5 (12.2-24.8)	**	23.7 (8.7-38.7)	23.7 (19.0-28.4)	23.3 (14.4-32.2)	18.1 (13.1-23.1)
Health Conditions						
Diabetes	1.6 (0.3-2.8)	4.6 (0-10.0)	0.5 (0-1.2)	4.0 (2.1-6.0)	3.4 (1.3-5.4)	3.8 (1.8-5.8)
Asthma	22.0 (15.6-28.3)	9.2 (2.1-16.4)	9.5 (3.5-15.5)	26.7 (22.4-30.9)	21.0 (14.0-27.9)	19.2 (15.5-22.9)
Disable	15.8 (10.8-20.8)	**	11.6 (3.3-19.9)	39.6 (34.6-44.6)	30.8 (21.7-40)	25.7 (20.4-31.0)
Preventive Care/screening						
HIV test ever	53.7 (47.8-59.6)	72.9 (61.0-84.8)	60.6 (48.9-72.3)	71.2 (67.5-74.9)	80.3 (73.8-86.7)	75.2 (71-79.4)
Pap smear past 3 yrs	76.3 (69.2-83.3)	**	84.9 (74.4-95.4)	91.0 (88.0-94.0)	95.1 (91.2-99.1)	88.7 (84-93.4)
Quality of life						
Fair/poor health	9.4 (5.5-13.3)	15.1 (5.9-24.4)	22 (12.4-31.6)	21.5 (18.2-24.8)	17.2 (11.1-23.4)	30.0 (25.8-34.2)
Dissatisfied w/life	11.4 (6.7-16.0)	**	12.0 (1.1-22.9)	14.6 (10.8-18.4)	18.6 (11.3-25.8)	13.1 (8.6-17.6)
Sad 15+ days past mo	10.8 (7.4-14.3)	15.6 (3.2-28)	15.0 (7.0-23.0)	19.8 (16.4-23.2)	17.5 (11.7-23.3)	17.8 (14.2-21.4)

Table 2C.2.5. Health care access, health risks, conditions, and behaviors, and quality of life¹ among women ages 18-44,

Tables 2C.2.1 to 2C.2.5 ¹See end notes for variable definitions ²Sample size for some variables are smaller than noted. *** sample size too small

by Race/ethnicity and insurance status BRFSS 1998-2003, age standardized to 2000 US Census (continued)

	Commercial insurance					
	White N=7714 ²		Black N=538		Hispanic N=653	
	%	95% CI	%	95% CI	%	95% CI
Health Care Access						
No insurance	0		0		0	
Inadequate insurance	10.9	(9.5-12.2)	12.3	(6.6-17.9)	21.1	(15.1-27.1)
Regular MD	93.0	(92.0-94.0)	94.5	(90.8-98.1)	84.8	(78.5-91.1)
Health Risks						
Overweight	30.9	(29.5-32.2)	54.7	(49.1-60.4)	45.2	(39.1-51.3)
Obese	10.0	(9.1-10.9)	22.4	(17.5-27.3)	12.4	(9.0-15.8)
No physical activity	14.7	(13.6-15.7)	29.9	(24.1-35.8)	38.8	(32.5-45.1)
Current Smoking	21.4	(20.3-22.6)	16.8	(12.3-21.2)	14.8	(10.9-18.7)
Binge drinking	17.7	(16.4-19)	8.3	(4.5-12.2)	11.3	(7.2-15.4)
Heavy drinking	7.4	(6.5-8.3)	5.4	(1.6-9.2)	3.4	(1.5-5.3)
< 5 fruits/veg/day	67.8	(66.2-69.5)	66.4	(59.1-73.6)	70.2	(61.8-78.6)
High blood pressure	7.1	(5.9-8.3)	16.3	(9.7-23.0)	7.5	(3.6-11.4)
Cholesterol check w/i 5 yrs	81.7	(80.2-83.3)	76.4	(69.7-83.2)	75.5	(69.1-81.9)
High cholesterol	18	(16.4-19.6)	13.9	(8.7-19.1)	16.7	(11.5-21.9)
Conditions						
Diabetes	1.1	(0.8-1.4)	3.3	(1.1-5.4)	1.1	(0-2.2.0)
Asthma	15.3	(14.2-16.5)	13.2	(8.3-18.1)	16.5	(12.0-21.0)
Disable	10.2	(9.2-11.3)	9.6	(4.5-14.6)	9.4	(6.0-12.8)
Preventive Care/screening						
HIV test ever	52.7	(51.3-54.1)	68.1	(62.5-73.8)	66.7	(61.6-71.8)
Pap smear past 3 years	94.1	(93.2-94.9)	94.2	(90.7-97.8)	92.4	(89.2-95.6)
Quality of life						
Fair/poor health	3.6	(3.0-4.2)	5.6	(2.4-8.8)	7.6	(4.9-10.3)
Poor health	0.7	(0.4-0.9)	0.7	(0-1.4)	0.4	(0-0.9)
Dissatisfied w/life	2.9	(2.3-3.5)	5.0	(2.1-7.8)	2.2	(0.8-3.6)
Sad 15+ days in past month	5.0	(4.3-5.6)	9.4	(5.4-13.5)	7.1	(4.2-10.0)

