

II. NEEDS ASSESSMENT 2005

A. Needs Assessment Process [Section 505(a)(1)]

Overview

Quantitative data: The PR MCH needs assessment process is a continuous activity carried out on a year-round basis. It is aimed at identifying the specific and changing needs of the different MCH population groups. This activity provides the necessary feedback to readjust the MCH work plan to respond better to changes in health needs of the target population. The needs assessment process was guided by several tools including, but not limited to, HP 2010 National Health Objectives related to the MCH population contained in Focus Areas 9, 16 and others; the 18 National PMs and 9 State negotiated PMs; 12 health status and 9 health systems capacity indicators; 6 national and one state outcome measures. Another complementary activity to the needs assessment is the identification at state and local levels of all activities, services and programs according to the MCH pyramid levels for each of the population groups.

Qualitative data: Input on qualitative data is necessary to improve the richness of information about health problems and health care access not revealed by the analyses of quantitative data. This was obtained from a broad array of stakeholders who provided their perspectives about different MCH health issues as well as their opinion on how to address them.

Early in the process of the needs assessment we involved different groups of the MCH population (recent mothers, Home Visiting participants, adolescents, families of CSHCN, among others); partners from multiple public agencies and non-governmental agencies that serve the same MCH population; partners from formal established groups such as SSDI Regional Working Groups, the Healthy Start Consortium (also the MCH Advisory Body), coalitions, and many other committees where the MCH/CSHCN staff are regular members. In addition, any conference or meeting where MCH issues are discussed is used as an opportunity to gain insight about the health needs and demand for services of this population. Another source of data, both quantitative and qualitative, is the media (print and broadcast).

The MCH priorities were determined on the basis of the identified needs, the state capacity to address these needs, the political priorities, and public input of a broad array of stakeholders. The trend analysis for at least 10 years of the rates of each national and negotiated state performance and outcome measures allowed us to set expected targets for future years.

As a result of this analysis, Title V funds were allocated to complement gaps in needed services, conduct new activities or implement new programs that will help us to achieve the established target of performance and long term outcome measures.

Currently, the Title V program has a section staffed with a highly qualified team of professionals whose main task is to gather the most accurate and timely quantitative and qualitative data. This is used to monitor the progress of all performance and outcomes measures, as well as the level of progress in improving the health and well-being of the Puerto Rican MCH population.

The SSDI resources are used to pay two positions; a demographer who is the coordinator and one epidemiologist. These two professionals are key for the collaboration in the five years needs assessment and the collection of data to monitor state and national performance measures, outcomes measures and health status indicators, among others.

B. Five Years Needs Assessment

1. Process for Conducting Needs Assessment

Methodology: The MCH Program is an important public health program, since it is responsible for over 50% of the population comprised by women in their reproductive age, their infants, children and adolescents, including CSHCN. It is important to underscore that in the new health care reform environment, the major public health functions are assessment, promoting public policy and assurance. The MCH programs are charged with conducting a comprehensive assessment of the health status and need for health services. Similarly, MCH programs have to assure that needed services are available, accessible, provided according to the most current established standards of care and utilized by the population. The following pages describe PR's compliance with the needs assessment process. The 2005 comprehensive needs assessment process began with an in-depth review of the Title V Law, current guidances, MCHB Strategic Plan, HP 2010 National Health Objectives established to monitor the MCH health status and well-being, and MCH needs assessment and health care system evaluation literature. This was an activity conducted by the MCH Director and the Evaluator. The outcome of this activity was the development of the logistics for the needs assessment and the design of several instruments to guide data collection and organization into tables and graphs for the appropriate analysis and interpretation. After this in-depth review and the development of the logistics, the MCH Director convened a meeting of a team of 22 key MCH/CSHCN staff that were charged with specific responsibilities for the needs assessment as well as for the FY 2003-2004 Progress Report.

The steps to gather required information to identify the needs of the MCH population groups are summarized as follows:

1. Review the current Title V Law and guidances emphasizing the minimal data items required for assessing performance and outcome measures, as well as health status and health system capacity indicators.
2. Preparing a table containing all data required, source of information and person responsible for gathering the data.

3. Developing an instrument to monitor trends beginning in 1990 of HP 2010 Objectives by MCH groups: women in their reproductive age and infants, children, adolescents and CSHCN.
4. Preparing a list of sources of secondary data, including demographic, socioeconomic, environmental, resources, health services, utilization, surveys and research concerning the MCH population.
5. Requesting the needed information in writing or through personal contacts with key personnel of agencies and programs.
6. Performing patient surveys to understand some MCH issues, such as late entry into prenatal care and reasons for the increasing C/S rates.
7. Performing a customized CDC PRAMS-like survey among postpartum women in randomly selected birthing hospitals. This survey is performed every other year to monitor the prevalence of behavioral risk factors, breastfeeding during the early postpartum period, at six and 12 months of age, and the characteristics of pregnancy outcomes.
8. Conducting studies to understand certain MCH issues better. These included, but were not limited to:
 - a. PRAMS like survey of recent mothers (N=1,004).
 - b. Survey of postpartum women who initiated prenatal care after the first trimester of pregnancy (N=265). This study was intended to identify reasons for late or no prenatal care.
 - c. Descriptive and analytic studies of maternal deaths occurring during 2002 and 2003.
 - d. Survey of recent mothers who were subjected to C/S compared with women who gave birth vaginally. The purpose of this study was to look at the perspective of the women regarding the increasing rate of C/S in PR (N=1,004).
 - e. Analysis of all infant deaths occurring during the period 1990-2003 (N=9,758), by birth weight and gestational age.
 - f. Descriptive analysis of all birth and infant death files reported in 2002-2003.
 - g. Study to determine the prevalence of overweight in an islandwide sample of second grade students enrolled in the public and private educational systems.
 - h. A focus group conducted with Home Visiting Nurses to obtain their input about sociocultural conditions influencing early teen pregnancy (<15 years) in PR.
 - i. SLAITS-like survey administered to the Pediatric Centers CSHCN population.
 - j. Study for assessment of the implementation of the medical home in PR, based on the AAP Medical Home Questionnaire.
9. Collecting data from Medicaid upon certification for the GIP for the identification of CSHCN, as well as data from the state program for CSHCN, ASES, Head Start program and others.
10. Updating an Integrated MCH Index (2003) consisting of 15 selected indicators to assess and compare the MCH status by municipalities.
11. Obtaining stakeholders' input by a wide array of activities such as focus groups, surveys, written input obtained at conferences and meetings, the media, among others.

12. Designing an instrument to compile the demographic profile, socioeconomic conditions, resources and services available by municipality.
13. Consolidating all collected data into tables and graphs to facilitate the analysis and determination of health needs and priorities that should be addressed in the action plan according to available resources.
14. Developing an instrument to help with the analysis and selection of the 10 priority needs. The instrument contains 11 items.
15. Selecting a set of 8 state performance measures based on the number of person affected and the availability of data: numerator and denominator.

Formal and Informal Collaboration: Formal collaboration among the public sector is mandated by several laws, executive orders and policies that indicate which agencies have to sit at the table to address different health and social issues. These policies include: Law 84 (1987) regarding newborn screening for hereditary diseases, Law 51 (1996) of education services for persons with disabilities 0 to 21 years of age, Law 70 (1997) that mandates the establishment of a committee to work with the prevention of infant mortality, and Law 177 (August 2003) that deals with the prevention of child abuse and neglect.

On the other hand, informal collaboration is obtained through participation in various committees, the Healthy Start Consortium, the Asthma Coalition, task forces, interagency meetings, etc. All these are effective means to share information, data and obtain input to address different needs of the MCH population.

Quantitative and Qualitative Methods: Among the quantitative methods to assess the needs of the different MCH population groups and geographical areas, rates, percentages and OR were widely used. Regarding qualitative methods, we used focus groups with different population groups: adolescents, CSHCN's families, Home Visiting Nurses and Healthy Start participants. In addition, the regular meetings held by the SSDI Regional Working Groups, the Healthy Start Consortium and the Interagency Coordination Council mandated by Part C of IDEA (P.L. 105-17) provide important qualitative data.

Methods to Assess Capacity: A tool has been designed for the identification of resources by municipality. This assessment is updated on regular basis (most recently in 2005) by the MCH regional and local staff (Community Health Workers). In addition, the State MCH/CSHCN team meets to identify the principal services and programs by levels of the pyramid.

Sources of Information: We used a wide array of sources of information including, but not limited to, Vital Statistics, Census, program data, requests to collaborating agencies, research studies, newspaper reports on special issues, surveys, registries, inventories of services, and others.

Strengths and Weaknesses: The major strength of the process was the wide participation of front-line MCH providers such as the Home Visiting Nurses, Community Health Workers, the MCH/CSHCN regional directors and coordinators (SSDI), the MCH central

staff, families of CSHCN, the Assistant Secretariat for Planning, Evaluation, Statistics and Information Systems, the Demographic Registry, ASES, Medicaid and a large number of directors of other programs and entities that serve the same MCH population.

The major weakness of the process was the poor response of the general public. Only two (2) entities responded to the invitation to evaluate the final draft of the MCH needs assessment and plan. It is important to highlight that this is the usual behavior of the general public if there are no funds to be distributed.

2. Needs Assessment Partnership Building and Collaboration

The community's and other partners' collaboration and input are obtained through focus groups held with the different MCH population groups and families, through the SSDI Regional Working Groups, comprised of members of different agencies and other entities which serve the same target population and families, through the Healthy Start Consortium, the Early Intervention System of Services Interagency Coordinating Committee, through our participation in various interagency committees, coalitions and meetings with many partners.

3. Assessment of Needs of the MCH Population Groups

A comprehensive needs assessment of the health status of the MCH population is performed every five years, guided by the methodology previously described. The MCH status is assessed and compared by municipalities by means of the Integrated Health Index (IISMI, Spanish acronym). This index is comprised of 15 selected indicators: 5 sociodemographic, 2 concerning the quality of prenatal care and 8 related to pregnancy outcomes.

4. Examine MCH Program Capacity by Pyramid Level.

Figure II-1(a, b) is an update of the services and programs for the different population groups. This figure was updated annually by the MCH/CSHCN working team.

5. Selection of State Priority Needs.

A total of 10 priority needs were selected based on data analysis, number of persons affected, input from collaborators, state political priorities, availability of resources to address identified needs, and reliable, culturally sensitive treatment or management options. An instrument for prioritization of identified needs was designed based on CDC/ASTHO criteria.

C. Needs Assessment Summary

Puerto Rico identified 10 priority needs that have focused the MCH work plan. These are to:

1. Improve maternal health.
2. Reduce unintended pregnancies.
3. Improve newborn health.
4. Reduce adolescent pregnancies.
5. Reduce behavioral risk factors among pregnant women and adolescents (smoking, alcohol and substance abuse).
6. Reduce unintentional injuries among children and adolescents.
7. Increase availability and accessibility to high-quality preventive and primary health care services for the MCH/CSHCN populations.
8. Decrease morbidity and mortality due to bronchial asthma.
9. Improve coordination among health care plans, primary physicians and the Pediatric Centers.
10. Promote successful transition of youth to adult life.

Needs Assessment Content

Overview of the Maternal and Child Health Status

The data compiled from different sources was assembled into tables, graphics and figures to facilitate its analysis and interpretation. The health needs and resources available for each subgroup of the MCH were derived from this process. For the purpose of this description, the following MCH subgroups were considered: (a) women in their reproductive age and infants; (b) preschool, school-aged children and adolescents; and (c) CSHCN. Priority health problems, health system gaps, system constraints, strengths and weaknesses were identified for each of these groups.

Summary of Selected Census Data:

In 2000, the Census Bureau reported 3,808,610 inhabitants in Puerto Rico. Based on this figure, the population density is estimated at an average of 1,080 persons per square mile. However, some metropolitan areas may have close to 10,000 persons per square mile.

There were 1,261,321 households, of which 27% were single-parent, female-headed families with children under 18. Seventy-one percent of these female-headed families were living below the federal poverty level, compared to 44% of families of married couples.

Half of the population, 50.5%, corresponds to the MCH population groups. These include 1,219,804 (32%) children and adolescents up to 19 years old; and 701,871 (18.5%) women between 20-44 years. The median age of the population was 32.1 years compared to 28.4 years in 1990.

A. Women in their reproductive age and infants:

The factors contributing to maternal and infant morbidity and mortality are myriad. Figure II-2, is the conceptual model which assists us in the assembling,

analysis and interpretation of collected data. For the purpose of this analysis the contributing factors to maternal and infant morbidity and mortality were classified into four main categories: (1) Sociodemographic Factors; (2) Lifestyles and Maternal Health; (3) Prenatal and Perinatal Factors; and (4) Postneonatal Factors.

1. Sociodemographic Factors:

Each year an average of 57,000 babies are born alive and nearly 650 stillborns are registered in Puerto Rico. Sadly, every year about 530 of the babies die before the celebration of their first birthday. Most of these babies (74.4%) die during the neonatal period (Figure II-3). Similarly, close to 25 mothers die as a result of a pregnancy related condition. These shocking statistics should make all stakeholders concerned with the HCDS of PR take notice and action regarding newborn and maternal health.

As previously stated, the underlying contributing factors that negatively affect newborn and maternal health are numerous. In order to understand and facilitate the analysis of these factors, they have been grouped into four broad categories: (1) sociodemographic/environmental factors; (2) behavioral and medical (clinical and obstetrical) factors; (3) prenatal/perinatal factors, and (4) postneonatal factors. In PR, infant deaths result from a combination of medical causes, social factors and systems failures that vary by health region.

According to the Census Bureau in 2000 the number of women in their reproductive age (WRA 10-49 years) was 1,131,206. This figure represents 29.7% of the total population in Puerto Rico. Among all WRA, 26.8% were in the age range 10-19, 38.9% were 20-34 and 24.3% were 35 or older. (Figure II-4)

In 2000, about 27% of families with children were headed by a female householder. This represents an increase over the share of female-headed families with children, in 1990 (22%). By contrast, in the U.S. the proportion of female-headed families increased from 20% in 1990 to 22% in 2000. It is important to underscore that between 1990 and 2000 the proportion of families with children headed by women increased in 77 out of 78 municipalities. The highest percentages of female-headed families with children were observed in PR's urban areas, particularly in San Juan (41%) and Cataño (37%). (Figure II-5)

Findings of the ESMIPR 2004 revealed that over 3 out of 4 recent mothers could be classified below the federal poverty level (\$18,810 in 2003). Among those mothers who reported their annual family income, 44.2% had an income less than \$10,000; 24% \$10,000-\$19,999; 18.5% \$20,000-\$39,999 and only 13.5% reported an annual income higher than \$40,000. The average number of family members depending on that family income

was four. Fewer than 4 in 10 surveyed mothers (38.2%) reported that they were employed outside the home.

In 2004, WRA holding the GIP numbered 455,905 in PR. This figure represents 40.3% of all WRA reported in the 2000 Census. A total of 50,803 live births were reported in 2003. An analysis of the health insurance plan of the mother at the time of birth revealed that 63.9% had the GIP, 34.1% a private health plan and 2.2% had another source of payment or none. It is important to highlight that 93.4% of mothers under 14, 92.7% of 15-17 and 90.1% of 18-19 years old had the GIP.

Educational attainment is a strong determinant of economic well-being. In PR women have a higher number of years of formal education than men. However, the proportion of women who had not completed 12 years of education at the time of birth is unacceptable. Even though the proportion of women without a high school diploma is decreasing, in 2003 over 1:5 (22.5%) of mothers who had a live birth had not completed high school. Pregnancy is the leading cause of school desertion in the Island.

Civil status is a variable that affects reproductive behavior and birth outcomes. Unmarried women are at higher risk of poor birth outcomes. In Puerto Rico, the increasing trend of the proportion of infants born to unwed mothers is worrisome. In 1977, only 18.6% of children were born to unwed women, compared to 53.2% in 2003. Nearly 8 of every 10 adolescent mothers (78.7% in 2003) were unwed. The proportion of unmarried mothers varied across geographical areas, ranging from 31% in Moca to 74% in Vieques (2003).

A long-term decline in fertility rates has been observed in Puerto Rico. In 1950, the fertility rate in PR was 5.2 births per women. By 1970, it had fallen to 3.2 births per women, and by 2000 it had dropped to 1.9 births per women. This level of fertility is slightly lower than the rate in U.S. as a whole—2.1 births per women—and substantially lower than the rate for women of PR descent, who had a rate of 2.6 births per woman in 2000. The decline in fertility rates in PR during the 1950s and 1960s is attributed to increasing levels of female sterilization during those decades. In fact, it is estimated that the percentage of sterilized women in PR ranges close to 47% (BRFS, 2002). This figure is higher than that of any other country for which data is available. Another factor influencing this low rate of fertility is the increase in the use of contraceptive methods. At this point it is important to mention that Puerto Rican women were used as guinea pigs in the decades of 1950s and 1960s to test the effectiveness of oral contraceptive methods.

An analysis of the number of live births and the crude natality rate was conducted for the period 1990-2003. The number of births per year

decreased from 66,555 in 1990 to 50,803 in 2003. The reduction was sustained after 1997. During the study period, the number of births decreased by 23.7%. The crude natality rate was 18.9/1,000 persons in 1990, declining to only 13.1/1,000 inhabitants in 2003. Figure II-6 clearly illustrates the fall in the trend of the crude natality rate in the Island.

2. Lifestyles and Maternal Health

Women's behaviors and exposure to risk factors before and during pregnancy, including but not limited to family planning, nutritional habits, smoking, alcohol consumption, illicit drug use, domestic violence, sexual behaviors, medical and obstetric conditions, are important variables that influence the health of the mother-infant dyad. This section summarizes the wealth of data and information collected on these issues.

The PR Title V program has institutionalized the PR Maternal Infant Health Survey (ESMIPR, Spanish acronym). This customized PRAMS-like survey was designed to collect primary data concerning the health and behaviors of recent mothers that influence maternal and birth outcomes. The last survey was conducted from June to September 2004 in a representative sample of 28 birthing hospitals which had at least 15 deliveries per week in 2002. A self-administered questionnaire was answered by 1,004 recent mothers in the postpartum ward.

Findings from the ESMIPR-2004 revealed that 66.5% of surveyed mothers did not plan the index pregnancy. This figure represents a very wide gap between the goal of H.P. 2010 that has established that 70% of all pregnancies should be planned. But even worse, 12.7% of the surveyed mothers said that they did not want the baby they had just delivered and would be taking home. (Figure II-7)

In 2002, the PR BRFSS queried surveyed persons regarding the type of birth control they were using to prevent a pregnancy. Forty-seven percent (47%) of women said they were sterilized, 15.5% were using oral contraceptives, 2.2% Depo-Provera shots, 1.6% the IUD, 9.7% periodic abstinence, 14.8% condoms, and several other methods accounted for less than one percent each. Nearly four percent (3.9%) of males reported they had the vasectomy.

When asked for the main reason for not doing anything to avoid pregnancy, 32.6% of women responded they were not sexually active/no partner, 7% wanted to get pregnant, 2.2% had a fear of side effects, 10.4% did not think they could get pregnant, 22.8% had a tubal ligation, 5.7% stated her partner had a vasectomy and others.