Notes on variable creation and analysis for race, health, and income analysis, BRFSS 1998-2003

Tables 2C.2.1 to 2C.2.5 ¹See end notes for variable definitions ²Sample size for some variables are smaller than noted. *** sample size too small

Income categories US Census bases poverty status on income and number of family members. For this analysis, we defined low income as $\leq 200\%$ of poverty level. However, since exact income is not reported in BRFSS, 200% of the poverty level could only be approximated. Below are Census cutoffs for 200% federal poverty level for each family size, and the corresponding cutoffs used for low income in this analysis.

	200% poverty level – US Census	New low income categorization
Family members: 1	\$18,620	< \$20,000
2	\$24,980	< \$25,000
3	\$31,340	< \$35,000
4	\$37,700	< \$35,000
5	\$44,060	< \$50,000
6	\$50,420	< \$50,000
7	\$56,780	< \$50,000
8	\$63,140	< \$50,000

Some BRFSS variables were only asked to/analyzed for a segment of the total sample. In addition, some variables were not included in the survey every year. The sample size for a particular question, therefore, may be smaller than that reported in the tables. Below is a list of variables, population analyzed for, years asked, and additional notes pertaining to the variable.

Health Care Access	Population	Years asked	Additional notes
No insurance	all	All	
Inadequate insurance	all	1998-2001	No insurance, not insured in past year, or insured but unable to see MD due to cost
Regular MD	all	2000-2003	Has person s/e thinks as personal health provider
Health Risks/conditions			
Overweight	all	All	BMI ≥ 25
Obese	all	All	BMI ≥ 30
No physical activity	all	1998, 2000-2003	No physical activity in past month
Current Smoking	all	All	
Binge drinking	all	1999, 2001, 2002	5+ drinks at one time in past month
Heavy drinking	all	1999,2001,2002	defined as > 60 drinks in past month for men, > 30 for women
< 5 fruits/vegetables/day	all	1998, 2000, 2002	
High BP	all respondents who ever had BP check	1999, 2001,2003	
Cholesterol check ever	all	1999, 2001,2003	
High cholesterol	all respondents who ever had chol. check	1999, 2001,2003	
Conditions			
Asthma	All	2000- 2003	
Diabetes	All	all	gestational diabetes not considered diabetes
Preventive Care/screening			

HIV test ever	Adults ages 18-64	All	
Pap smear past 3 years	all women w/out hysterectomy	1998-2002	Asked only on 1 split in 01
Quality of life			
Fair/poor health	all	All	
Poor health	All	All	
Dissatisfied w/life	all	1998-2001	
Sad 15+ days in past mo.	all	All	

Weighting variable

Data were weighted using popwt variable in 1998-1999 and finalwt variable for 2000 – 2002.
Weights were transformed to sum to the sample size.