Research in the late 1960's and early 1970's began proving what we know today: pre-pregnancy weight and prenatal weight gain influence infant

birth weight (Chez.). Maternal obesity has been associated with pregnancy complications and adverse outcomes due to increased rates of hypertensive disease, pregestational and gestational diabetes, toxemia, increased cesarean rates, as well as poor newborn outcomes. These include higher risk of congenital anomalies such as neural tube defects, heart defects and multiple anomalies (Watkins et al., Pediatrics, May 2003). On the other hand, pre-pregnancy underweight has been associated with intrauterine growth restriction (IUGR).

The ESMIPR collected data to estimate the BMI at the beginning of the pregnancy (height and weight). Among 922 surveyed mothers who reported their pre-pregnancy height and weight, it was found that 52.5% had a normal BMI (18.5 kg/m² to 24.9 kg/m²), 20.6% were obese (≥ 30 kg/m²), and 18.1% were underweight (<18.5 kg/m²). Almost one half of surveyed women began pregnancy with an inappropriate BMI. The BMI is used to guide prenatal care providers in the estimation of the number of pounds that the pregnant women should gain during the course of her pregnancy. However, 22.5% of the group of studied women gained weight below the recommendations and 40.1% gained more than the recommendations. Findings herein described may reflect poor nutritional behaviors among pregnant women in the Island.

In PR over 70% of pregnant women are participants of the WIC program. This should not be a surprise considering the high proportion of pregnant women (78%) that live below the FPL. In addition, nearly 50% began pregnancy either at the underweight or obese levels. In FY 2003-2004, the WIC program served an average of 24,705 pregnant women per month. The most frequent risk factors for enrollment in the WIC program were: overweight/obesity 32.3%, underweight 13.2%, decreased weight gain during pregnancy 19.3%, increased weight gain during pregnancy 4.5% and anemia 11.7%.

Among surveyed women, 56.3% did not consume folic acid or multivitamins during the month prior to conception. This behavior is associated with an increased risk of bearing a baby affected with NTDs and other anomalies such as cleft lip/palate and congenital heart diseases.

The ESMIPR 2004 found that 3.6% of surveyed mothers smoked, 4.4% reported alcohol consumption and 3.5% (2000) used some illicit drug during the first trimester of pregnancy. Smoking during pregnancy was significantly higher in women under 19 years and unmarried. In contrast, the proportion of women who smoked was significantly lower as the number of years of education completed increased. Similarly, women who were employed were less likely to be smokers. Women holding the GIP also showed a significantly higher level of smoking compared to those who had private health insurance. Late entry or no prenatal care at all was

associated with increased smoking and other unhealthy behaviors. In 2000, the ESMIPR revealed a history of physical abuse sometime during their lifetime by their husband or partner in 6.2% of surveyed recent mothers.

Having sexual intercourse with infected partners constitutes a behavioral and lifestyle factor that contributes to a broad array of poor birth outcomes: stillbirths, LBW, prematurity and neonatal mortality among others. In PR a significant proportion of WRA are infected with sexually transmitted infections (STIs) and many of them go undetected during the prenatal period.

Early, continuous, comprehensive and quality prenatal care is the most cost-effective strategy to detect, treat and prevent STIs infections. However, several birth outcomes suggest that there are perinatal system failures that contribute to these preventable adverse newborn outcomes. As a matter of fact, in 2004, 80 pregnant women (156 cases per 100,000 live births) were found to be HIV positive. But only 66 (82.5%) received antiretroviral medications aimed at preventing perinatal transmission. The 80 HIV positive women delivered 79 infants and one had an abortion. Two of the infants (2.5%) were HIV positive.

Congenital syphilis may be considered an outcome of an unhealthy behavior of pregnant women, as well as an indicator of poor quality prenatal care. It is important to highlight that a total of 265 cases of congenital syphilis were identified between 1991 and 2004. This figure represents an average of 18.9 cases per year and an estimated rate of 36.5 cases per 100,000 live births. This situation is unacceptable. (Figure II-8)

Congenital syphilis is 2.4 times more likely to occur in single than in married women; 31 times more frequently in illegal drug users than in non drug users; 30 times more frequently in women holding the GIP vs. those with private health insurance. About 9% of the cases of congenital syphilis fall through the crack of the perinatal health care system without treatment.

In 2003, the STDs Surveillance Office reported 2,161 cases of chlamydia for a rate of 70.6 cases per 100,000 inhabitants. Over eighty-three percent (83.1%) of all cases were females compared to only 12.9% males. It is important to highlight that 98% of all infected women were between 15 and 44 years of age. However, there is no information about the number of infected pregnant women, if any. On the other hand, only 276 cases of gonorrhea were reported for a rate of 7.1 per 100,000 persons. The prevalence of infected males with gonorrhea was higher, 56.2% compared to 48.8% for females. Of all infected women with gonorrhea, 92.6% were in the age group 15-44 years old.

Based of the prevalence of congenital syphilis we must ensure the standards for prenatal care related to screening of gonorrhea and Chlamydia are being implemented.

Domestic Violence: Domestic violence is an alarming and complex public health problem in Puerto Rico. This statement is supported by selected sociodemographic data, MCH health indicators, data from the Police Department and two islandwide studies using pregnant women as the target population. One of these studies looked at the nature and extent of domestic violence inflicted by partners. The findings of this study were staggering, showing a prevalence of 34.8% of pregnant women subjected to domestic violence by their partners (de Jesús, 1994). The second study examined the prevalence of certain risk behaviors among pregnant women including the problem of domestic violence (1998).

This public health problem is a concern for government officials, legislators, women's advocacy groups, health professionals and the public at large. In fact, the issue is frequently brought to public attention through mass media communications in headline news. However, in spite of the well-documented needs and awareness regarding the problem, programs and services for addressing this issue are limited due to the lack of fiscal resources. In addition, there is a need of a well coordinated and concerted action plan between the evolving health care system in Puerto Rico, other public agencies and community intervention programs concerned with providing services to victims of domestic violence during or around the time of pregnancy. The current system for screening, routinely assessing, preventing, referring and directly intervening in cases of domestic violence is quite deficient. The only programs that screen, assess and coordinate services among entities and programs concerned with intervention of domestic violence cases are the Title V Home Visiting Program and the Rape Crisis Center (RCC). Unfortunately, our health professionals' training and skills in the area of domestic violence are limited.

Smoking, alcohol consumption, drug abuse, domestic violence during pregnancy and sexual intercourse with infected partners are behaviors and lifestyle factors that contribute to the escalating rates of LBW, infant morbidity and mortality in Puerto Rico. As many studies have demonstrated worldwide, women who practice unhealthy behaviors are more likely to have LBW infants. These seem to be important factors that are currently impacting an unknown but significant number of expectant women in our Island.

During the decades leading to the turn of the century, the issue of domestic violence against women by intimate partners has changed from being

considered a private or taboo matter to being recognized as a large public health problem with underlying causes and consequences not only for the victims, but also for the society in general. This is a very complex public health problem that requires the partnership of a variety of public and private entities in developing strategies for improving systems of care to be effective in the prevention, identification, and management of victims as well as in developing public policy.

Several research studies suggest that women may be at higher risk of domestic violence by intimate partners around the time of pregnancy. Therefore, pregnancy provides a window of opportunities for the identification and management of abuse against women. This is so because women usually come in contact more frequently with the health care system during pregnancy. However, primary health care providers (MD's, RN's, social workers, nutritionists, and others) need to be very well trained to appropriately perform screening for domestic violence at all their interventions. Data from the Police Department and two studies with pregnant women across the Island demonstrate that domestic violence during pregnancy is an alarming situation in Puerto Rico.

Since the enactment of the law for the Prevention and Intervention Against Domestic Violence, this issue has been brought into public attention (Law #54 of August 15, 1989). There has been an escalating trend of domestic violence reports to the Police Department since 1988. During the last 10 years the number of incidents reported has increased in 46%. A similar trend in the request for protective orders has been observed.

In reviewing the data collected by the Police, there are 9 female victims of domestic violence for each male victim. In fact, the average number of women killed by their partners (spouse, ex-spouse, boyfriend, or partner) per year is around 29, versus five men killed by their female partners. This represents a proportion of six women to each man killed by their respective partners.

As mentioned earlier; in addition to the selected sociodemographic data, perinatal data and the Police reports on domestic violence, two recent studies of pregnant women across the Island underscore the problem of domestic violence in Puerto Rico. Angela de Jesús, Ph.D., carried out the first investigation on this issue in 1994, as her requirement to earn her doctorate degree in Public Health Education. Twenty-five of the 84 then-existing public prenatal clinics were randomly selected across the Island to participate in the study. The purpose of the study was to explore the nature and extent of physical, sexual and emotional abuse against pregnant women in Puerto Rico. The target population was all pregnant women from 12 to 40 years of age who received prenatal care services in the selected clinics. The research used a self-administered questionnaire: "An

Estimate of Victimization of Pregnant Women” (EVPW). The questionnaire consisted of 17 items related to demographic information and 20 items aimed at estimating the prevalence and frequency of the different manifestations of abuse. The last section included body maps on which the women could indicate the site or body areas where physical abuse had been experienced during current or previous pregnancies.

A total of 1,695 questionnaires were distributed to pregnant women throughout the 25 randomly selected prenatal clinics. Of these, 1,616 (95.3%) questionnaires were completed and returned. The findings were staggering. Over one-third (34.8%) of respondents had been abused during current or previous pregnancies. This means that one in three (1:3) pregnant women in Puerto Rico was victim of physical, sexual or emotional abuse inflicted by her intimate partner (or guardian in case of adolescents). Even worse, the abuse was not an isolated incident, but rather a frequent event. Adolescents with low educational attainment and low family income were at higher risk of abuse.

The highest incidence of abuse (21.9%) was found in the Northern Health Region of Bayamón, while the lowest (1.2%) was reported in the western Health Region of Aguadilla. The abuse was most frequently reported to occur during the second and third trimesters of pregnancy (41.3%). In terms of time of the day, it occurred most frequently at night (58.4%).

Among the 562 abused pregnant women, 90% indicated that they were victims of emotional abuse, 63% physical abuse, and 28% were sexually abused. The signs and symptoms of emotional distress most often reported by respondents were: emotional abuse caused by the intimate partners (83.6%), feeling depressed (75.1%), becoming repulsed toward their partners during sexual relations (60.5%), feeling shy (56.2%) and developing low self-esteem (51.1%).

The leading types of physical abuse in decreasing order of frequency were: being slapped, being hit with a fist, being pushed, developing black and blue marks, being forced to have sexual relations, being kicked, being shaken, being threatened with a knife, being threatened with a gun, suffering an abortion, experiencing fractures, and being burned. These types of physical injuries occurred primarily during the current pregnancy.

Another local study was conducted in Puerto Rico in 1998. The MCH Division prepared a Spanish-language short version of the CDC PRAMS questionnaire, selecting those items related with tobacco, alcohol, illicit drug use and domestic violence. The instrument was self-administered to a representative sample (n=662) of WIC participants islandwide. Among respondents, 4.8% were smokers, 4.6% consumed alcohol, 1.7% used drugs and 6.2% had experienced physical abuse by intimate partners.

These behaviors seem to be important contributors to the increasing rates of LBW and premature births in Puerto Rico. Statistics of WIC participants revealed that women who were subjected to domestic violence were 2.7 times more likely to have a premature infant.

In view of these statistics, it becomes clear that to decrease infant mortality and morbidity on the Island we must intervene to eliminate or at least ameliorate the lifestyles and high-risk behaviors in which our pregnant women engage. Therefore, developing, establishing and implementing the practice of universal screening for alcohol consumption, smoking and illegal drug use in pregnant women, as well as for domestic violence is a worthwhile endeavor in trying to decrease IM and women's homicides. This intervention should be included as part of the standards of care for prenatal care. It is important to mention here that the Puerto Rico Department of Health submitted a proposal requesting support to implement a program for training primary providers for universal screening for domestic violence during prenatal care. Unfortunately, the proposal was not approved in spite of the well-documented need.

The adverse effects of domestic violence during pregnancy have been documented in the scientific literature. However, most medical providers do not perform the practice of universal screening for domestic violence during prenatal care visits as part of the routine health care of the pregnant women. Although the public health sector is keenly aware of the importance of the universal screening and the economic benefits of preventing domestic violence, one of the most difficult barriers to implementing universal screening for domestic violence is motivating the medical providers to adopt this intervention in their practices. Medical providers are often oblivious to the importance of public health issues such as universal screening for substance use and domestic violence and the consequences that an inadequate identification of these risks poses for them and their practice.

3. Prenatal and Perinatal Factors

In Puerto Rico there is an excess of morbidity and mortality among Puerto Rican women and infants residing in the Island. This is so not only when they are compared with white American women, but also with women of Puerto Rican descent residing in the US mainland. This situation may be the result of personal as well as health care system characteristics. Personal characteristics include age, educational attainment, marital status, socioeconomic conditions, unhealthy and health seeking behavior, pre-pregnancy and obstetric conditions. In addition, analyses of different sources of secondary and primary data collected through questionnaires administered to recent mothers and focus groups point to system barriers and failures. There are several indicators (i.e. congenital syphilis) that suggest an inappropriate implementation of current standards of quality

prenatal care. Similarly, the escalating rate of cesarean sections and other perinatal clinical practices negatively impact the maternal and newborn health.

Comprehensive prenatal care must include screening for a variety of unhealthy behaviors in which a significant proportion of pregnant women may be involved, and counseling or anticipatory guidance according to identified risks. However, our most recent study, the ESMIPR, shows a wide window to improving comprehensive antenatal care on this regards. Surveyed women told us that they received orientation on several queried topics by physicians, nurses, nutritionists, health educators, social workers and others. Nevertheless the frequency of the orientation and anticipatory guidance varied among providers and topics. The proportion of pregnant women who received orientation by her medical provider fluctuated between 38.1% and 81.3% according to the topics. It is important to underscore that the medical provider comes in contact with expectant women on an average of 10 times before delivery. But unfortunately these opportunities to promote healthy behaviors and prevent associated complications during pregnancy are lost. Only 79.1% of pregnant women received orientation on preventing premature births, 60% on smoking, 60.2% on alcohol consumption, 62.7% on illicit drug use, 80.8% on the effect of non-prescribed medications, 56.1% on physical abuse by her partner, 74.1% on folic acid consumption during pregnancy, 43.8% on the importance of breastfeeding, 81.3% on the importance of the postpartum visit, 51.1% on the importance of proper nutrition and only 38.7% were counseled regarding the proper position to lay her baby to sleep.

On the other hand, the orientation provided by nurses hovered between 7.1% and 26.3%; nutritionists between 2.1% and 26.3%; health educators between 0.3% and 9.9%; and social workers between 0.3% and 5.8%. At this point it is important to underscore that not all pregnant women in PR are fortunate enough to come in contact with health educators, social workers or nutritionists in the current health care system based on a managed care model.

The prevalence of pregnancy complications requiring between one and over four hospitalizations was 28.4% (ESMIPR 2004). Among the most common reasons for hospitalizations were premature contractions (48.9%); vomiting and dehydration (17.4%); urinary tract infections (11.9%); placenta problems and bleeding (10.4%); high blood pressure (8.3%); diabetes (5.8%); and others (32.4%). Almost all these conditions are associated with a high proportion of prematurity and LBW babies.

Concerning the oral health-seeking behavior, only 33.5% of expectant mothers contacted an oral health provider. The dentist visit was for treatment of an oral health ailment instead of for prevention of conditions

associated with premature births. Therefore, private health plans, including the GIP, are paying for a service that is used by only one out three pregnant women. There are personal and system reasons that explain this behavior.

Vital statistics data for Puerto Rico in 2003 reported that approximately 1 in 5 pregnant women initiated prenatal care after the first trimester or had no prenatal care at all. This group of women is more likely to have poor maternal and birth outcomes. A study entitled “Descriptive Study of the Barriers Encountered by a Group of Women in Puerto Rico with Late Entry or No Prenatal Care” was conducted by the MCH program staff (Sixto J. Merced-Rolón, MD, Roberto Varela Flores, MD, MPH) from January to March 2005.

The methodology consisted of a self-administered questionnaire given to women who met the following criteria: residents of Puerto Rico, who had given birth recently in one of 33 hospitals with at least 100 births in 2003 and who had no prenatal care or who began their prenatal care after the first trimester of pregnancy (>13 weeks). A non-probabilistic sample was selected since the event occurs rarely in each hospital. A descriptive analysis of the variables was performed.

The study revealed that almost all (96.6%) of the 265 respondents initiated prenatal care after the first trimester and 3.4% had no prenatal care. The main barriers identified were: Did not know they were pregnant (64.7%), Did not have medical insurance at the time pregnancy started (21.1%), Were afraid of telling their parents (15.8%), and had transportation problems (9.8%). After seeking prenatal care, 9.4% of the women had to wait 1 to 5 days to be admitted to the service, 28.7% waited 1 to 4 weeks, and 12.8% waited > 4 weeks.

In conclusion it would be said that personal barriers (lack of awareness of the signs of pregnancy, psychosocial factors), a combination of personal and system barriers (transportation problems, lack of health insurance coverage), and health care delivery system barriers (the time lapse between requesting prenatal care and the actual admission to prenatal health services) may explain reasons for late or no prenatal care in PR.

The barriers for the initiation of prenatal care in the first trimester are multifactorial. Reducing these barriers should be a concern of all the stakeholders of the health services system and social sectors related to the promotion of health and the prevention of risk factors among pregnant women and their babies. A trend analysis of the first trimester admission rate shows almost a plateau during the last decade. In 2003, the first trimester admission rate was 82.4% (Figure II-9).

Time analyses of fetal, neonatal, perinatal, postneonatal, infant and maternal deaths by person, place and causes of deaths were conducted looking at the understanding of fundamental causes, contributing factors and determinants of fetal and infant deaths by age groups and birth weight. These analyses demonstrate a wide gap between the current infant mortality rate (9.8 in 2003) and maternal death ratio (25.6 per 100,000 live births) as determined by the Maternal Mortality Surveillance System and set targets for 2010. Infant and maternal death rates are two sentinel indicators that reflect not only the maternal and infant health status, but also the socioeconomic well-being of a community or a nation. In 1913, Julia Lathrop said “infant mortality is the most sensitive index we possess of social welfare” (U.S. Children’s Bureau, 1913).

Fetal Deaths: The target set by HP 2010 regarding fetal deaths is 6.8/1,000 live births. In 2003, 548 stillbirths were registered in Puerto Rico. This represents a stillbirth rate of 10.7/1,000, which is 1.6 times higher than the established goal.

An analysis of fetal death revealed the following:

- 80.8% of the mothers began prenatal care during the first trimester of pregnancy
- 61.0% of stillbirths had a gestational age between 20-27 weeks
- Only 10% were ≥ 37 weeks old
- 64% were low birth weight and very LBW
- The five leading causes of death of stillborns in order of frequency were (1) conditions originating in the perinatal period, (2) disorders related to short gestation and LBW, (3) fetus affected by complications of placenta, cord and membranes, (4) fetus affected by maternal complications of pregnancy, and (5) congenital malformations, deformations and chromosome anomalies.

These findings show that in PR most fetal deaths occur in the early fetal period (20-27 weeks) and 6 out of 10 stillbirths are very low birth weight. This situation reflects problems associated with maternal health prior to pregnancy as well as problems related with the quality of care received during pregnancy.

In order to assess the maternal and infant health status and to compare it by municipalities, an Integrated Index of Maternal and Infant Health Status (IIMIHS) by Municipality was developed by the MCH Division in 1998. The Index includes 15 indicators selected from birth and death files. The IIMIHS is comprised of five sociodemographic indicators: (1) Natality rate, (2) Percent of unmarried women, (3) Percent of adolescent mothers, (4) Percent of unmarried adolescent mothers, and (5) Percent of

mothers with less than 12 years of education. Two are related with the adequacy of prenatal care: (1) First trimester admission rate, and (2) Kotelchuck Index. The remaining eight reflect the pregnancy outcome indicators: (1) Percent of prematurity, (2) Percent of VLBW, (3) Percent of LBW, (4) Neonatal mortality, (5) Postneonatal mortality, (6) Infant mortality rate, (7) Stillbirth rate, and (8) Perinatal mortality rate. (Table II-1)

Methodology: Making use of available data from birth and death files, the value of each of the 15 indicators is determined for the 78 municipalities. These are ranked according to the value of the indicator. The sum of all the 15 ranks obtained by a municipality constitutes the IIMIHS. In theory, if a municipality ranks in the first position for each selected indicator it would have an IIMIHS of fifteen (15). In the contrary, if it ranks in the last position (78) for each selected indicator it would have an index of 1,170. The IIMIHS has been used as a tool for the allocation of resources and to raise awareness among different stakeholders regarding maternal and infant health across different geographical areas (Table 1).

In 2003, there were 50,803 live births in Puerto Rico and the crude natality rate was 13.1 per 1,000 inhabitants. Only 58 births (0.1%) occurred outside a health facility. Nearly one of every two births (45%) was performed by cesarean section.

Of all registered births, 53.2% were to unmarried women, and 17.7% to women under 20 years of age. About 8 in 10 (78.7%) of adolescent mothers were unwed. Over one in five (22.5%) of all mothers had not attained a high school diploma.

More than eighty percent (82.4%) of all births occurred in women who initiated prenatal care during the first trimester. On the other hand, 79.3% had an adequate Kotelchuck Index.

The interrelation of sociodemographic factors and quality prenatal care contribute to maternal, fetal and infant outcomes. An analysis of 2003 births shows the following outcomes: 1.5% of all births were VLBW; 11.5% LBW; 18.5% were born prematurely. The neonatal mortality rate was 7.2/1,000 live births; 2.5/1,000 died during the postneonatal period and the infant mortality rate was 9.8/1,000 live births. The perinatal mortality rate was 8.9 and the stillbirth rate reached 10.7 per 1,000 births.

The 10 best municipalities according to the Integrated Index of Maternal and Infant Health Status in 2003 were Moca, Camuy, Isabela, San Sebastián, Aguas Buenas, Aguada, Utuado, Ceiba and Culebra. Five of these are located in the North-West region of the Island (Figure II-10).

By the contrast, the worst 10 municipalities were Salinas, Humacao, Yabucoa, Adjuntas, Canóvanas, Arroyo, Maunabo, Cataño, Guayama and Loíza. Figure II-10 depicts the localization of these municipalities.

Cesarean Section: Historically, C-section rates in Puerto Rico have been higher than those in the mainland USA (Vázquez-Calzada, 1988). A descriptive study was carried out to provide updated information to concerned individuals and organizations to generate discussion regarding the possible causes that lead to the increased use of this birthing method in Puerto Rico.

Stratified analyses from linked birth and death files provided by the State Vital Statistics Office were performed using the most relevant data available to describe the picture and to generate hypotheses regarding the problem. A total of 183,400 C-section live births for the 1990-98 period were evaluated. The C-section delivery rate had increased from 31.0% in 1990 to 35.1% in 1998. Primary C-section rates rose from 19.9% to 21.2% (6.5% change) and repeated C-sections increased from 13.5% to 13.9% (3%). Overall, C-section rates vary greatly according to maternal age; in 1998, mothers between 20-34 years old were three times as likely to have a cesarean delivery as teenage mothers (75% and 14.7%, respectively), in contrast to the 1.9% experience observed among women 40 years or over. C-section rates were higher for mothers with private health insurance (44.8%) followed by those with the Government Insurance Plan (32.7%) and then by those with the Medicaid plan (21.5%). The rate of vaginal births after previous cesarean delivery (VBAC) was down 7.7%, dropping from 1.3% in 1997 to 1.2% in 1998. The most prevalent birth complications reported across all the study period were cephalopelvic disproportion (15.9%) and breech presentation (5.3%). Also, hypertension (5.1%), anemia (4.3%) and diabetes (2.9%) were the most common complications found during pregnancy. Among all deaths of infants born by C-section in Puerto Rico, the percentage increased slightly from 40.6% in 1997 to 41.1% in 1998, contrary to the steady decline observed among deaths of infants born by vaginal route for the same years (59.3% to 57.8%). Tuesdays (18.3%) followed by Wednesdays (17.8%) were the most frequent days and Sundays (6.7%) followed by Saturdays (8.4%) were the least frequent for C-sections and the majority of the procedures were performed in the afternoon (56.9%). The procedure was performed more frequently between 12:00 and 6:00 PM. The proportion of C-sections ranged from 9% to 69% at different birthing centers. These findings suggest that convenience may be an underlying factor for the increase in C-section rates in Puerto Rico.

This study has been used to raise general awareness of the problem among OB/GYN specialists and the Association of Hospitals to help them to develop policy and practices aimed at reducing C-sections in Puerto Rico.

A C-Section Evaluation Committee was created, comprised of representatives from MCH, PR Chapter Academy of Pediatrics, PR ACOG Chapter, School of Medicine, Hospitals Association, Puerto Rico Health Insurance Administration, an OB/GYN Residency program, Health Insurance Companies, Center for Excellence in Women's Health and Hospitals Assurance Committee representatives. The C-Section Evaluation Committee analyzed the findings of the study conducted by the MCH staff. They generated a list of medical and non-medical reasons that may lead to a C/S. Among the non-medical reasons the group listed the following: (1) defensive medical practice, (2) group or peer pressure, (3) monetary incentive, (4) group vs. solo practice, (5) clinician attitude, (6) socioeconomic factors, (7) patient insurance movement from the public sector to the private sector, (8) need of midwives or other trained personnel in hospital's perinatal units, (9) need of a 24 hour OB/GYN Consultant on duty at the hospital, (10) patient or family request, and (11) convenience factor.

In order to prove or reject each of the above reasons, two other studies have been conducted. A chart audit of a representative sample of 560 cases of C/S in 1999 was conducted in 2002. This study did not prove that the high rate of C/S could be explained by existence of medical conditions; at least, the evidence was not found in the evaluation of the vital files nor hospital records.

The other study recommended by the C-Section Committee is a survey of women subjected to C/S. From July 2004 to February 2005 the MCH staff (Marianne Cruz-Carrión, MS, Evelyn Torres-Rodríguez, MS, Roberto Varela-Flores, MD, MPH, Himirce Vázquez-Rivera, MD) conducted the study entitled "Election of Childbirth By Cesarean Delivery: Attitudes and Experiences of the Woman and Physician Characteristics in the Decision Making". This is a very interesting study looking at primary data from the perspective of the mother that may help us to explain the high and increasing rates of C/S in PR. The study looks for associations between attitudes and experiences of the woman and the characteristics of the physician in the decision making to deliver by C/S.

The methodology consisted of a self-administered questionnaire that collected socio-demographic data, medical history, prenatal care utilization, experiences before and during pregnancy, delivery information, newborn data, and the mother's opinion about and preference for the type of delivery. It was submitted to 1,004 primiparous women (502 cases and 502 controls) who had a live birth in 31 hospitals that registered 10 births or more per week during 2002. The magnitude and significance of the association (OR) between cesarean delivery and the

influence of the woman and the characteristics of the physician was determined by a Multinomial Regression Model.

Adjusting by socio-demographic data, medical history, prenatal care utilization, experiences before and during pregnancy, delivery information, and newborn data, the risk of having a cesarean delivery increases when the birth is attended by a male obstetrician (OR=2.02; p=0.04). Although there was no evidence of statistical significance (p>0.05), an excess risk of having a cesarean delivery was identified if the pregnancy was unintended (OR=1.50), the mother had a negative experience during pregnancy (OR=1.77), or the mother had concerns during pregnancy (OR=1.55). There was no statistical evidence that solo practitioners increased the risk for cesarean delivery (OR=1.00; p=0.99).

In conclusion, the woman's attitudes and experiences and the sex of the physician may affect the decision of the method used for delivery. Efforts to reduce the incidence of cesarean section need to focus on the continuing education of health care providers and on reducing unintended pregnancies, negative experiences and concerns during pregnancy.

Maternal Mortality: Since 1956, the maternal mortality ratios (MMR) have declined by 95% in Puerto Rico, according to Vital Statistics reports. However, maternal mortality (MM) continues to be an important public health problem that affects the woman, the family and society overall. Reports of maternal deaths based on death certificates are usually underestimated. Actual numbers are two to three times greater.

Several studies had identified under-reporting of maternal deaths in Puerto Rico due to misclassification of the cause of death. In 1982, Comas and others found 71.4% under-reporting of maternal deaths. These and other studies led to the inclusion of checkbox No. 21 in the death certificate in 1989. This checkbox helps to identify women who have been pregnant at the time of death or during the 12 months prior to death.

According to vital statistic reports from 1990 to 1998, the number of maternal deaths fluctuated between 4 and 14. However, it is important to highlight that these deaths are those that occurred around the perinatal period and represent the most severe pregnancy complications leading to maternal deaths (ICD9 Codes N630-N676.9). (Figure II-11)

Maternal and infant mortality are basic health indicators that reflect the nation's health status and well being. Current MMR's are unacceptable, not only in Puerto Rico, but also in the US mainland, considering the amount of resources and technology invested in health care services. Since 1982, no progress has been made in the U.S. towards achieving the H.P. year 2010 goal of 3.3 maternal deaths per 100,000 live births. In fact,

preliminary data for 2003 showed MMRs of 13.8 per 100,000 live births in PR compared to 8.9 per 100,000 live births (2002) in the U.S.

To better understand the underlying causes of maternal deaths in PR, a descriptive study was carried out at the PR MCH Division. During the study period (1991-98) a total of 510,073 live births and 75 maternal deaths were reported in Puerto Rico. This represents an average of 14.7/100,000 maternal deaths for the period. However, the investigators (Roberto Varela Flores, MD, MPH, Cristóbal Cintrón, MS and Himirce Vázquez, MD) could identify 149 associated maternal deaths, representing an average of 29.1/100,000 live births, with a discrepancy of 50 percent as compared with data from vital statistics. (Figure II-11)

Regarding selected socio-demographic characteristics, the study revealed that 54.1% of mothers were in the extremes of their reproductive age (<19 or >35 years of age), 41.6% had attained less than high school education, over fifty percent (51.7%) resided in rural areas, 55.7% were married, 37.6% unmarried, 4.7% divorced and 2.0% separated.

Most maternal deaths were clustered in two geographical areas: the northeast and the south. Of the 149 associated maternal deaths, 44.3% (66) occurred after a live birth, 8.1% (12) after stillbirths, 6% (9) after abortion, 2.7% (4) after ectopic pregnancy and 38.9% (58) were unknown or other outcomes.

The interval between the time of birth or pregnancy termination and death of the mother was known in 86% of the cases. Eighty-eight (59.1%) of the mothers died during the postpartum period, 28 (18.8%) while pregnant and 12 (8.1%) during labor and delivery.

The five leading causes of deaths were postpartum hemorrhage (16.1%), thrombotic pulmonary embolism (11.4%), sepsis (9.4%), CNS insult (8.1%) and disseminated intravascular coagulation (6.0%).

During the current fiscal year the MCH Division developed the Maternal Mortality Surveillance System. The first phase of the Maternal Mortality Surveillance System (SiVEMMa), which included the revision of all death, birth, and fetal death certificates (2002-2003) of women residing in PR, 10-54 years old and who died of pregnancy-associated causes has been completed. A second phase includes reviewing hospital records, autopsies, and family interview. The ACOG and CDC Pregnancy-related death definition was used.

A total of 59 cases were identified. Among these, 37% were pregnancy-related, 14% not-pregnancy-related, 24% undetermined, and 25% had occurred more than 1 year after termination of the pregnancy. The

pregnancy-related mortality ratios were 17.0 and 15.6 per 100,000 live births for 2002 and 2003, respectively. The most frequent specific causes of death among the pregnancy-related group were eclampsia/pre-eclampsia (31%) and embolism (26%).

In conclusion, a discrepancy of 125% and 86% more maternal deaths was determined for 2002 and 2003, respectively, as compared with the traditional reporting system. Preventable conditions were the most frequent causes of pregnancy-related death.

SiVEMMa identified the need to re-evaluate the quality of care, access to and utilization of services, and behaviors during pregnancy in order to reduce preventable pregnancy-related deaths. In addition, this surveillance confirms what has been found by many investigators: that Vital Statistics reports are not reliable for measuring the true prevalence of maternal deaths.

4. Postneonatal Factors

The postneonatal mortality rate should not surpass the rate of 2.4 per thousand live births by 2010. In Puerto Rico the postneonatal mortality rate is close to that target. From 2001-2003, a total of 159,652 live births were registered in Puerto Rico. Of these, 387 babies died during the postneonatal period for a rate of 2.4/1,000 live births. Therefore, PR has reached the established goal set for this pregnancy outcome. Our problem resides in the perinatal and neonatal periods. Deaths during the neonatal period are associated with events surrounding the pregnancy and delivery. On the other hand, postneonatal deaths are more likely associated with conditions or events that arise after the delivery and discharge of the baby from the hospital. The causes of deaths in the postneonatal period reflect the effect of the use of technology in preventing deaths of VLBW babies and those with congenital anomalies. This effect also impacts on the cause of deaths among preschool and school age children, 1-14 years. In these age groups, congenital anomalies and cerebral palsy were the third and fifth leading causes of death respectively.

In addition, some of the postneonatal deaths result from injuries, whether intentional or not. It is important to mention that sudden infant death syndrome has not been identified as a significant cause of death in the postneonatal period in PR, as is the case in the US mainland.

Infant Mortality

Negative social conditions, unhealthy physical environments, quality of prenatal, perinatal and postneonatal care have a bigger impact on a newborn than in any other period of life. Therefore, the number of infants who die before the first birthday is a sentinel indicator not only of health

conditions but also of the socioeconomic conditions of a community or nation.

The target for the IMR set by H.P. 2010 is that no more than 4.5 deaths per thousand live births (1,000 LBs) should occur in any group of population or geographical area. In 2003, the IMR in the mainland was 6.9/1,000 LBs while in PR we registered a rate of 9.8/1,000 LBs. These data show that the current infant mortality rate in the Island is 1.2 times higher than the U.S. mainland and 2.1 times above the set target for the 2010. This is a significant disparity between what has been achieved on this important health outcome and the expected.

An analysis of the trends in infant mortality rates revealed a drop of 29% between 1990 and 2003 (Figure II-12). Looking at the IMRs by health regions, Arecibo (7.4/1,000 LBs) and Aguadilla (7.7/1,000 LBs) were the health regions with the lowest IMRs. In contrast, Mayagüez (11.8 per 1,000 LBs) and Ponce (10.7 per 1,000 LBs) were the health regions with the highest IMRs. Only five (5) municipalities had an IMR below 5/1,000 LBs, whereas 29 (37.2%) municipalities recorded IMRs above 10.0 per 1,000. Figure II-13 depicts the health regions and municipalities with the highest IMR.

B. Children and Adolescents Health:

Size and Composition

According to the Census Bureau, in 2000 there were 1,219,804 children and adolescents aged 0-19 years. This figure represents 32% of the overall population in Puerto Rico. However, as shown in Table II-2, the size of all child and adolescent groups declined 5.3% from 1980-2000. This decline may be explained by the drop of the natality rate observed during the last decade as well as the migration of Puerto Rican WRA to the U.S. mainland. As a matter of fact, in 2003 the number of births reached a never-seen low number of only 50,803. Of these, only 45,018 (85.2%) were born to Puerto Rican women 1,338 (2.4%) to Dominicans and 5,949 (11.7%) to women of other nationalities.

Determinants of Children's and Adolescents' Health

Improving the health of children and adolescents is one of the Commonwealth of PR's highest priorities. Health insurance coverage is critical for improving the overall health and well-being of both mothers and children. In 2004, 63% of all births were to women covered by the GIP. Similarly in 2004-2005, nearly 79.8% of Head Start children had the GIP, 19.0% private health insurance and only 1.3% did not have health insurance. The GIP is financed through a mixture of funds including 84.7% state and municipal funds, 12.1% Medicaid and 3.2% SCHIP funds.

The impact of childhood poverty on health and well-being is well known. In 2000, nearly 27% of families with children in PR were headed by a female householder. This represents an increase over the share of female-headed families with children reported in 1990 (22%). In the US, female headed families increased from 20% in 1990 to 22% in 2000.

Child health begins well before birth, with a woman in optimal health at the time of conception and who receives early, continuous, comprehensive and high quality prenatal care. Inadequate prenatal care utilization is associated later with reduced number of well child visits and incomplete immunizations. In 2004, 4:5 (82.4%) of pregnant women in the Island initiated prenatal care during the first trimester and the Kotelchuck Index was only 79%. It is important to mention that the first trimester admission rate has increased only 14% during a 14 years period: 70.8% in 1990 vs. 82.4% in 2003.

Low birth weight and preterm birth are an increasing problem in PR. In 2003, the LBW rate was 2.3 times higher than the established rate for 2010. The preterm birth rate is also increasing. In 2003, it reached 18%. Both LBW and prematurity represent a significant number of infants who survive with greater risk of developing a wide variety of physical disabilities (e.g. cerebral palsy) and developmental delays. (Figure II-14)

In addition, LBW and prematurity are the leading causes of infant mortality on the Island (Figure II-15). The second cause is congenital anomalies. As a matter of fact, the IMR has not declined as expected during the last decade in PR. Instead, it increased from 9.2 in 2001 to 9.8 per 1,000 live births in 2003.

Infant health and development can be greatly promoted through breastfeeding. Breastfeeding rates in the early postpartum period have leveled up in PR, from 42.2% in 2000 to 64.5% in 2004.

Morbidity

Unlike mortality data, morbidity data are more difficult to obtain. Morbidity data can be obtained by means of sample surveys. However, undiagnosed conditions will not be reported. Another problem with surveys is that subgroups with greater access to health care will often appear to have greater incidence of certain conditions. In addition, it is important to mention that PR is not usually included in national surveys intended to assess the health needs of the pediatric population, such as the Pediatric Nutrition Surveillance Systems and the SLAITS.

During the first half of the 20th century, infectious diseases were the primary threat to child health. The first causes of death were pneumonia, gastroenteritis and dehydration, bacterial meningitis, parasitosis, malnutrition, anemia and vaccine-preventable illnesses. However, with the advent of antibiotics, immunizations, purgatives, and other effective medical and environmental

interventions such as potable water, pasteurization of milk and electricity, morbidity and mortality from infections declined markedly.

As we enter the 21st century, child health problems have become more strongly related to external or environmental and difficult to prevent causes, such as injuries, congenital anomalies, cancer and child neglect and abuse. Therefore, to address current child health problems we must focus on issues such as family structure and support services, injury prevention, reduction of family violence, appropriate management of chronic illnesses, mental health and the provision of social services, among others.