**Table 2D.3.1 Child's Health Status
National Survey of Children's Health, 2005¹**

	All Children ²		CSHCN ²		non-CSHCN	
	% US	% MA	% US	% MA	% US	% MA
% children whose overall health is excellent or very good	84.1	88.7	66.0	72.3	87.9	93.4
% children with health problems rated as moderate or severe by parents	7.9	10.4	44.6	46.9	0.0	0.0
% children with asthma whose families are greatly or moderately affected in some way by child's health condition	16.3	16.9	20.0	20.7	8.8	6.4 ³
% children affected by asthma during past year	8.0	9.7	32.6	33.0	2.9	3.2
% children ages 0-5 with injuries requiring medical attention during past year	9.4	11.3	14.5	14.7	8.8	10.8
% school age children who missed 11 or more days of school in the past year due to illness or injury	5.2	6.0	13.5	12.6	3.0	3.6
% children ages 0-5 whose parents have one or more concerns about child's learning, development, or behavior	36.6	37.9	60.3	71.7	33.7	32.5
% children ages 3-17 with moderate or severe difficulties in the area of emotions, concentration, behavior, or getting along with others	9.2	9.8	31.0	30.3	3.9	3.3
% children ages 0-5 who were breastfed for any length of time	72.3	71.5	66.2	65.4	73.1	72.5

1. Child and Adolescent Health Measurement Initiative (2005). National Survey of Children's Health, Data Resource Center on Child and Adolescent Health website. Retrieved 07/05/2005 from www.nschdata.org.
2. Sample sizes vary depending on the questions asked. Missing data are excluded from analysis. n= 102,353 (18,578 CSHCN) and 2,114 (429 CSHCN) for US and MA, respectively.
3. n= 63 for non-CSHCN in MA, a lower n than typical for these analyses.

**Table 2D.3.2 Child's Health Care
National Survey of Children's Health, 2005¹**

	All Children ²		CSHCN ²		non-CSHCN	
	% US	% MA	% US	% MA	% US	% MA
% children currently insured	91.2	96.4	94.8	96.2	90.5	96.4
% children currently uninsured or not insured for some period during the past year	14.9	9.1	12.6	11.4	15.4	8.5
% children with a preventive medical care visit in the past year	77.8	92.3	86.5	95.2	75.9	91.5
% children with both a preventive medical care visit and a preventive dental care visit in the past year	58.8	74.9	69.3	81.0	56.5	73.2
% children with current emotional, developmental, or behavioral problems who received some type of mental health care during the past year	58.7	67.6	60.6	69.9	48.5	50.6 ³
% children who have a personal doctor or nurse from whom they receive family-centered, accessible, comprehensive, culturally sensitive and coordinated health care	46.1	60.3	44.2	47.4	46.6	64.0

1. Child and Adolescent Health Measurement Initiative (2005). National Survey of Children's Health, Data Resource Center on Child and Adolescent Health website. Retrieved 07/05/2005 from www.nschdata.org.
2. Sample sizes vary depending on the questions asked. Missing data are excluded from analysis. n= 102,353 (18,578 CSHCN) and 2,114 (429 CSHCN) for US and MA, respectively.
3. n= 18 for non-CSHCN in MA, and estimates are unstable.

**Table 2D.3.3 Child's School, Family, and Neighborhood
National Survey of Children's Health, 2005¹**

	All Children ²		CSHCN ²		non-CSHCN	
	% US	% MA	% US	% MA	% US	% MA
% children ages 3-5 who regularly attended preschool , kindergarten, Head Start or Early Start during the past month	60.7	67.0	69.5	65.2	59.3	67.3
% children ages 6-17 who participate in one or more organized activities outside of school	81.0	87.0	79.3	82.6	81.4	88.6
% children ages 6-17 who repeated at least one grade in school	11.3	11.5	17.7	20.0	9.6	8.5
% children ages 6-11 who stayed home alone during the past week	15.9	16.9	17.9	21.1	15.4	15.5
% children ages 0-5 read aloud to by family members every day during the past week	47.8	57.8	55.0	55.7	46.9	58.1
% children who live in households where someone smokes	29.5	27.1	35.1	34.4	28.2	24.9
% children who attend religious services at least once a week	55.7	39.5	54.2	37.6	56.0	40.1
% children with mothers whose overall physical and mental health is excellent or very good	58.9	66.2	50.5	50.9	60.7	70.7
% children living in neighborhoods parents describe as supportive	81.4	84.4	77.9	81.0	82.1	85.4
% children living in neighborhoods or communities parents feel are usually or always safe	83.8	86.0	82.8	84.4	84.0	86.4
% children ages 0-5 whose parents had to make different child care arrangements in the past month or a job change for child care reasons in the past year, or both	33.2	34.9	43.7	50.1	31.9	32.5

1. Child and Adolescent Health Measurement Initiative (2005). National Survey of Children's Health, Data Resource Center on Child and Adolescent Health website. Retrieved 07/05/2005 from www.nschdata.org
2. Sample sizes vary depending on the questions asked. Missing data are excluded from analysis. n= 102,353 (18,578 CSHCN) and 2,114 (429 CSHCN) for US and MA, respectively.