The percentage of children who are adequately immunized is another important indicator of child health. Puerto Rico has one of the highest levels of immunized children. In 2004, the immunization coverage among children between 19 and 35 months of age was 93%, compared to 81% in the US. In Puerto Rico, vaccine preventable diseases have almost disappeared, except for chickenpox. (Figure II-16)

The incidence of vaccine preventable diseases shows a marked decline during the period 1999-2003. The incidence of tetanus has fluctuated from 0-4 cases per year. All reported tetanus cases have been found among people over 65 years. Looking at the trends of Whooping Cough, the highest number of cases were observed between 1990 and 1993, and 85% of the cases occurred on infants under one year of age. However, in 2003, only one case was reported in an 11-year-old child. The last epidemic of measles in Puerto Rico was reported in 1990. At that time, 1,817 cases were recorded for an incidence rate of 51 per 100,000 inhabitants. Most affected children (62%) were between 0-4 years of age. The epidemic affected a significant proportion of infants under 1 year, who usually are not vaccinated against this infectious disease.

It is important to mention that after 1995 only 13 cases of measles have been reported in the Island. Similarly, during a period of 14 years (1990-2003) only 3 cases of German measles, 4 cases of mumps, 0 cases of diphtheria, 0 cases of polio and 35 cases of H. Influenza B has been reported. Currently, we are very proud to have one of the highest levels of immunization rates among children in all jurisdictions of the U.S.

Intentional Injuries: Child Abuse and Neglect

In spite of Puerto Rico's efforts to prevent child abuse and neglect, the annual number of cases reported to the Department of the Family is overwhelming. Underlying causes for this serious health problem may be related to the significant proportion of unplanned and unwanted pregnancies (33.5% and 12.7% respectively, ESMIPR 2004) and drug abuse in the mother and partner. Frequently the abuser is not the biological father of the affected child. Also, the proportion of children born to teenagers, most of them unmarried (80%) is another contributing factor.

On a given day in Puerto Rico, nearly 140 cases of child abuse and neglect are reported to the Department of the Family. However, it is important to highlight that for every reported case, there are three who are being abused. But unfortunately, nobody sees or hears anything, and nobody reports the affected child. In 2004, the number of families engaged in this violent behavior was 20,302 and 50,227 children were neglected or abused. Based on the current classification for reporting child abuse and neglect it was found that:

- 27,922 (55.6%) were classified as child abuse and neglect
- 8,560 (17%) multiple abuse
- 5,788 (11.5%) physical abuse
- 5,451 (10.9%) emotional abuse
- 2,496 (9.9%) sexual abuse
- 60 (0.12%) exploitation

Preschool Children Aged 1-4

The prevalence of hereditary diseases screened for at birth is 21 for hypothyroidism, 37 for phenylketonuria, 0.5 for galactosemia, 23 for sickle cell and 6.7 for congenital adrenal hyperplasia cases per 100,000 children.

In 2004-2005, the number of children enrolled in Head Start programs came to 35,299. Of these, 15.3% were children with special health care needs. The most common health conditions reported in Head Start children in order of frequency were dental caries 42.7%, bronchial asthma 16.7%, anemia 11.8%, overweight 10.9%, underweight 5.2%, and only 5.2% had incomplete immunizations at the time of entrance into the Head Start program. The prevalence of insulin dependent diabetes was 0.1%.

A group of pediatricians at the P.R. Pediatric Annual Meeting held in February 2005 said that the most common reasons for ambulatory request of services in preschool children are asthma, upper respiratory infections, otitis media and gastroenteritis.

In 2003, there were 47 deaths in preschool children aged 1-4. The five leading causes of death were (1) congenital anomalies, (2) unintentional injuries, (3) cardiac disease, (4) malignant tumors, and (5) diseases of the blood.

School Age Children 5-14

As reported by the group of pediatricians the most common conditions seen at the office are pharyngitis, upper respiratory infections, asthma, obesity, hyperactivity syndrome and injuries. On the other hand, in 2003 the Department of Education registered 69,126 (nearly 11% overall school aged children) with the following conditions in order of frequency: specific learning disabilities, mental retardation, speech and language impairment, multiple disabilities, emotional disturbance,

hearing impairment, autism, orthopedic impairment, visual impairment, and others.

In addition to the conditions listed above, there is a large population of children with asthma, overweight and juvenile diabetes. The estimated rates for diabetic children is 18/100,000 accounting for nearly 50,000 affected children.

The problem of overweight among second grade students of the public and private education systems was recently documented by an islandwide study conducted by the MCH division and a group of partners in April 2005. We are on the process of analyzing the collected data.

Mortality

The H.P. 2010 objectives call for death rates below 18.6 per 100,000 children 1-4 years of age. Mortality among children 1-14 years of age has declined during the past decades. In 2003, the death rate in the age group 1-14 was 15.2/100,000 vs. 22.4 in 1998. The leading causes of death were unintentional injuries, congenital anomalies and malignant tumors.

In 2003, a total of 79 deaths were reported among children aged 5-9. The five leading causes of death were (1) unintentional injuries, (2) malignant tumors, (3) congenital malformations, (4) cerebral palsy and (5) cardiac disease. It is important to note that aside from unintentional injuries and malignant tumors, the other three causes of death can be traced back to conditions originating during the perinatal period.

Adolescents Aged 10-19

In 2000, 16.2% (619,236) of the population in PR was between 10 to 19 years of age; 8.6% were males and 7.7% females. This group has decreased 9.7% since 1980.

Morbidity

The principal health conditions of adolescents are related to unhealthy behaviors and psychosocial factors. Puerto Rican adolescents are involved in a high proportion of unintentional injuries that increase their morbidity and mortality rates. They engage in unprotected sexual behavior leading to unwanted adolescent pregnancy and STIs. The rates of smoking, alcohol consumption and illicit drug used are alarming. These behaviors result in delinquent activity which is the root cause of violence measured by the rates of homicides, suicides and juvenile arrests.

According to the group of pediatricians the most common health conditions among the adolescent group are overweight, alcohol and illicit drug abuse, mental health including depression and anxiety disorders, and STIs such as herpes.

Ambulatory Care

Puerto Rican adolescents generally rely on ambulatory care, especially physician offices and the emergency room for medical treatment. In 2002, only 50% of the adolescent population with either private health insurance or the GIP seek ambulatory care. Females aged 15-19 had the higher number of contacts. The most common reasons to seek ambulatory care were pregnancy, upper respiratory infections, viral syndromes, acne, routine physical examinations and asthma. The most common reasons leading males to seek care were acne, routine physical examination, asthma and the hyperactivity syndrome.

Adolescents holding the GIP were more likely to use ambulatory services than those with private health insurance. Overall, 13.7% of adolescents were using a medication for a chronic condition and 54.5% of them were females.

Hospitalizations

Adolescent females between 15-19 years old had the highest rates of hospitalizations. They were three times more likely to be hospitalized than males. Among the reasons for their hospitalizations were pregnancy-related diagnoses, asthma, gastroenteritis and depression. Nearly 65% of all females requiring hospitalizations had the GIP. The most common reasons for hospitalizations of males were appendicitis, asthma, neoplasm, gastroenteritis, cellulitis, fractures, dengue fever and diabetes.

Of all dental visits, 53.3% were done by adolescents holding the GIP. Adolescents aged 10-14 accounted for 56.1% of all visits to dentists.

Risk Behaviors

Risk behaviors in areas such as driving, substance use and abuse, physical exercise, diet and sexuality contribute to the leading causes of morbidity and mortality later in life. The Youth Risk Behavior Survey (YRBS) measures the incidence and prevalence of these behaviors. Risk-taking behaviors and teen sexual activity affect the future health of a significant proportion of Puerto Rican youth. This situation is a long-standing concern of a broad sector of stakeholders in the Commonwealth of Puerto Rico. In this section, we intend to describe selected behaviors in which our Puerto Rican public school students (PRS) are engaged in comparison with the U.S. mainland. The description is based on data from the 2001 YRBS.

Injury, Violence and Suicide

Among PRS aged 10-19, motor vehicle deaths account for 22% of all deaths. This figure is much lower than the national average (31%).

- 6% of PRS rarely or never use a safety belt, compared to 14% nationally.
- 36% of PRS rode in a vehicle with a drinking driver during the previous month, compared to 31% nationally.

- 26% were in a physical fight the previous year, compared to 33% nationally.
- 10% carried a weapon during the previous month, compared to 17% nationally.
- 17% attempted suicide during the previous month, compared to 9% nationally.
- 7% of PRS have ever been forced to have sexual intercourse, compared to 7.7% nationally.

Tobacco, Alcohol and Drug Use and Abuse

- 43% of PRS have ever smoked cigarettes, compared to 64% nationally.
- 12.8% of PRS have smoked cigarettes during the previous month, compared to 28% nationally.
- 69% of PRS have ever drunk alcohol, compared to 47% nationally.
- 41% of PRS had drunk alcohol during the previous month, compared to 47% nationally.
- 23% of PRS reported binge drinking during the previous month, compared to 30% nationally.
- 2% of PRS have ever used cocaine, compared to 9% nationally.
- 4% of PRS have ever used heroin, compared to 3.1% nationally.
- 13% of PRS have ever used marihuana, compared to 42.4% nationally.

Sexual Behavior

This behavior is associated with unintended pregnancies and STIs among adolescents.

- 28.3% of PRS have ever had sexual intercourse, compared to 46% nationally.
- 4.6% of PRS have had four or more sex partners, compared to 14% nationally.
- 4.9% of PRS used oral contraceptives at last intercourse, compared to 13% nationally.
- 18.2% of PRS had had sexual intercourse during the previous three months, compared to 33.4% nationally.
- 67% of PRS did not use a condom at last intercourse, compared to 42% nationally.
- 14.3% of PRS reported the use of alcohol or an illicit drug at last sexual intercourse, compared to 22% nationally.
- 86.8% of PRS reported they had received HIV/AIDS information at school, compared to 85% nationally.

Adolescent Pregnancy

Adolescent pregnancy is a concern in PR as well as in many other parts of the world. Mass media frequently bring this issue as its headline news. It is important to mention that we do not collect information about the number of pregnancies in

adolescents. Therefore, when we talk about this issue we refer to the proportion of live births among women between 10-19 years old.

Analyses of the rates of births among adolescents show a steady increase from 1990 to 1997. After that a downward trend is observed, reaching the lowest level in 2003. (Figure II-17)

Currently, every day in PR some 25 live births occur in adolescent mothers. Nearly 30% are repeated pregnancies. Eight out of 10 adolescent mothers are unwed. According to ESMIPR 2004, only 28% of adolescent mothers plan their pregnancy.

Pregnant teens are more likely to begin prenatal care after the first trimester of pregnancy and to have poor birth outcomes in comparison with women between 20-34 years of age.

Sexually Transmitted Infections (STIs)

The proportion of PRS who reports ever have sexual intercourse has declined from 32.2% in 1991 to 28.3% in 2001 (YRBS). However, the percentage that used condoms to prevent a pregnancy or an STI has dropped from 40.3% in 1995 to 33% in 2001. This risk behavior may explain our rates of unintended pregnancies and STIs among adolescents in Puerto Rico.

Since the beginning of the HIV/AIDS epidemic in the early 1980s, a total of 180 cases of HIV/AIDS among adolescent aged 10-19 have been reported in the Island (Figure II-18). Of these, 59 have died for a case fatality rate of 33%.

Among male adolescents the most common routes of infection are intravenous drug use (21.6%) followed by same-sex intercourse (14.7%). Girls are most commonly infected through sexual contact followed by intravenous drug use.

It is important to note that the number of pediatric AIDS cases (0-13 years of age) has been markedly reduced during the past 12 years. In 1992, a total of 48 cases were reported and after 1999 the number of cases fluctuates between 0 to two cases. This outcome could be attributed to the public policy aimed at providing counseling for the universal screening of pregnant women and the provision of the appropriate treatment of those found HIV positive.

Chlamydia is the most common STI among adolescents in Puerto Rico. Its prevalence varies by age group and sex. Females aged 10-14 and 15-19 are 10.8 and 7.3 times respectively more likely to be infected than males. Among females 10-14 years old, the average prevalence is 24.8/100,000, while in males it is 2.3/100,000. The rate increases exponentially in the 15 to 19 years age group. In this age group, females have an average prevalence rate of chlamydia of 469.6/100,000, while the males have an average rate of 64/100,000.

Figure II-19 presents trends in chlamydia infections among adolescents by age group and sex.

Syphilis and Gonorrhea

The prevalence of Syphilis infections among the adolescent group has been decreasing since 1990. The prevalence among male adolescents 10-14 years, declined from 6/100,000 in 1990 to 0 in 2003. In the group of female adolescents 10-14 years, the prevalence rate did not change significantly. For adolescents between 15-19 years of age, in 2003 the prevalence was 2 times higher among female adolescents (43/100,000) than in males in the same age group (23/100,000). (Figure II-20)

In relation to Gonorrhea infections, the prevalence rate in male adolescents 10-14 years was 0 in 2003 and 0.67/100,000 in females of the same age group. In adolescents 15-19 years, the rate was more than 2 times higher in the female group (13.5/100,000) than in the male group (6.5/100,000). It is important to note that the prevalence rates in 2002 and 2003 had a reduction of almost 50 percent in each age groups. (Figure II-21)

Mortality

During 1990-2002 the mortality rate among adolescents 10 to 14 years of age fluctuated between 16.7 (2000) and 29.3 per 100,000 (1995), with an average of 23.1. The average number of deaths per year is 76 for this group. Death probability for males is 1.9 higher than for females. (Figure II-22)

For adolescents 15 to 19 years of age, mortality rate fluctuated between 75.5 (1990) and 107.5 (1993) with a yearly average of 94.3 deaths per 100,000. The average number of deaths per year for adolescents 15 to 19 years of age is 313. Death probabilities are 5.4 times higher for males than for females. This group of older adolescents (15-19) shows a death probability that is 4.1 times higher than the 10 to 14 years group (Vital Statistics 1990-2002). (Figure II-23)

When comparing the principal causes of death for adolescents five decades ago (1950) to the last decades of the 20th Century, we find a considerable difference. During the 1940's adolescents died mainly of infections and biological causes. The main causes of death in 1950's, based on frequency were: (1) infections; (2) external causes; (3) systemic diseases; (4) cancer and (5) maternal deaths. Among the infections we should mention tuberculosis (white plague), diarrhea, pneumonia, and childhood diseases that are prevented by immunization such as tetanus, measles and whooping cough. Anemia, parasitic infections such as uncinaria and malaria; and puerperium (maternal deaths during childbirth) claimed the life of many adolescents. Deaths due to external causes (suicides, homicides) represented only 20% of all deaths among adolescents during the end of the first half of the 20th Century (Vital Statistics 1950).

In 1990-2001 a total of 907 deaths were reported for the age group of 10-14 and 3,757 deaths for adolescents 15-19 years of age. For adolescents 10-14 years of age death was due to an unintentional injury in 34.7% of cases. The second position for cause of death was malignant tumors and homicide with 8.4% each, congenital anomalies occupied a third place with 3.0%, and a fourth place for heart diseases with 1.3% of cases. Three deaths by suicide were reported. In general, 43.4% of deaths for this group can be attributed to external causes such as unintentional injuries (34.7%), homicides (8.4%) and suicides (0.3%).

When considering cause of death for adolescents in the 15-19 age group, deaths due to external causes were 72.8% of the total: homicides (43.7%), unintentional injuries (28.1%) and suicide (1.0%). Another 3.4% of deaths were consequence of malignant tumors and 2.6% due to heart disease.

In 1950 morbidity and mortality causes among adolescents were very different to those described at the end of the century and beginning of the new millennium. Back then, most health problems were cared for with antibiotics, purgatives, immunizations, adequate food and good environmental health. At the end of the century, on the contrary, adolescents' health problems are intimately related to social problems that lead to risky behaviors and violence. A biomedical service model is not enough to promote the optimum state of health and well being our adolescents deserve and have the right to.

At the end of the 20th Century and beginning of the 21st, adolescents did not die due to biological causes. Three out of four died of violent causes such as motor vehicle crashes, homicides and suicides.

Magnitude of the Unintentional Injuries Epidemics

Unintentional injuries are not accidents, because they can be predicted and prevented. An unintentional injury is defined as harm to the body due to acute exposure to thermal, mechanical, electrical or chemical energy; or by absence of the heat or oxygen our body requires.

Unintentional injuries are caused by external circumstances not intended to harm anyone. Roads present the highest risk for adolescents, with alcohol and illicit drugs use and careless and negligent driving as the most important contributing factors.

The most common causes for unintentional injuries in Puerto Rico among children and adolescents (1-19 years) are associated with motor vehicles, poison, drowning, choking, falls and burns.

During 1990-2001 unintentional injuries in Puerto Rico claimed the lives of 1,369 youngsters: 315 in the group of 10-14 years and 1,054 in the 15-19 age group. Our greatest concern is not the number of fatalities, but the thousands of survivors afflicted with handicapping conditions such as trauma to the brain or spinal cord

and others suffering lifelong emotional and physical scars. The general public should be convinced that unintentional injuries are not accidents and can be prevented.

For the decade under consideration, unintentional injuries were a significant public health concern in Puerto Rico. They were the first cause of death among adolescents 10-14 years of age and the second cause for death for the 15-19 years group.

Figures II-22 and 23 show the disparities between males and females in death related to unintentional injuries. Males show a higher risk of death due to unintentional injuries. In Puerto Rico, as in other countries, reliable unintentional injuries death data is available, but we do not know the number of survivors who totally recover or who suffer lifelong injuries. A formula is available to estimate the magnitude of the unintentional injuries epidemic: for each unintentional injury death there are 40 hospitalizations, 1,120 emergency room visits, and 1,600 outpatient visits (Physicians Office).

During the 1990-2001 period, Puerto Rico registered 1,369 deaths among the 10-19 years of age group. If we apply the formula mentioned above to this 11-year period, the estimate of hospitalizations would be 54,760, 1,533,280 emergency room visits and 2,190,400 physician office visits due to unintentional injuries among adolescents in Puerto Rico. These numbers have an impact on the Puerto Rican society, representing a great loss of school days, years of life, and fiscal resources.

C. Children with Special Health Care Needs (CSHCN)

The primary goal of this needs assessment is to strengthen the efforts and collaboration between the MCHB, the Puerto Rico Department of Health (PRDOH), public agencies, private organizations and other key partners in the communities through the identification of the specific needs of CSHCN and their families. It is expected that the collected information will convey the strengths and weaknesses of the current health care infrastructure to address the needs of CSHCN and families and will assist us in the identification of priorities and the implementation of activities to improve the system of care.

The specific focus of this need assessment efforts are the children 0-21 years of age living in PR whose chronic health, development, emotional or behavioral conditions require an increased number and intensity of services use when compared to the rest of the children without these conditions. Our definition includes children with diverse diagnoses, including children with autism, mental retardation, asthma, genetic and metabolic disorders and physical/mental impairments. The Division of Habilitation Services has already identified ASSMCA, the mental health service agency under the PR Department of Health, as an important partner in the following years. However we shouldn't

underestimate that mental health disorders constitute a real burden for adults as well as for children in our island.

Research Questions

1. What are the needs of children with special health care needs (CSHCN) 0-21 years old in Puerto Rico?
 - What are the most frequent health conditions of the CSHCN in PR?
 - What are the barriers and gaps of services for the families with CSHCN?
2. What are the resources of the Puerto Rico's system of care?
 - What are the available services in PR?
 - Services at the Pediatric Centers
 - Other services
3. What is missing?
4. What is going to be done with the identified needs?

Methodology for the Needs Assessment of CSHCN

The foundation of this need assessment is to obtain information that describes the characteristics, barriers and gaps related to services among families of children with special health care needs (CSHCN), as well as the assessment of available resources in the system of care. The compilation of data about CSHCN and available services will contribute to the improvement of the system of care for CSHCN and their families. For CSHCN, the system components include the children, families, private providers, educational and health institutions, communities and government agencies. The following paragraphs will discuss the various data sources and the collected information, followed by the analysis to determine which pieces of data will contribute to improve the systems of care. Data will then be organized and analyzed to build on suggestions for improvement, including the dissemination of results.

This needs assessment will be guided by the Healthy People 2010 objectives: 1) Focus Area 16: Maternal, Infant and Child Health, Objective 16.23: Building a system of care for CSHCN and 2) Focus Area 24: Respiratory Diseases, Objectives 24.1; 24.2; 24.3; 24.7 and 24.8, the five National Performance Measures (NPM) for CSHCN and the State Performance Measures (SPM). The analysis for this needs assessment will be performed using existing data, as well as data specifically collected for this study. The results represent qualitative and quantitative data from year 2004.

Methodology limitations

The main limitation of the needs assessment's methodology is the scarcity of reliable data sources to estimate the prevalence of CSHCN in Puerto Rico. As an initial step to determine the prevalence of special conditions islandwide, the CSHCN Title V Program has requested assistance from Michael Kogan, PhD (Director of Data and Program Development HRSA- MCHB) and presented our intent to administer the Spanish version of the State and Local Area Integrated

Telephone Survey (SLAITS) for CSHCN to our population. This version needs to be revised, adapted and validated to assure cultural competency.

Data Sources

a. Quantitative data

1. Health Services Administration (ASES)

ASES provided claims data of children eligible for the Governmental Health Insurance (Reform) with physical, developmental and emotional/mental conditions registered for year 2004. ASES reports the number of conditions among children who received at least one service during the year. With the data provided by ASES we can not estimate the prevalence of children with special health care needs since cases may be duplicated. These data do not include children who did not received services during the last year.

2. Health Insurance Commissioner Office (HICO)

The HICO compiles claims data from twenty-two (22) private health insurance companies. The main limitation of this data source is that only thirteen (13) of the private health insurance companies reported data to the HICO for the year 2004 (59%). The data used for the analysis was preliminary. As with ASES data, information from HICO could not be used to estimate the CSHCN's prevalence in PR, since it does not include children who did not received services the last year.

3. PININES Medicaid self reported data

PININES is a family survey administered annually at the time the family of a child with a special condition is certified for the Government Health Card (GHC). This data source includes children that were eligible for the GHC (n= 16,280), but excludes those who were not eligible.

4. The DSM-IV rates of child and adolescent disorders in Puerto Rico (2004)

G. Canino and collaborators sampled a total of 1,886 child-caretaker dyads in the Island using a multistage probabilistic sample design. Children from 4 to 17 years and their primary caretakers were face to face interviewed to assess the mental health, impairments and service use of children and adolescents in Puerto Rico. This study does not include information about children 0- 3 or youth 18- 21 years old.

5. Medical Home Survey (MHS)

A family survey was performed with a non-probabilistic stratified sample on the Pediatric Centers' population. There are seven (7) Pediatric Centers located islandwide, one at each health region, that serves the Title V population. The main purpose of the MHS was to determine the proportion

of families of children eighteen (18) years and younger who indicated that their children receive services under a medical home. A Spanish version of the American Academy of Pediatrics (AAP) questionnaire was used to assess the medical home concept. This questionnaire was translated, adapted and validated with the target population. The survey was developed using a self-administered questionnaire to which other questions were added to assess the six (6) CSHCN National Performance Measures (NPM). Questions to assess the national performance measures were obtained from the SLAITS Spanish version. The main limitation of this survey is that its results can not be generalized to the CSHCN population in Puerto Rico.

6. Department of Education Annual Child Count

Data from the child count as of December 2004 was obtained to assess the most prevalent diagnoses among children 3-21 years served by the Department of Education (DOE), Special Education Program. The main data source limitation is that the number for the most common condition is over-represented, probably because a large number of children are still being evaluated.

7. Puerto Rico Continuous Health Survey

A study made with an island-wide probabilistic sample, provided data on developmental disabilities for the pediatric population in Puerto Rico. This survey gathers data about health conditions as other information via face to face interview islandwide. The biggest strength of this survey is that the sample selection methodology leads to make inferences on the Puerto Rican population twenty two (22) years and younger. Unfortunately, a self-reported survey confronts all the risks related to memory and under report of conditions, the main limitation of this data source.

8. Puerto Rico Birth Defects Surveillance System

This surveillance system compiles epidemiologic data of thirteen (13) congenital conditions diagnosed at birth. Although most of the reported conditions are screened before hospital discharge, in some cases diagnoses may be confirmed later during childhood, up to six (6) years of age. One of the strengths of this data source is that as of September, 2004 reporting these conditions is mandatory by Law #351. However, due to its recent implementation, it may be unknown by many physicians. The main limitation with the birth defects data base is that some conditions are not included until the diagnosis is confirmed and the rates per condition could vary during the year.

b. Qualitative data

1. Family focus groups

Seventy (70) families had the opportunity to share their experiences in seven (7) focus group sessions celebrated islandwide. Approximately ten (10) family members in each one of the seven (7) Pediatric Centers answered the following questions:

- What was the referral source to the Pediatric Center?
- Did you receive any orientation or training to assist parents in advocating for their children?
- Did your child's doctor listen to your concerns?
- Are the services that you receive comprehensive?
- Do you consider that there is communication between your child's primary doctor and specialists?
- Do you consider that the services that you receive are continuous?
- Do you think that your child's primary physician and other health professionals are sensitive to your child's needs?
- Do you consider that doctors are up to date regarding the availability of community services and support groups?

2. Survey among key informants (physicians, providers, agencies and Pediatric Centers' Administrators and Medical Directors): The key informants' survey was performed during the months of April and May 2005 and examined the perception of fifty-nine (59) professionals closely related with the needs of CSHCN population and families. A four questions questionnaire was administered to gather information about:

- services of greatest demand in Puerto Rico,
- difficulties interfering with the services delivery process,
- their perception about the services provided to CSHCN and
- Recommendations to improve the provision of services.

3. Parents' Training and Advocacy Center (APNI)

APNI, a non profit organization provided the list of available community resources for CSHCN 0-21 years islandwide.

Data Analysis

Three different data sources were used to assess the three most common health conditions among the CSHCN population in Puerto Rico: ASES, HICO and PININES (Table II-3).

According to data provided, bronchial asthma, congenital anomalies and mental disorders resulted as the first four most frequent conditions in every data source. Diabetes Mellitus was the third most common diagnosis in CSHCN according to ASES claims, while it was number six in HICO and eight in PININES.

G. Canino et al, (2004) identified that 16.4% of the children 4-17 years in Puerto Rico have at least one DSM-IV diagnosis. The most prevalent mental health condition was Attention Deficit/ Hyperactivity Disorder (8.0%), followed by Oppositional Defiant Disorder (5.5%) (Table II-4).

Puerto Rico Continuous Health Survey

The Puerto Rico Continuous Health Survey recently submitted the first report on the prevalence of some conditions related to developmental disabilities in the pediatric and adult Puerto Rican population (Table II-5).

According the Puerto Rico Basic Sample Survey, Attention Deficit Disorder (ADD) was the most common disability among males and females younger than six (6) years. Disability for ADD maintains the highest rate among males between six (6) and sixteen (16) years, but among females with the same ages, it is surpassed by Mental Retardation. Finally, Mental Retardation is the most prevalent disability in males, as well as in females in the seventeen (17) through twenty-two (22) years old age group.

Medical Home Survey

A total of 377 families of children served at the Pediatric Centers participated in the Medical Home Survey during February, 2005. Two questions were asked to assess if families felt like partners in the decision making process and were satisfied with the services that they receive (NPM #2). Forty-five (44.8%) of families answered that their doctors always or usually made them feel like a partner in the decision making process and that they were satisfied with the services that they received (n= 362). Considering the answers by each question separately, 85% of families said that their doctors always or usually made them feel like partners and only 46% said that they were very satisfied with the services they received. However, no specifications were included in the instructions to distinguish between services provided by the primary physicians and specialist's care.

To answer the NPM #3 (CSHCN receiving coordinated ongoing comprehensive care within a medical home) a 49 items scale was self-administered to families (n=328). According to the cutting points, two out of every three families described the services they received as moderately or totally medical home consistent. Accessibility, as well as ongoing services were the components with the lowest ratings. According to families, 60% of the services they receive are considered as accessible and ongoing.

Seventeen percent (17%) (n=311) of families answered that their children have all of the following: 1) health insurance coverage at the time of the interview, 2) no gaps in coverage during the year prior the interview, 3) their coverage always or usually met the child's needs, 4) the cost of services not covered by the insurance were reasonable, and 5) the coverage always or usually permitted the child to access the needed providers (NPM #4). Considering the response to each

question we found that ninety-seven percent (97%) of families indicated that their children have some health insurance; seventy-two percent; (72%) of those were enrolled in the government plan, twenty-six percent (26%) had private insurance and two percent (2%) had both medical plans (public and private). Thirty percent (30%) said that there was a gap in coverage during the last year, seventy-two percent (72%) answered that the medical plan always or usually covered the services to satisfy children's needs, thirty-three percent (33%) said that the costs of services not covered were always or usually reasonable and eighty-two percent (82%) answered that their health coverage always or usually permitted the child to access the needed providers. Sixty-eight percent (68%) of families indicated that community services were always or usually organized for easy use (NPM #5).

Ninety-nine (n=99) of the respondent families had at least one child 13 years of age or older. Of those 99, nine percent (9%) answered all the questions related to the services that youth with special health care needs receive (NPM #6). Less than a half (43.3%) of families answered that physicians have talked to them about the changing needs as child becomes adult. About one out of every three families (34.3%) said that they have prepared a plan with their doctors for addressing changing needs. One out of every three families (34.3%) answered that their doctors have discussed with them the need to change to an adult provider and 14.1% said that their children have received some vocational or occupational orientation to help them get a job in their adulthood.

A total of 87,485 children with disabilities between 3 and 21 years old received services under the Department of Education (DOE). The Table II-6 presents the eight (8) most common conditions in the DOE register. The most common conditions among children 3 to 21 years were Specific Learning Disabilities (53%), followed by Speech and Language Disorders (22%) and Mental Retardation (14%). Although Specific Learning Disabilities was the most common disability among children 6 to 21 years, it was the second for children 3 to 5 years old. The first impairment for children 3 to 5 years old was Speech and Language Disorders, while for children 6 to 21 it was the second most common disability.

Puerto Rico Birth Defects Surveillance System

The Birth Defects Surveillance System at the PRDOH showed that the three most prevalent conditions diagnosed at birth or until age six in Puerto Rico for year 2004 were: Congenital Heart Defects with 33 per each 10,000 live births, followed by Cleft Lip and/or Palate with 10 and Down Syndrome with 6 per 10,000 live births.

Family Focus Groups

In order to more effectively contribute to a system of care for CSHCN it is important to ask families what their needs are. Children make transitions within, inside and out of the system, but families are the constants in their children's life.

We will start mentioning those services which families said they need and can not find or access easily. Some of the barriers include by families are:

1. Slow and difficult referral process from primary providers to specialist or sub-specialists.
2. Lack of care coordination and family-centered services.
3. Economic strains on families due to non-covered costs by health insurance.
4. Assistive technology services and equipment not under GHC benefit package.
5. Transitions from Part C Early Intervention Program to Preschool do not ensure continuity of services.
6. Sub specialist Services not available in the community where family lives.
7. Lack of information on available services and how to gain access to services.
8. Services are fragmented; lack of communication among specialists and primary physicians results in non-compliance with specialists' recommendations and follow up.
9. Physicians show limited knowledge of typical child development.

Survey among key informants

Results of a survey distributed among physicians, providers, Pediatric Center's staff and agencies that provide services to children from 0 to 21 years old with special health care needs are summarized as follows:

High demand services for this population in Puerto Rico:

- High demand services include: behavioral and conduct management, sub-specialist services, and therapy services especially speech and language therapy, orthopedics, neurology, dental and recreational, assistive technology and family support services.
- The high demand services are speech therapy, orthopedics and neurology.
- Demand for medical supplies and equipment including wheels chairs, walkers, and oxygen tanks among others.

Mayor difficulties for families of CSHCN

- Among the mayor difficulties that affect families of children with special health care needs is the availability of referrals from their primary health care physicians to a sub specialist and to have the child under the special needs coverage (at the health insurance risk).
- Another area is lack of family centered services, including service coordination.
- Economic issues for the families include the high cost of health care and inaccessibility to assistive technologies equipments due to elevated costs. Family support is also needed, including child care services for other children since parents spend so much time in the hospitals with the special health care needs children.
- Difficulty in gaining access to preschool services upon transition from early intervention services to preschool.
- Accessing and locating community resources.

- For the children under GHC it's the access to specialized services, therapies, equipment and others. In the private and public sectors the need for coordination, information and access to available services.
- With the change in the early intervention system of service delivery from a clinical to a family centered model, services have turned more of an education and orientation role for parents in the management of patients and no treatment, which makes the habilitation process more difficult. (Note: This is explained on the basis that services individualized, outcome oriented and according to families' needs. Activities are integrated to daily routines and in the natural environments, as required by IDEA Part C Law).
- All services are not found in one center and services are fragmented. There is a huge time gap between being evaluated and being seen for treatment. The components of the system are unaware of other's recommendations within the system.
- Lack of information about the services the patients have rights to.
- Difficulty for receiving services in a timely fashion. Difficulty in the coordination of appointments. Poor communication between specialists prolongs waiting time for services which affects the child's health. Difficulty for parents to understand medical terminology.
- Limited knowledge of the normal development of infants and little commitment in the specialists' recommendations.

How are the services that are offered to this population?

- They have expressed that they are of good quality and offered by professionals committed to excellence. Others expressed they are fragmented and insufficient.
- They are distant from the medical home concept. The majority of health plans don't cover the services and not every family qualifies for the health reform.
- Services are few and far from living areas. Lack of transportation options.
- Services help in less complicated cases but they are still not very accessible to most of the children and they don't cover all their needs.
- Early intervention services at the Pediatric Centers for children 0 to 2 years old are provided through "Avanzando Juntos" and are not under the GHC package.
- Excellent quality of services at the Pediatric Centers, but the process of buying equipment is too long and time consuming.
- In some cases services are late and poorly coordinated. Not all specialists' services are available at every Pediatric Center. In other cases the service is incomplete because the parents don't know where and how to receive services.

Recommendations to improve services:

- Increase the number of specialists and sub specialists Islandwide.
- Better coordination between health care plans, primary physicians and Pediatric Centers.
- Facilitate referrals from primary physicians to sub specialists

- Make the medical home a reality and not just a concept.
- Involve private agencies to expand economic resources including equipment and places of service.
- Take advantage of the location of the Pediatric Centers to have experts in the care of these children who at the same time serve as resources for pediatricians in the community and improve the coordination of these cases.
- Provide the option for the parents to choose the service/treatment they prefer.
- Develop an education campaign for the pediatricians of the Health Reform about the available services and encourage cooperation to expedite specialist referrals.
- Assign pediatricians that are experts in child development and experienced in special health conditions.
- A return to direct patient services as it was in the past where the results were noticeable (Medicaid vs. Manage Care).
- More personnel is needed, publication of information on print, radio and television.
- Faster less bureaucratic process.
- A better selection of pediatricians to work with the health reform. Provide special education courses to pediatricians and other specialists. Create legislation in favor of people with handicaps for a better quality of services.
- Provide orientation to physicians in private practice on availability of services for CSHCN as a means of increasing the number of referrals to Pediatric Centers.
- Monitor follow-up of skills at home with parents or caretakers.
- Expand and diversify services throughout the island. Create programs for respite care and specialized day care centers for the special needs population.
- More economic resources for the community based agencies that serve this population.

Services/ Resources Availability

Pediatric Centers and Government Health Card

Pediatric Centers of Habilitation Services of the PRDOH, located one at each of the seven (7) health regions, continue to provide specialized services for CSHCN and families and serve as a safety net for this population islandwide.

According Child Count for FY 2003-2004 a total of 8,214 CSHCN were served at the Pediatric Centers, one third at the Metropolitan Pediatric Center, 20% at the Mayagüez Pediatric Center in the west coast, and 17% at Ponce in the south coast. This number represents an increase of 9% compared to previous year. With the implementation of the HCR in 1994 Pediatric Centers have experienced a gradual decrease in the total number of children served (17.8%).

Medical services showed a decrease of 6% due to resignation of some of the sub-specialist, mainly orthopedics, optometric and ophthalmologist services now provided through managed care clinics. In addition, surgical sub specialists do not want to contract with HMO the surgical procedures, assistants, implants

among others. Previous to HCR clinical services and surgical procedures were reimbursed by the DOH directly to providers, placing the billing responsibilities away from the physicians, which was previously an incentive to contract with the Pediatric Centers. On the other side, vacant positions are very difficult to be occupied due to limitations for recruitments imposed by government as a result of budget constraints in Puerto Rico. Among specialized services providers, those serving the largest number of children include: ophthalmologists followed by orthopedics and genetics.

The case coordination component is essential to achieve Title V CSHCN goal to make services accessible to children and families. In fact case coordinators working in collaboration with service providers through the medical home contribute to families well being.

In Puerto Rico, case coordination is being provided at the Pediatric Centers only for very compromised children by a small number of trained nurses/social workers. Case coordination is not under the benefit package of health insurances.

In spite of a comprehensive array of services under the GHC, families of CSHCN have difficulties to access the services their children need. The same holds true for families with private commercial plans except for access to specialists. The service coordination component is not included under the GHC benefit package. However, each insurance plan under GHC has identified a Case Manager for CSHCN at the Central level of each company in order to assist families. This person provides support to families on specific issues such as refusal of primary physicians to provide referrals for sub specialized care, access to medications out of the list provided by each company, among others. However, the demands of the special needs children are by far beyond this personnel scope, and is mainly geared to high utilization issues. Furthermore, it does not empower parents in advocating for their children's rights through orientation on the availability of services and how to access them. This is an area for improvement which needs to be addressed.

The Government Health Card beneficiaries, including CSHCN, have a comprehensive benefit package including primary, secondary and tertiary services. Among these are dental services, physical, occupational and speech therapies (physical therapies limited to 15 per year and recommended by an orthopedist or a physical medicine and rehabilitation physician). Nevertheless, services to the special needs population are scarce since therapists experienced in serving CSHCN do not contract with Reform, or are no available in the communities. Another limitation is that services are provided independently, not by multidisciplinary groups and geared to functional outcomes as recommended for this population.

According to data provided by the Office of Information Systems Development of the PRDOH and the Medical Examiner's Board (year 2001 to 2004), the

composition of pediatric medical specialists and subspecialties islandwide as shown in Table II-7.

Forty-four (44) to 78% of all medical specialists and sub specialists are located in the Metropolitan Area followed by Ponce and Caguas regions. Pediatric Centers have procedures in place for the referral of children to the nearest Center where the specialist is available. Services are available for children with private or government plans; deductible payments are collected accordingly. GHC and private insurance companies are billed for services provided and reimbursed money are reinvested in the Pediatric Centers to cover some costs not under health insurance and for some Pediatric Center's infrastructure expenses.