Table 2D.7.1: Injury-related Hospital Discharges

2003

MASSACHUSETTS CHILDREN, AGES 0-14 YEARS

- ◆ There were 2,736 injury-related hospital discharges among Massachusetts children ages 0-14 in 2003, a rate of 221.6 per 100,000.

INJURY CAUSE	INJURY INTENT					Total Number	Percent of Total	Crude Rate per 100,000 ²
	Unintentional	Intentional		Undetermined	Other & Legal ¹			
		Self-inflicted	Assault					
Cut/pierce	57	10	5	0	0	72	2.6	5.8
Drowning/submersion	13	0	0	0		13	0.5	1.1
Fall	976	1	1	1		979	35.8	79.3
Fire/burn	51	0	0	2		53	1.9	4.3
Firearms	1	0	3	0	0	4	0.1	--
Machinery	6					6	0.2	0.5
Natural/environmental	143	0		0		143	5.2	11.6
<i>Dog bites</i>	57	0		0		57	2.1	4.6
<i>Other bites & stings</i>	68	0		0		68	2.5	5.5
<i>All other (e.g. extreme cold)</i>	18	0		0		18	0.7	1.5
Overexertion	29					29	0.0	2.3
Poisoning	127	91	0	14	0	232	8.5	18.8
Struck by, against	200	0	8	0	1	209	7.6	16.9
Suffocation/hanging	39	0	1	0		40	1.5	3.2
Transport Injuries:	396	0	0	0	0	396	14.5	32.1
<i>Motor vehicle traffic-related</i>	222					222	8.1	18.0
<i>Occupant</i>	90					90	3.3	7.3
<i>Motorcyclist</i>	11					11	0.4	0.9
<i>Pedal cyclist</i>	34					34	1.2	2.8
<i>Pedestrian</i>	79					79	2.9	6.4
<i>Other person</i>	5					5	0.0	0.4
<i>Unspecified person</i>	3					3	0.1	--
<i>Pedal cyclist, other</i>	110					110	4.0	8.9
<i>Pedestrian, other</i>	9					9	0.3	0.7
<i>Other transport</i>	55					55	2.0	4.5
Other specified & classifiable	159	0	32	0	0	191	7.0	15.5
Other specified, not classifiable	61	3	10	8	0	82	3.0	6.6
Unspecified	96	2	11	8	0	117	4.3	9.5
Adverse Effects ³						50	1.8	4.0
No cause or intent provided						120	4.4	9.7
TOTAL NUMBERS	2,354	107	71	33	1	2,736	100%	221.6
Injury Hospitalization Rate by Intent	190.7	8.7	5.8	2.7	0.1	n/a	n/a	n/a

Source: MA Hospital Discharge Database, MA Division of Health Care, Finance and Policy.

¹ Legal Intervention includes injuries resulting from police actions and operations of war.

² Rates are not calculated on counts of less than five. Rates that are based on counts less than twenty may be unstable.

³ Adverse Effects can be related to medical and surgical care procedures, or to the use of therapeutic substances (including allergic reactions).

—An emergency department injury discharge is defined as any case having an ICD9-CM Nature of Injury Code of 800-999 assigned to any of the ICD9 diagnosis fields [cases having the following codes are excluded if no other valid ICD9-CM code is assigned: Certain Adverse Effects (995.0-995.4, 995.6, 995.7, 995.86, 995.89), Complications of Surgical & Medical Care (996-999), and certain Late Effects (909.3, 909.5)]

—Categories and groupings are based on a modified version of the CDC's "Recommended framework of E-code groupings for presenting injury mortality and morbidity data." This framework does not provide for intentionality for certain cause categories as indicated by gray shading.

—Injury subcategories are italicized. Analysis is based on a fiscal year (Oct 1, 2002 - Sep 30, 2003). Only Massachusetts residents with valid zip codes (01001-02791, 05501, 05544) are included. Injury hospitalization cases transferred to another acute care facility or subsequently dying in the hospital, are excluded from this analysis.

—Population data used to calculate rates are based on 2003 population estimates generated by the US Census Bureau (www.census.gov/popest/states/asrh/files/SC-EST2003-race6-AL_MO.csv).

—Data were extracted and compiled by the Injury Surveillance Program, Center for Health Information, Statistics, Research and Evaluation, MDPH, July 2005.

Table 2D.7.2: Injury-related Hospital Discharges

2003

MASSACHUSETTS YOUTH AND YOUNG ADULTS, AGES 15-24 YEARS

◆ There were 4,594 injury-related hospital discharges among Massachusetts youth ages 15-24 in 2003, a rate of 540.9 per 100,000 residents.

INJURY CAUSE	INJURY INTENT					Total Number	Percent of Total	Crude Rate per 100,000 ²
	Unintentional	Intentional		Undetermined	Other & Legal ¹			
		Self-inflicted	Assault					
Cut/pierce	94	155	160	2	0	411	8.9	48.4
Drowning/submersion	6	0	0	0		6	0.1	0.7
Fall	523	10	1	4		538	11.7	63.3
Fire/burn	36	4	1	0		41	0.9	4.8
Firearms	27	1	99	18	0	145	3.2	17.1
Machinery	29					29	0.6	3.4
Natural/environmental	53	0		0		53	1.2	6.2
<i>Dog bites</i>	13	0		0		13	0.3	1.5
<i>Other bites & stings</i>	24	0		0		24	0.5	2.8
<i>All other (e.g. extreme cold)</i>	16	0		0		16	0.3	1.9
Overexertion	101					101	0.0	11.9
Poisoning	201	721	1	109	0	1,032	22.5	121.5
Struck by, against	189	0	175	0	2	366	8.0	43.1
Suffocation/hanging	8	8	1	0		17	0.4	2.0
Transport Injuries:	1,218	2	2	0	0	1,222	26.6	143.9
<i>Motor vehicle traffic-related</i>	1,040	2	2	0	0	1,044	22.7	122.9
<i>Occupant</i>	793					793	17.3	93.4
<i>Motorcyclist</i>	94					94	2.0	11.1
<i>Pedal cyclist</i>	17					17	0.4	2.0
<i>Pedestrian</i>	108					108	2.4	12.7
<i>Other person</i>	3					3	0.0	--
<i>Unspecified person</i>	25					25	0.5	2.9
<i>Pedal cyclist, other</i>	57					57	1.2	6.7
<i>Pedestrian, other</i>	6					6	0.1	0.7
<i>Other transport</i>	115					115	2.5	13.5
Other specified & classifiable	152	3	32	0	0	187	4.1	22.0
Other specified, not classifiable	76	28	33	3	0	140	3.0	16.5
Unspecified	114	10	28	3	0	155	3.4	18.2
Adverse Effects ³						43	0.9	5.1
No cause or intent provided						108	20.0	12.7
TOTAL NUMBERS	2,827	942	533	139	2	4,594	100.0	540.9
Injury ED Visit Rate by Intent	332.8	110.9	62.8	16.4	0.2	540.9	n/a	n/a

Source: MA Emergency Department Discharge Database, MA Division of Health Care, Finance and Policy.

¹ Legal Intervention includes injuries resulting from police actions and operations of war.

² Rates are not calculated on counts of less than five. Rates that are based on counts less than twenty may be unstable.

³ Adverse Effects can be related to medical and surgical care procedures, or to the use of therapeutic substances (including allergic reactions).

—An emergency department injury discharge is defined as any case having an ICD9-CM Nature of Injury Code of 800-999 assigned to any of the ICD9 diagnosis fields [cases having the following codes are excluded if no other valid ICD9-CM code is assigned: Certain Adverse Effects (995.0-995.4, 995.6, 995.7, 995.86, 995.89), Complications of Surgical & Medical Care (996-999), and certain Late Effects (909.3, 909.5)]

—Categories and groupings are based on a modified version of the CDC's "Recommended framework of E-code groupings for presenting injury mortality and morbidity data." This framework does not provide for intentionality for certain cause categories as indicated by gray shading.