Mental services under GHC are provided by external subcontractor groups. According to information published in one of our largest circulation newspaper, Mr. José Galarza Arbona, Chief of the Mental Health Services Agency (ASSMCA), presented to the Governor Evaluative Commission of Health Systems, that three of every four mentally ill children and youth in Puerto Rico (75%), are not receiving the necessary services for their emotional conditions and most of those who have access to mental health care receive deficient services (El Nuevo Día Newspaper, article: *Deficientes servicios de salud mental*, May 16, 2005).

Infant Mental Health is one of the components of the State Early Childhood Comprehensive System Grant (SECCS). One of the goals established in the SECCS Strategic Plan is to support families and communities in their efforts to build early childhood service systems that address the critical components of access to comprehensive pediatric care services. This goal will help to achieve that children enter school with well developed cognitive and positive socio-emotional development to achieve academic success.

To accomplish this goal several objectives have been developed: a) establish a State Interagency Steering Committee with key leaders, b) develop and implement an in-service curricula in child care and pre-school centers integrating mental health strategies to assure nurturing environments for children, and c) establish partnerships between mental health professionals, teachers and care providers to plan intervention strategies for high-risk families in their communities.

For the first objective, the Department of Health established a State Interagency Steering Committee that includes key leaders from the community, including mental health leaders. This Committee is actively participating in monthly meetings. Members include the Department of Health (Maternal and Child Health Division and Habilitation Services Division), Department of Family, Department of Sports and Recreation, Department of Housing, Labor Department, Child Evangelism Fellowship, United Funds, American Academy of Pediatrics, Association of Parents of Children with Disabilities (APNI), School of Public

Health, Mental Health/ASSMCA, Legal services through “Vanguardia de la Niñez” and family representatives.

To accomplish the second objective, several activities are proposed: integrate behavioral health services into community child care setting; develop island-wide training about the indicators of positive parent and child relations and prevention of mental health issues addressed to people who work with families and very young children, and development of a mental health resource center to provide/develop strategies to assure an adequate socio emotional development of children.

To accomplish the third objective it is necessary to target cross programs and policies that connect literacy development with socio emotional development, identify the competencies for staff who will screen, evaluate, treat and supervise the interventions for identified children and families and develop or adapt curriculums for intervention models.

There are four tertiary hospital facilities in Puerto Rico. Very compromised children with multiple conditions/diagnosis are referred to a supratertiary facility, the Pediatric University Children’s Hospital at the Puerto Rico Medical Center in San Juan for hospitalizations. At the Metropolitan Pediatric Center in the same location, a Myelomeningocele and Cleft Lip/Palate Multi-specialty Clinics is held weekly serving children islandwide. Outpatient clinics for subspecialties include: ophthalmology, orthopedics, neurology, neurosurgery, nephrology, urology, hematology, infectious diseases, cancer, endocrinology, cardiology and pneumology.

The Pediatric Pulmonary Program, located at the Cardiovascular Hospital of Puerto Rico and the Caribbean, provides specialized health services to children with Asthma and other chronic respiratory conditions, including children dependent on assistive technology equipment. Services are provided by a multidisciplinary group including pneumologists, social worker, nutritionist, nurse, laboratory technician and a respiratory therapist.

II. Other resources

Table II–8 depicts other programs and resources that provide services for CSHCN.

III. Parent Groups/ Associations

- 1) Association of Parents of Children with Spina Bifida and Hydrocephaly
- 2) Association of Parents of Children with Disabilities
- 3) Association of Parents of Children
- 4) Down Syndrome Foundation
- 5) Puerto Rico Lung Association
- 6) Puerto Rico Epilepsy Association
- 7) Albinism Association

- 8) Association of Parents of Deaf-Blind Children
- 9) Association of Parents of Children with Genetic and Metabolic Disorders

IV. Coalitions

Asthma Coalition

This coalition was incorporated as an organization comprised by public organizations, private entities, academia and parents. Its' goal is to reduce morbidity rates due to Asthma.

Allies Against Asthma

Funded by Robert Wood Johnson to develop strategies to improve morbidity due to Asthma among children resident of two communities islandwide.

V. Applicable Laws

During the past decade, Puerto Rico has experienced an increase in the number of legislative pieces signed into law with the purpose of advancing equal rights, access and opportunities for persons with disabilities. For the purpose of this assessment we will mention those most recently approved with impact on the CSHCN's Title V population.

- 1) Law number 351 of September 16, 2004: Law for the Surveillance System of Congenital Defects.
- 2) Law number 103 of April 24, 2004: Bill of Rights of Children and Adults with Autism Spectrum Disorders.
- 3) Law number 318 of December 28, 2003 for the development of Public Policy related to the population with Autism Spectrum Disorders.
- 4) Law number 482 of September 23, 2004 to establish a uniform coverage in all public and private medical and hospital insurance coverage of those families in which one or more of its members require a physician's prescribed mechanical ventilator to sustain life.
- 5) Law number 311 of December 19, 2004 to require all birthing hospital to performed a hearing screening to all newborns before discharge. The aim of this law is that every baby with hearing loss receive the needed hearing aids at age of six (6) months.
- 6) Law # 194 of August 25, 2000 that creates the Patient's Bill of Rights and Responsibilities.

VI. List of Identified Needs

- *1. Decrease Asthma morbidity and mortality.
- *2. Improve coordination between health care plans, primary physicians and the Pediatric Centers.
- *3. Youth with special health care needs do not receive the services necessary to make successful transitions to adult life.
4. High prevalence of mental disorders.
5. Increase availability of specialists and sub-specialists islandwide.

6. Economic strains due to non coverage of some health services.
**Out of this list three priorities were identified.*

VII. Plan to address the identified priorities

1) Decrease Asthma morbidity and mortality

Asthma morbidity and mortality are addressed through Title V State Performance Measure #7 (rates of deaths to children aged 1-14 caused by asthma) and Health System Capacity Indicator # 1 (rate of children hospitalized for Asthma (ICD-9 Codes: 493.0- 493.0) per 10,000 children less than five years of age), in addition to a CDC Grant at present in its second year geared to the elaboration on an Asthma Plan and the implementation of an Asthma Surveillance System.

2) Improve coordination between health care plans, primary physicians and the Pediatric Centers.

The Champions for Progress initiatives will be continued through the creation of a Committee composed of representatives from public agencies, private non profit organizations, the Council on Developmental Disabilities and families to develop a strategic plan to comply with the PM #3 on Medical Home.

3) Youth with special health care needs do not receive the services necessary to make successful transitions to adult life.

The Committee mentioned above will also include representatives from the Department of the Family, Administration Juvenile Correction and the Vocational Rehabilitation Program under the Labor Department, to elaborate the strategies and activities specific for PM #6 on transitions of youth to adult life.

One of the established priorities based on the needs assessment is that CSHCN population receive the necessary services to make the transition to all aspects of adult life. To address this priority it is necessary to develop a task force with representatives of agencies, organizations and families to develop a working plan to accomplish the activities for this priority. Technical assistance is being requested to assist the Title V CSHCN Program in the planning and development phases of a comprehensive strategic transition plan partnering with all stakeholders to comply with the NPM#6.

MCH Program Capacity by Pyramid Level

Figure II-1a summarizes current services and programs available to address the needs of the different MCH population groups. These are depicted according to the MCH pyramid levels: Direct, Enabling, Population-Based and Infrastructure Building services. Please refer to Section III for a detailed description of each program and services listed in Figure II-1a.

Figure II-1b depicts the Puerto Rico Title V Block Grant Performance Measurement System. It integrates the 10 selected priorities based on the needs assessment; the services and programs available to address these priorities; the national and state performance measures to monitor progress towards expected outcomes set for 2010.

Analyses of Health Care Delivery Systems (HCDS)

The needs assessment of the different MCH population segments describes their size as well as their critical health needs. It clearly depicts the wide opportunity gap between the current health status in comparison to the targets established in Healthy People 2010 for the MCH population (Focus areas 9, 16, and others). This is the challenge for the health care delivery system (HCDS) for WRA and their children.

The HCDS for WRA and children must pursue their optimum health status by implementing science-based interventions to prevent disease and promote health. Another goal of the HCDS should be the elimination of disparities among population subgroups to ensure equity in access to quality health care. As with any other system, the HCDS is comprised by a set of differentiated structures and processes that must be well communicated and coordinated in order to achieve its goals. This seems to be the Achilles' heel of the Puerto Rico HCDS.

The Title V MCH Program has statutory responsibilities for systems assessment and reporting as well as to provide leadership at the local, state and national levels in developing and auditing systems response to the needs of WRA and the needs of children and youth (OBRA '89). In response to this mandate, we designed a tool to direct us in mapping the available resources, selecting the municipality as the unit of analysis.

The capacity of the PR HCDS for addressing the MCH/CSHCN needs was guided by the Starfield Model. In 1992, Starfield developed a model aimed at understanding the health care system functions and for devising approaches for measuring its performance. The Starfield model is comprised of three main components which include structure (inputs), process (provision and receipt of care), and outcomes. It is important to note that the performance of the HCDS is influenced by the social, economic, political and physical contexts. For the purpose of this analysis we will focus on those components of the PR HCDS that may promote the health of the MCH/CSHCN population groups.

Structure

The target population of the PR HCDS is about 4 million persons. Forty-two percent (42%) of the population qualifies for the GIP. As of December 2004, 1,521,981 persons held the GIP. In FY 2003-2004 PR spent over \$1.3 billion in health insurance for the low-income population. Overall the MCH population represents 51.5% of the individuals holding the GIP. In 2003, the total number of live births was 50,803. For 64% (32,470) of them, the mothers' plan at the time of delivery was the GIP.

In PR preventive and primary care services are provided through a variety of practices: solo, IPA's and HMO groups unevenly distributed across the different geographical

areas. Services are provided through a managed care model based on a capitation. This model leads to constraints in services and delay in referrals to specialists. By September 2004, the network of providers of the three health insurance carriers contracted by ASES was comprised of 410 OB/GYN, 570 pediatricians, 239 family physicians, 1,062 GPs, 436 internists, and 1,289 dentists.

A total of 43 health care facilities fairly well distributed across the Island provide maternity services. Among these, only four are considered Level III accordingly to the standards established by the Committee on Fetus and Newborn, Levels of Neonatal Care, Pediatrics, November 2004. Thirteen (13) may be classified as Level II and the rest of as Level I. It is important to underscore that level III (NICUS) are very unevenly distributed; 3 of them are located in San Juan and one in Caguas. This situation leads to the delivery of VLBW babies at the inappropriate level of care (Figure II-24) (PM 17). Currently, PR has 40 neonatologists in active practice. This figure represents one neonatologist per 1,250 live births.

The PR Medical Center is the supratertiary facility of PR. It is the center for referrals of very critically ill patients from any part of the Island. It houses the Medical Sciences Campus of the University of PR, which includes the Schools of Medicine, Dentistry, Public Health, Nursing and Allied Health Professions and Pharmacy. The School of Public Health offers a Certified Nurse Midwifery Training Program. The University Hospital with residency in OB/GYN and high risk prenatal clinics, the University Pediatric Hospital with residency in pediatrics, fellowship in neonatology, high risk clinic for NICU survivors and the Hereditary Diseases Screening Program are also affiliated with the Medical Sciences Campus. The Municipal Hospital, a tertiary facility with OB and NICU services for the residents of San Juan, is also found within the PR Medical Center.

The Health Department and its public health programs complement direct services not covered by the GIP. In addition, it is the major provider of support services, population based services and infrastructure building services for the MCH population. These are the responsibility of the Title V MCH programs and other federally funded programs that serve the same target population:

The Division of MCH services provides family planning methods for the participants of the GIP; home visiting services for pregnant women, postpartum women, and children under two years of age with social and medical risk factors; and outreach services.

The Division of Habilitation Services provides specialized services through seven pediatric centers; one Pulmonary Pediatric Center; Early Intervention Services; and the Universal Newborn Hearing Screening Program.

Other programs include the Pediatric AIDS Program, seven Immunology Centers, the WIC Program, Medicaid/SCHIP, the Catastrophic Illness Program (financial support), the Pediatric Emergency System, Rape Victim Center, which has five Satellite Clinics, the Immunization Program and others.

Outside the Department of Health other programs also render services to the MCH population. These include the Title X Program, PROFAMILIA (Planned Parenthood affiliate), 19 federally funded 229/330 centers, the Head Start and Early Head Start Programs, and many other non governmental organizations.

The Health Department administers various population based information systems including but not limited to the Demographic Registry, Office of Information and Technology Advances, Congenital Anomalies Registry, STD/AIDS Surveillance System, BRFSS and others. All these information systems are very collaborative with the MCH program sharing collected data.

However, one of the weakness of the HCDS is its capacity to collect reliable data about the number of individuals served without duplication, and the type of services rendered. Puerto Rico does not participate of the National Discharge Survey.

Process - Process measures such as number of patients served, without duplication, and utilization are not meaningful because they do not indicate whether services meet the needs of the population. The processes in HCDS have two domains: 1) provision of care aimed at problem recognition (diagnosis and management) and 2) the receipt of care (service utilization, acceptance, and satisfaction).

In order for a HCDS to achieve its set goals, all its components (inputs) must have well defined functions. Standards of care, clear mechanisms of referral across the levels of care, and effective communication among all the components are critical. We understand that this is the weakest aspect of the PR Perinatal System of Care.

The PR DOH is responsible for the implementation of the core functions of public health as established by the Institute of Medicine: Needs Assessment of all segments of the population; developing, implementing and enforcing public policies (Standards of Care); and quality assurance. It has the instruments to carry out these functions. Among these are the Secretariat for Regulation and Certification of health care facilities, Administrative Orders, boards for certification of health professionals; commissions, Vital Statistics, surveillance systems and laws. In addition, hospitals have to be periodically subjected to the evaluation by the Joint Commission.

However, in spite of all the instruments available to monitor and evaluate the opportune access to quality preventive care, indices of system failure exist. For example, high rates of congenital syphilis, infant deaths due to erythroblastosis fetalis, a high number of VLBW born at facilities classified at Level I, high proportion of C/S without documented clinical indications, low Kotelchuck Index in mothers who initiated prenatal care in the first trimester, preventable maternal and infant deaths, etc. A significant proportion of the MCH population is unsatisfied with the quality of services provided and the continuity of care.

The HCDS is broken and need to be fixed. The communication among its components must be improved in order to be more effective and efficient in achieving better maternal and infant outcomes. The components of the system are there, but its outcomes are poor.

Outcomes – An excessive number of babies are dying before delivery, in the neonatal period and the post neonatal period. Similarly, an unacceptable number of mothers die every year, leaving their children orphans. Therefore, the need to fix the PR HCDS is urgent.

External Environment: An Evaluation Commission to assess the Health Care Reform was appointed by the Governor of PR. The first report and recommendations are expected to be available by August 2005. This report and its recommendations should be helpful to address the situation herein described. Last June the MCH/CSHCN directors participated in a public hearing held by a Sub-Committee of the Evaluation Commission. All the issues described in this section were brought to the members of the Sub-Committee in oral and written form.

Selection of State Priority Needs

A total of 10 priority needs were selected based on data analysis, number of persons affected, input from collaborators, state political priorities, availability of resources to address identified needs, and reliable, culturally sensitive treatment or management options. An instrument for prioritization of identified needs was designed based on CDC/ASTHO criteria.

1. Improve maternal health.
2. Reduce unintended pregnancies.
3. Improve newborn health.
4. Reduce adolescent pregnancies.
5. Reduce behavioral risk factors among pregnant women and adolescents (smoking, alcohol and substance abuse).
6. Reduce unintentional injuries among children and adolescents.
7. Increase availability and accessibility to preventive and quality primary health care services for the MCH/CSHCN populations.
8. Decrease morbidity and mortality due to bronchial asthma.
9. Improve coordination among health care plans, primary physicians and the Pediatric Centers.
10. Promote successful transition of youth to adult life.

Needs Assessment Summary

We hope that the Puerto Rico MCH Needs Assessment has provided a clear vision not only of the needs of the MCH population; but also of our efforts toward improving the health of the Puerto Rican women, infants and children. The data compiled from different sources was assembled into tables, graphics and figures to facilitate analysis and

interpretation. The health needs and resources available for each subgroup of the MCH population were derived from this process.

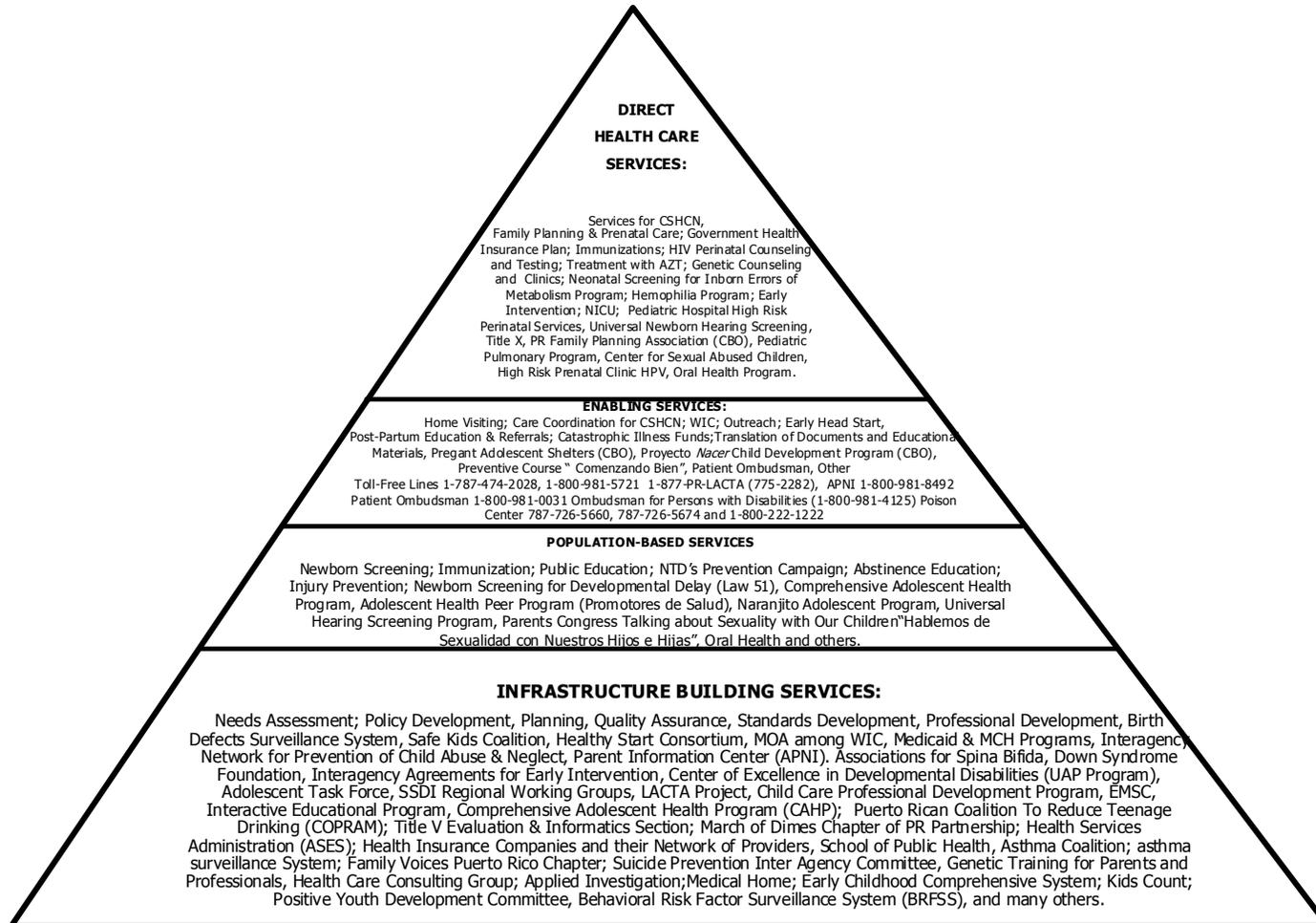
The health status of the PR MCH population has shown some improvement in maternal and child health outcomes across the last decade. However, there is a significant disparity among neonatal, post neonatal, infant, perinatal and maternal mortality rates in comparison to national achievement and set targets for 2010. The contributing factors are myriad and many of them are resistant to a model based on clinical services. Therefore, the partnership of all sectors of the society is critically needed in order to reduce the gap between where we are now and the set goals.