—Injury subcategories are italicized.

—Analysis is based on a fiscal year (Oct 1, 2002 - Sep 30, 2003). Only Massachusetts residents with valid zip codes (01001-02791, 05501, 05544) are included.

—Injury hospitalization cases transferred to another acute care facility or subsequently dying in the hospital, are excluded from this analysis.

—Population data used to calculate rates are based on 2003 population estimates generated by the US Census Bureau (www.census.gov/popest/states/asrh/files/SC-EST2003-race6-AL_MO.csv).

—Data were extracted and compiled by the Injury Surveillance Program, Center for Health Information, Statistics, Research and Evaluation, MDPH. July 200!

Table 2D.7.3: Injury-related Emerg. Dept. Visits

2003

MASSACHUSETTS CHILDREN, AGES 0-14 YEARS

- ◆ There were 144,799 injury-related emergency department visits among Massachusetts children ages 0-14 in 2003, a rate of 11,727.3 per 100,000.

INJURY CAUSE	INJURY INTENT					Total Number	Percent of Total	Crude Rate per 100,000 ²
	Unintentional	Intentional		Undetermined	Other & Legal ¹			
		Self-inflicted	Assault					
Cut/pierce	10,203	199	40	9	0	10,451	7.2	846.43
Drowning/submersion	59	0	0	0		59	0.0	4.78
Fall	48,055	2	3	13		48,073	33.2	3,893.44
Fire/burn	2,204	3	0	5		2,212	1.5	179.15
Firearms	1	0	1	0	5	7	0.0	0.57
Machinery	101					101	0.1	8.18
Natural/environmental	6,599	0		2		6,601	4.6	534.62
<i>Dog bites</i>	1,962	0		0		1,962	1.4	158.90
<i>Other bites & stings</i>	4,164	0		0		4,164	2.9	337.24
<i>All other (e.g. extreme cold)</i>	473	0		2		475	0.3	38.47
Overexertion	11,160					11,160	0.0	903.85
Poisoning	1,652	208	0	139	0	1,999	1.4	161.90
Struck by, against	31,343	0	1,029	0	5	32,377	22.4	2,622.22
Suffocation/hanging	253	3	3	1		260	0.2	21.06
Transport Injuries:	11,979	0	0	0	0	11,979	8.3	970.18
<i>Motor vehicle traffic-related</i>	6,742					6,742	4.7	546.04
<i>Occupant</i>	5,428					5,428	3.7	439.61
<i>Motorcyclist</i>	100					100	0.1	8.10
<i>Pedal cyclist</i>	301					301	0.2	24.38
<i>Pedestrian</i>	699					699	0.5	56.61
<i>Other person</i>	46					46	0.0	3.73
<i>Unspecified person</i>	168					168	0.1	13.61
<i>Pedal cyclist, other</i>	4,154					4,154	2.9	336.43
<i>Pedestrian, other</i>	118					118	0.1	9.56
<i>Other transport</i>	965					965	0.7	78.16
Other specified & classifiable	9,027	0	237	6	1	9,271	6.4	750.86
Other specified, not classifiable	1,278	39	209	30	0	1,556	1.1	126.02
Unspecified	7,157	26	98	43	3	7,327	5.1	593.41
Adverse Effects ³						109	0.1	8.83
No cause or intent provided						1,257	0.9	101.80
TOTAL NUMBERS	141,071	480	1,620	248	14	144,799	100%	11,727.28
Injury ED Visit Rate by Intent	11,425.4	38.9	131.2	20.1	1.1	n/a	n/a	n/a

Source: MA Emergency Department Discharge Database, MA Division of Health Care, Finance and Policy.

¹ Legal Intervention includes injuries resulting from police actions and operations of war.

² Rates are not calculated on counts of less than five. Rates that are based on counts less than twenty may be unstable.

³ Adverse Effects can be related to medical and surgical care procedures, or to the use of therapeutic substances (including allergic reactions).

—An emergency department injury discharge is defined as any case having an ICD9-CM Nature of Injury Code of 800-999 assigned to any of the ICD9 diagnosis fields [cases having the following codes are excluded if no other valid ICD9-CM code is assigned: Certain Adverse Effects (995.0-995.4, 995.6, 995.7, 995.86, 995.89), Complications of Surgery & Medical Care (996-999), and certain Late Effects (909.3, 909.5)]

—Categories and groupings are based on a modified version of the CDC's "Recommended framework of E-code groupings for presenting injury mortality and morbidity data." This framework does not provide for intentionality for certain cause categories as indicated by gray shading.

—Injury subcategories are italicized.

—Analysis is based on a fiscal year (Oct 1, 2002 - Sep 30, 2003). Only Massachusetts residents with valid zip codes (01001-02791, 05501, 05544) are included.

—ED injury cases subsequently dying in the hospital are excluded from this analysis.

—Population data used to calculate rates are based on 2003 population estimates generated by the US Census Bureau (www.census.gov/popest/states/asrh/files/SC-EST2003-race6-AL_MO.csv).

—Data were extracted and compiled by the Injury Surveillance Program, Center for Health Information, Statistics, Research and Evaluation, MDPH, July 2007

Table 2D.7.4: Injury-related Emerg. Dept. Visits

2003

MASSACHUSETTS YOUTH AND YOUNG ADULTS, AGES 15-24 YEARS

- ◆ There were 153,834 injury-related emergency department visits among Massachusetts youth ages 15-24 in 2003, a rate of 18,112.3 visits per 100,000 residents.

INJURY CAUSE	INJURY INTENT					Total Number	Percent of Total	Crude Rate per 100,000 ²
	Unintentional	Intentional		Undetermined	Other & Legal ¹			
		Self-inflicted	Assault					
Cut/pierce	14,836	897	708	64	3	16,508	10.7	1,943.6
Drowning/submersion	21	1	0	0		22	0.0	2.6
Fall	21,917	8	5	21		21,951	14.3	2,584.5
Fire/burn	2,422	15	12	5		2,454	1.6	288.9
Firearms	80	0	84	30	5	199	0.1	23.4
Machinery	878					878	0.6	103.4
Natural/environmental	3,561	1		1		3,563	2.3	419.5
<i>Dog bites</i>	899	0		0		899	0.6	105.8
<i>Other bites & stings</i>	2,218	0		0		2,218	1.4	261.1
<i>All other (e.g. extreme cold)</i>	444	1		1		446	0.3	52.5
Overexertion	18531					18,531	0.0	2,181.8
Poisoning	1,199	1,294	11	738	3	3,245	2.1	382.1
Struck by, against	25,343	0	5,857	0	106	31,306	20.4	3,686.0
Suffocation/hanging	21	15	8	3		47	0.0	5.5
Transport Injuries:	35,132	5	2	0	0	35,139	22.8	4,137.2
<i>Motor vehicle traffic-related</i>	32,474	5	2	0	0	32,481	21.1	3,824.3
<i>Occupant</i>	29,204					29,204	19.0	3,438.5
<i>Motorcyclist</i>	693					693	0.5	81.6
<i>Pedal cyclist</i>	289					289	0.2	34.0
<i>Pedestrian</i>	898					898	0.6	105.7
<i>Other person</i>	72					72	0.0	8.5
<i>Unspecified person</i>	1,318					1,318	0.9	155.2
<i>Pedal cyclist, other</i>	1,319					1,319	0.9	155.3
<i>Pedestrian, other</i>	79					79	0.1	9.3
<i>Other transport</i>	1,314					1,314	0.9	154.7
Other specified & classifiable	6,514	6	730	16	0	7,266	4.7	855.5
Other specified, not classifiable	1,418	182	1,364	45	0	3,009	2.0	354.3
Unspecified	6,701	71	699	84	22	7,577	4.9	892.1
Adverse Effects ³						172	0.1	20.3
No cause or intent provided						1,913	1.2	225.2
TOTAL NUMBERS	138,628	2,495	9,480	1,007	139	153,834	100.0	18,112.3
Injury ED Visit Rate by Intent	16,322.0	293.8	1,116.2	118.6	16.4	18,112.3	n/a	n/a

Source: MA Emergency Department Discharge Database, MA Division of Health Care, Finance and Policy.