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Figure II – 1a

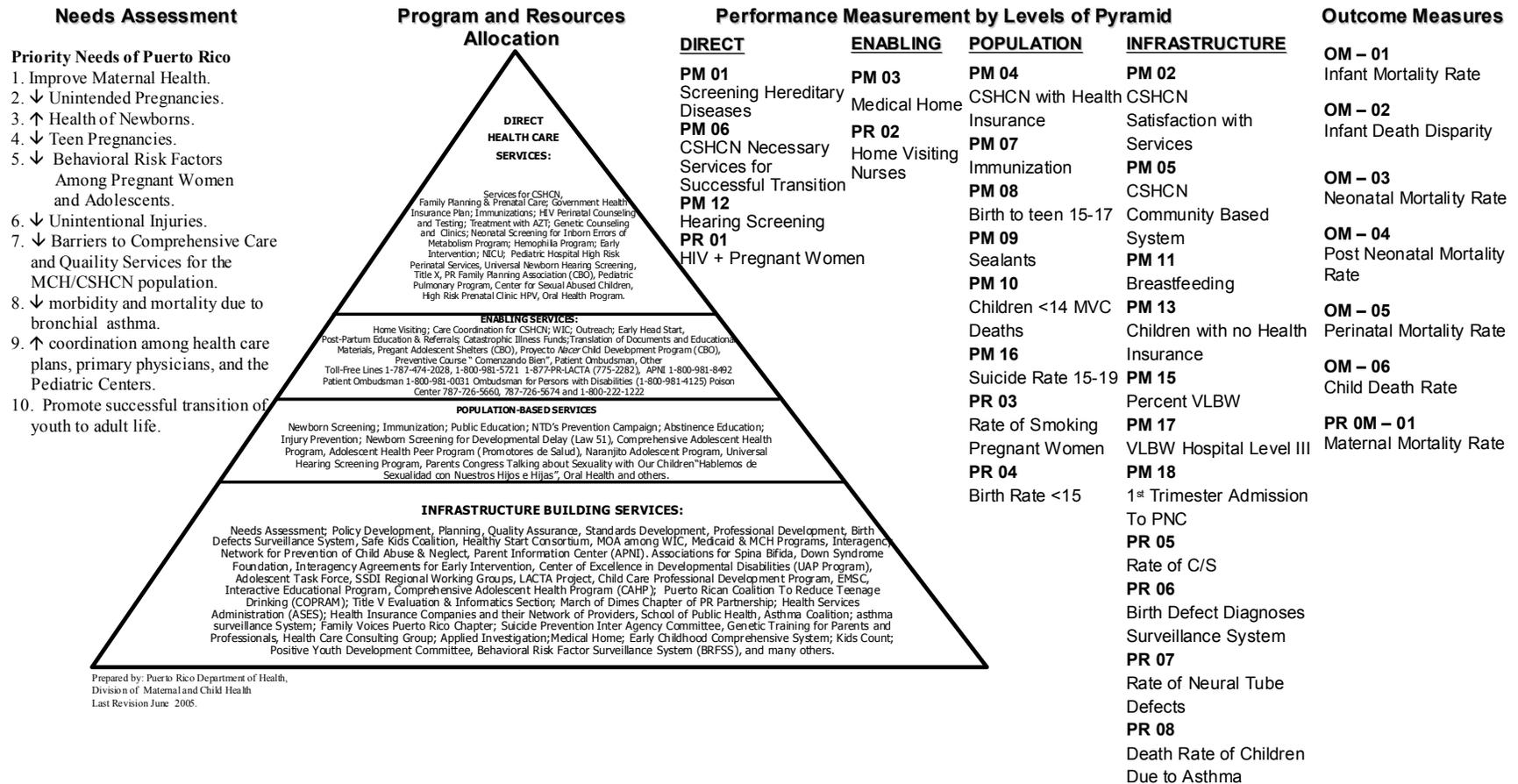
Puerto Rico Title V MCH Pyramid Program and Resources Allocation



Prepared by: Puerto Rico Department of Health,
 Division of Maternal and Child Health
 Last Revision June 2005.

Figure II – 1b

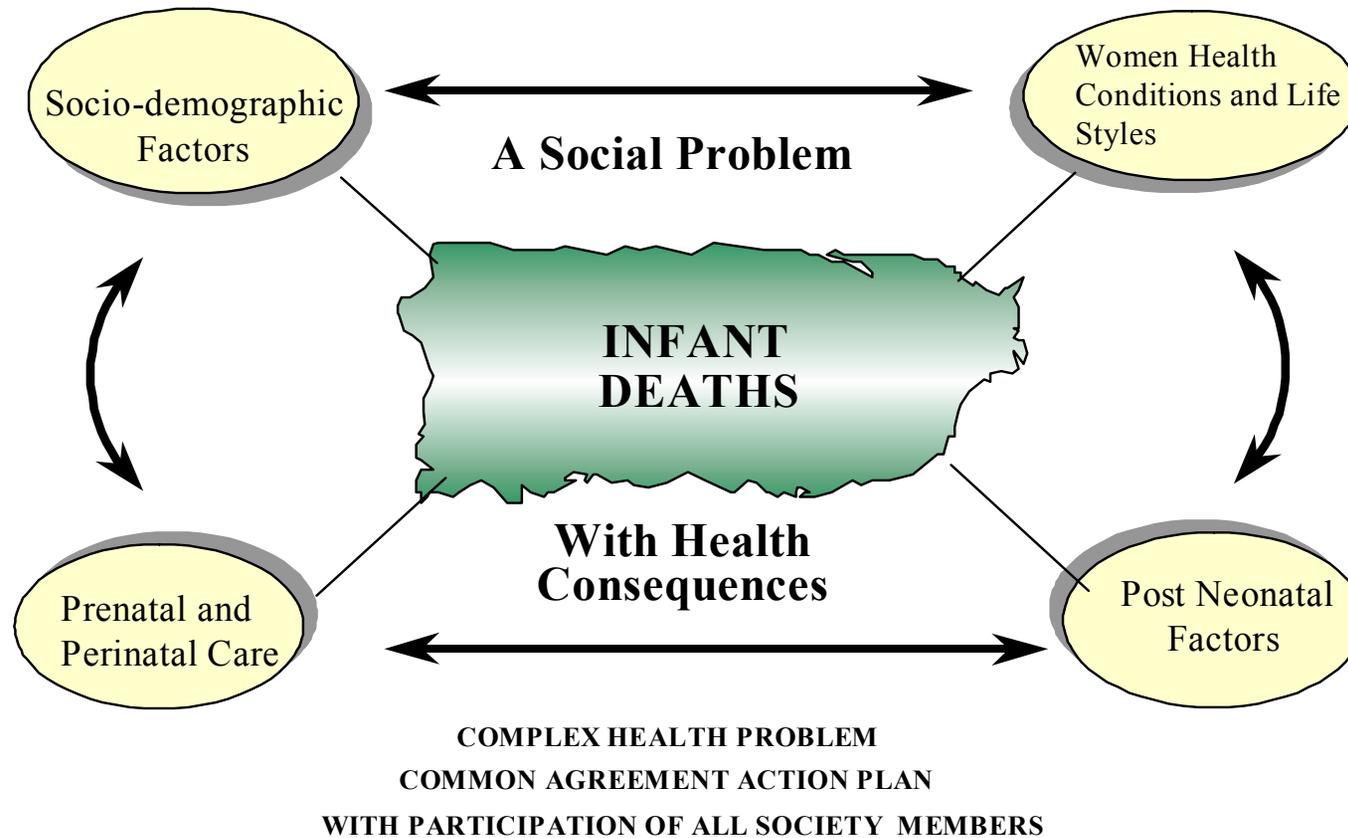
Puerto Rico Title V Block Grant Performance Measurement System



Prepared by: Puerto Rico Department of Health,
Division of Maternal and Child Health
Last Revision June 2005.

Figure II - 2

Factors Affecting Infant Mortality

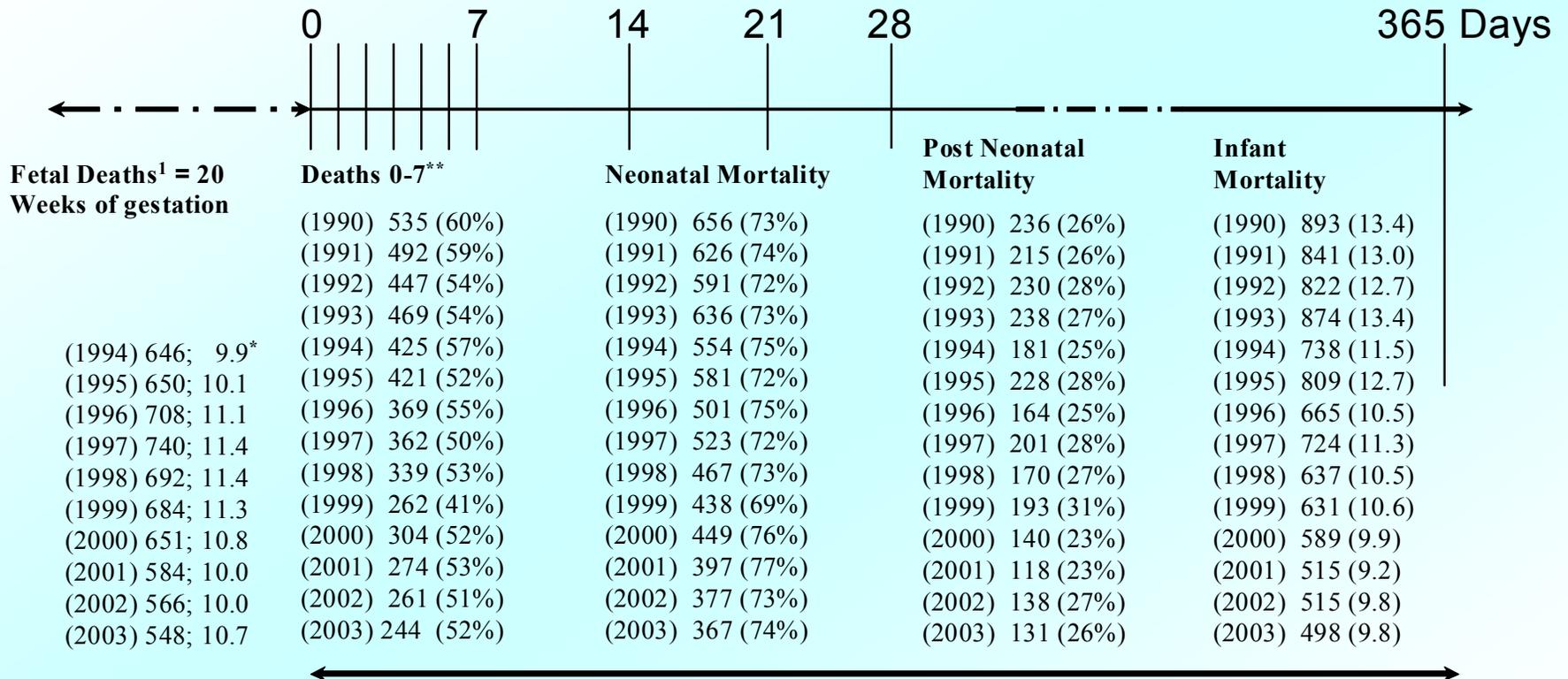


By: Roberto Varela-Flores, MD, MPH
Division of Maternal and Child Health
January 1997

Figure II - 3

Fetal and Infant Deaths by Age

Puerto Rico 1990-2003



Source: Maternal and Child Health Division. Title V .

* = Rate per 1,000 live births

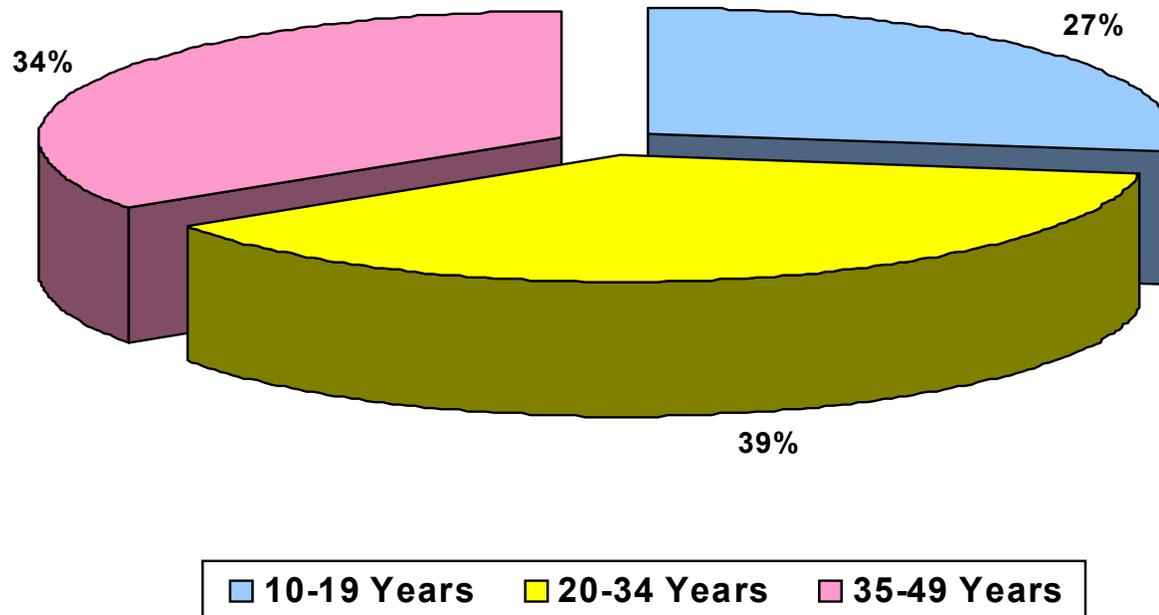
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Note = To obtain the percentage, the total number of infant deaths was used as denominator.

¹= Fetal Death Registry started in 1994.

Figure II - 4

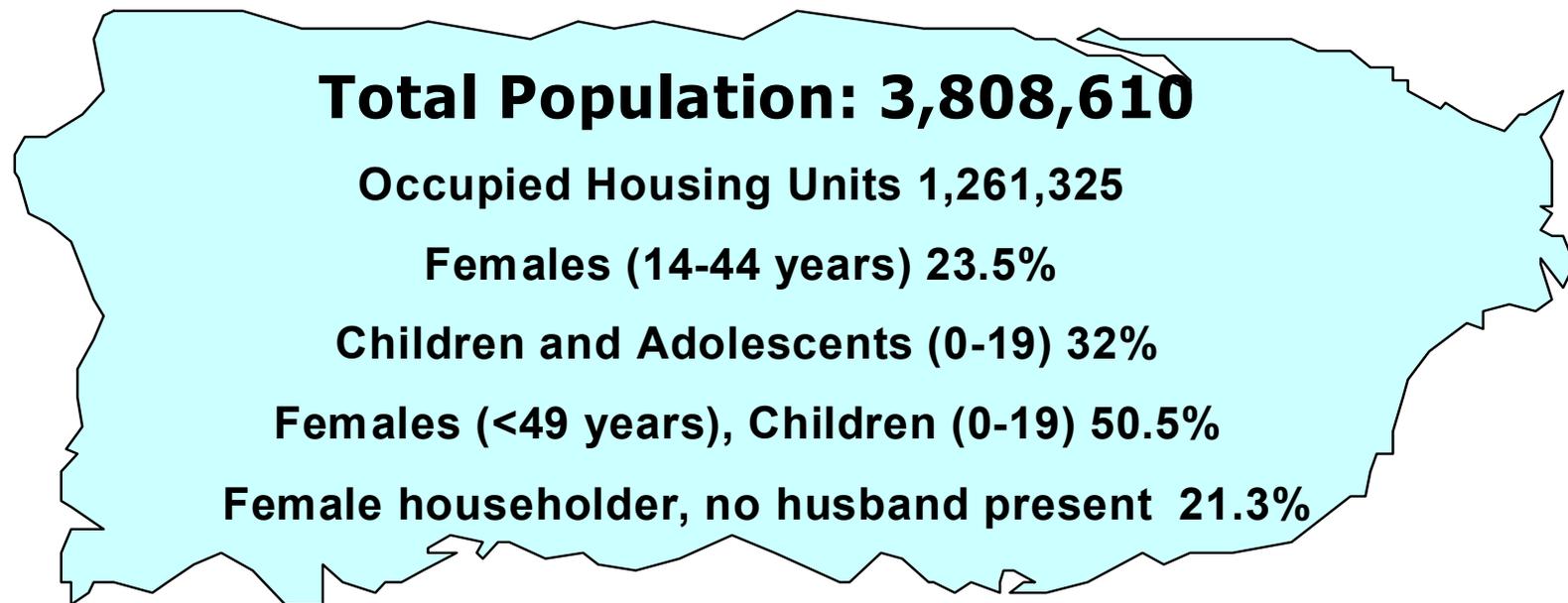
Women in Reproductive Age by Age Group in Puerto Rico Year 2000



Source: US Census 2000
Prepared by: Monitoring and Evaluation Section
Division of Maternal and Child Health

Figure II - 5

Maternal, Infant and Pediatric Population Puerto Rico: 2000

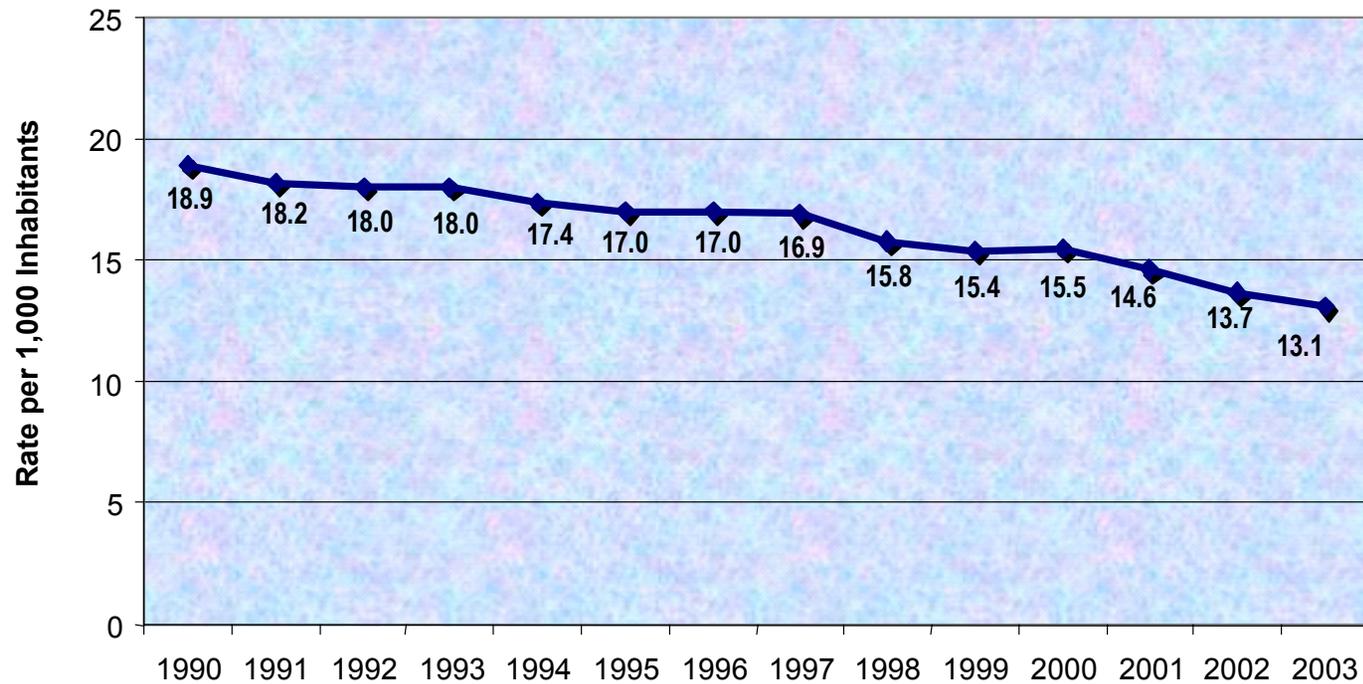


Source: Puerto Rico Planning Board. 2000 Census.