¹ Legal Intervention includes injuries resulting from police actions and operations of war.

² Rates are not calculated on counts of less than five. Rates that are based on counts less than twenty may be unstable.

³ Adverse Effects can be related to medical and surgical care procedures, or to the use of therapeutic substances (including allergic reactions).

—An emergency department injury discharge is defined as any case having an ICD9-CM Nature of Injury Code of 800-999 assigned to any of the ICD9 diagnosis fields [cases having the following codes are excluded if no other valid ICD9-CM code is assigned: Certain Adverse Effects (995.0-995.4, 995.6, 995.7, 995.86, 995.89), Complications of Surgical & Medical Care (996-999), and certain Late Effects (909.3, 909.5)]

—Categories and groupings are based on a modified version of the CDC's "Recommended framework of E-code groupings for presenting injury mortality and morbidity data." This framework does not provide for intentionality for certain cause categories as indicated by gray shading.

—Injury subcategories are italicized.

—Analysis is based on a fiscal year (Oct 1, 2002 - Sep 30, 2003). Only Massachusetts residents with valid zip codes (01001-02791, 05501, 05544) are included in this analysis.

—ED injury cases subsequently dying in the hospital are excluded from this analysis.

—Population data used to calculate rates are based on 2003 population estimates generated by the US Census Bureau (www.census.gov/popest/states/asrh/files/SC_EST2003-race6-AL_MO.csv).

—Data were extracted and compiled by the Injury Surveillance Program, Center for Health Information, Statistics, Research and Evaluation, MDPH, July 2003

Table 2E.3.2: Massachusetts infants likely to access specific* tertiary care treatment services in MA due to their being identified by newborn screening: January 15, 1999 through January 14, 2005.

Cases and births are based on mother's residence

Condition	Cases Detected by NBS (in 6 Years)	Average Number of Cases Detected per year by NBS	Annual Cases Expected	Number of births per 1 case
Cystic Fibrosis	141	24	19 ¹	3,316 ²
MCADD ³	25	4	2 ⁴	18,705 ⁵
Classical Galactosemia	8	1.3	1.3 ⁶	58,452 ⁷
Hemoglobin Disease	206	34	16 ⁸	2,270 ⁹
Hemoglobin Trait	8,878	1,480	—	53

Data Source: New England Newborn Screening Program of University of Massachusetts Medical School (NENSP). Funding Sources: NENSP and The New England Newborn Screening and Genetics Collaborative (HRSA contract #U22MC03959A0)

¹Expected Annual Cases based on carrier frequencies of 1/25 Whites, 1/65 African American, 1/46 Hispanic American, 1/90 Asian American and adjusted for population composition per 2000 Census.

²Range: 2,143-6,848 across 9 MA regions; 5 CF Centers across the state with 3 in Boston

³ NENSP working definition of MCADD: two DNA variants presumed to be pathogenic or biochemical profile consistent with MCADD.

⁴ Minimum estimate, based on 1/110 carrier frequency of common mutation, 985A>G, observed in de-identified MA population

⁵Range: 12,235-59,232 across 9 MA regions: 4 Centers across the state with 3 in Boston.

⁶Projections based on estimated birth incidence of 1/47000 in whites [Suzuki, M.; West, C.; Beutler, E. : Large-scale molecular screening for galactosemia alleles in a pan-ethnic population. *Hum. Genet.* 109: 210-215, 2001. PubMed ID : 11511927] and 79% White population.

⁷Range: 23,738-62,866 across 9 MA regions: 3 Centers in Boston.

⁸ Minimum projections based on estimated birth incidence of 1/375 SS and 1/835 SC in African Americans [Sickle Cell Disease Guideline Panel. Sickle cell disease: screening, diagnosis, management, and counseling in newborns and infants. Clinical Practice Guideline No. 6. AHCPR Pub. No. 93-0562.

Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, U.S. Department of Health and Human Services. April 1993.] and 5.26 % Black population

⁹Range: 800-12,858 across 9 MA regions; highest incidence in Boston; 4 Centers in Boston, 1 each in Central and Western MA

* Preliminary data and not inclusive of all disorders screened by the state of Massachusetts; seminal disorders indicative of some particular services are provided.