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health.
June 2005

Figure II - 6

Natality Rates in Puerto Rico 1990 - 2003



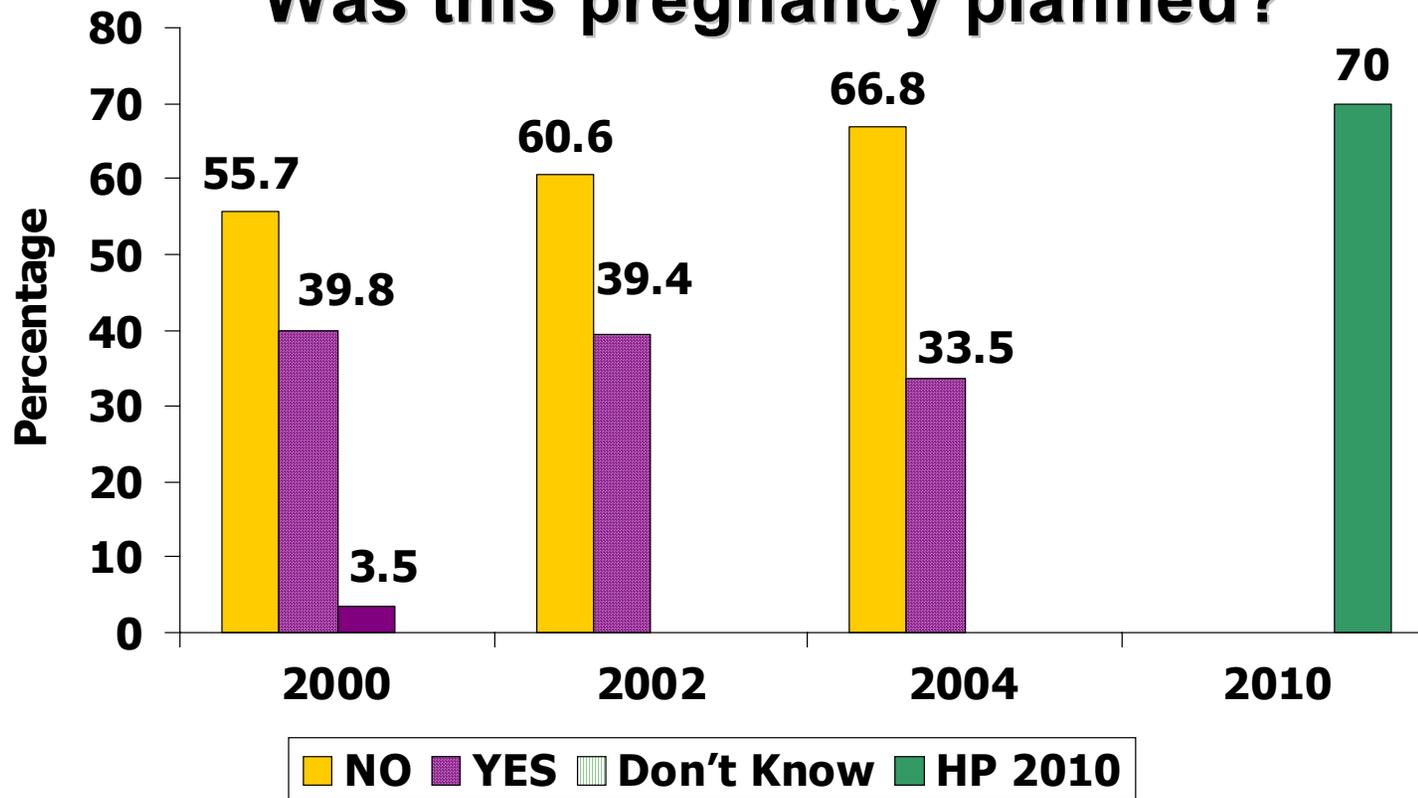
Source: PR Planning Board, Census Office
Vital Statistic Report. Puerto Rico Department of Health, SAPEESI, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Unit.
Division of Maternal and Child Health

Figure II - 7

Puerto Rico Maternal - Infant Health Survey (ESMIPR)

Was this pregnancy planned?

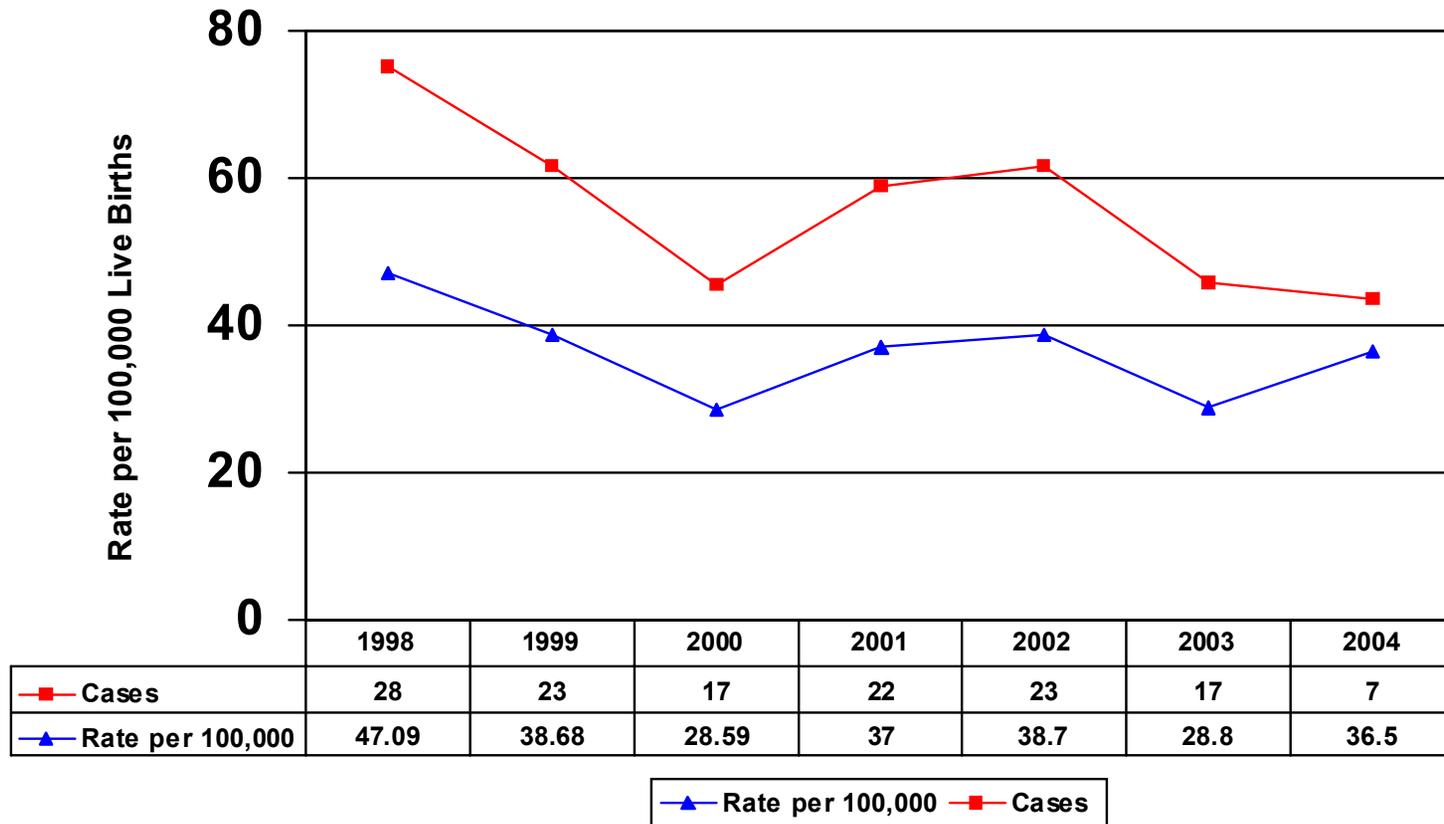


Source: ESMIPR 2000, 2002, and 2004

Prepared by: Monitoring and Evaluation
Section, Division of Maternal and Child Health.
June 2005

Figure II - 8

Congenital Syphilis Puerto Rico: 1998-2004

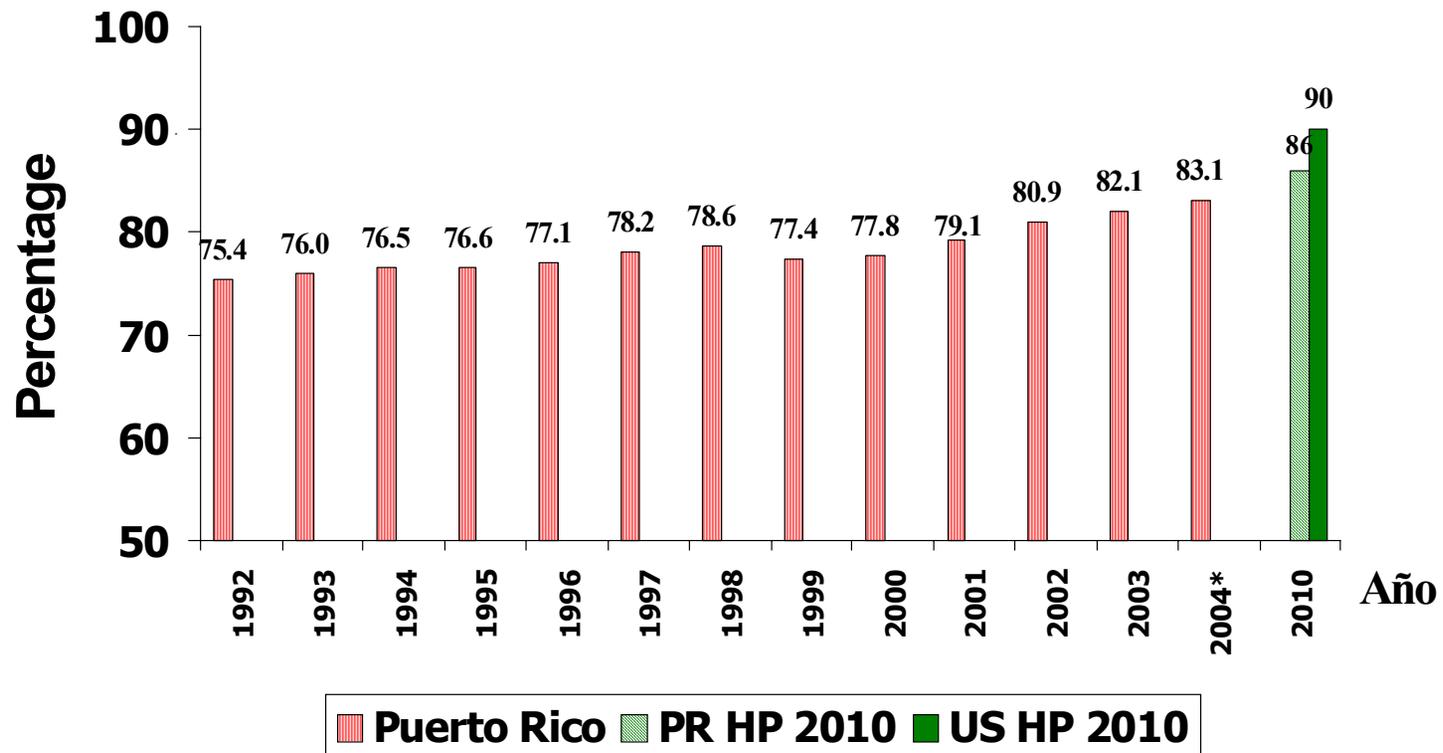


Source: Puerto Rico Department of Health. STD Surveillance System.
 Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health.

June 2005

Figure II - 9

Early Prenatal Care Puerto Rico 1992-2004*



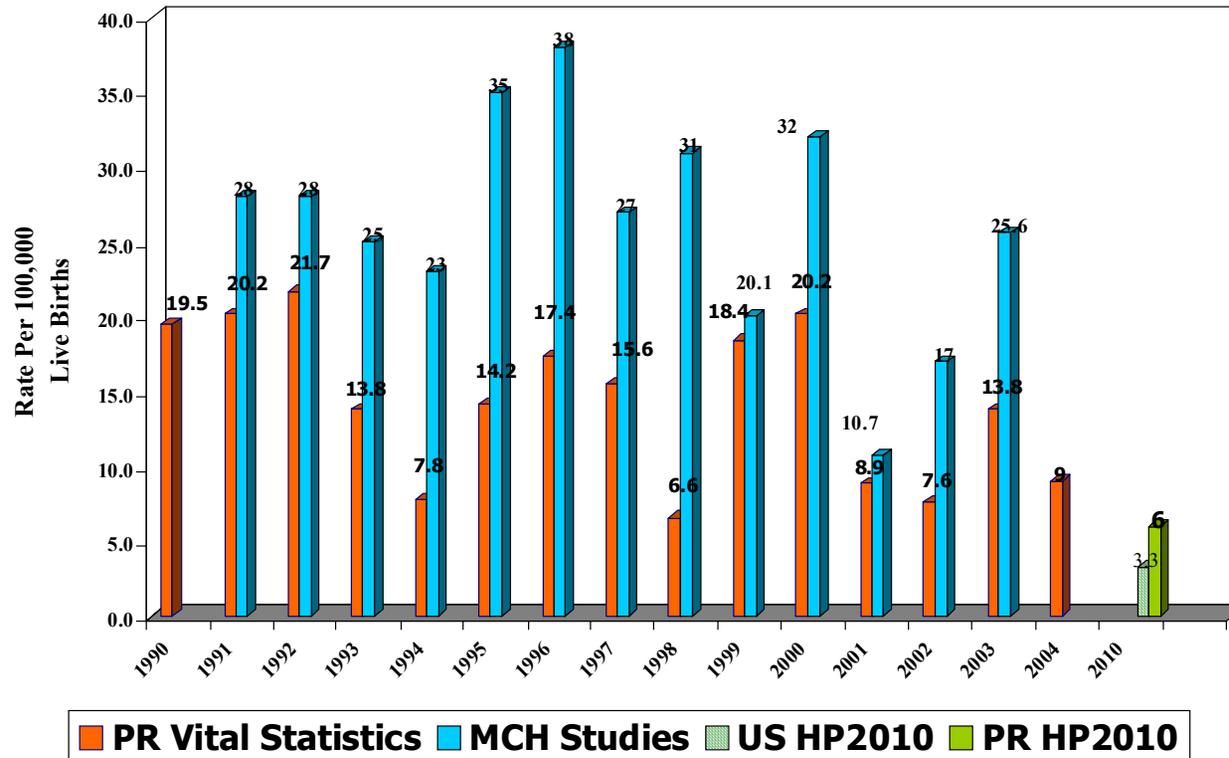
*2004 preliminary data.

Source: Puerto Rico Department of Health. SAPEESI.

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health.

Figure II - 11

Maternal Mortality Rates Puerto Rico, 1990-2004*



*2004 preliminary data.

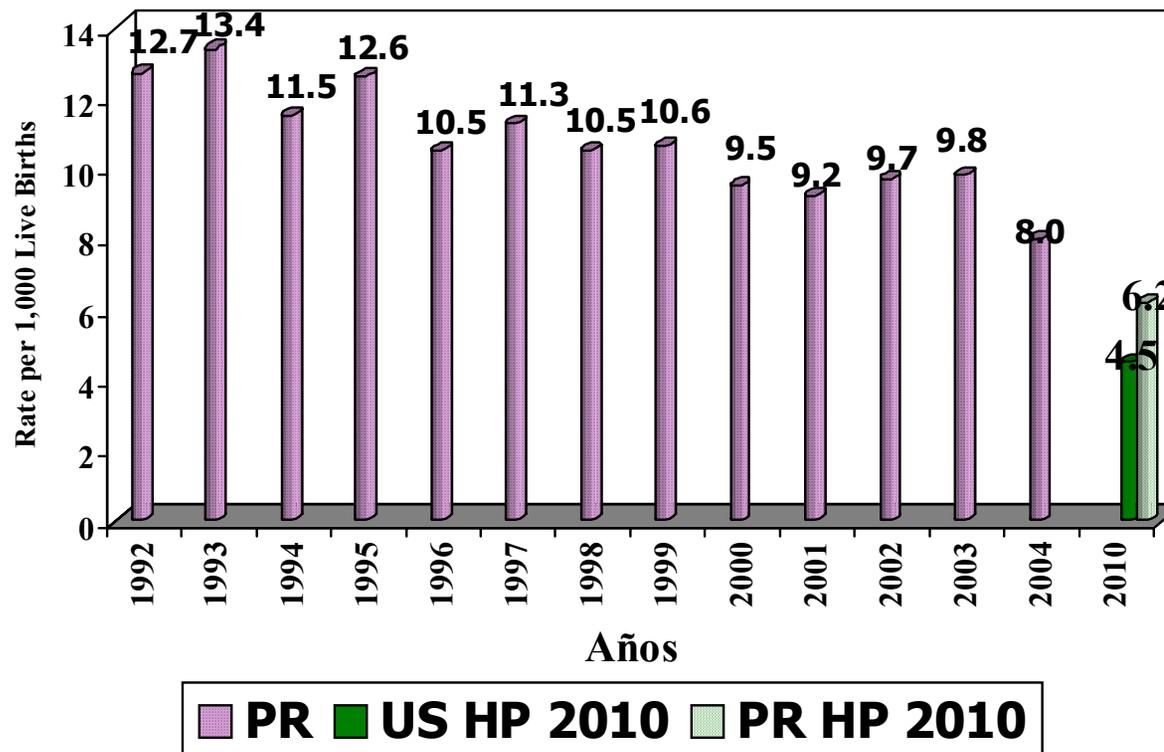
Source: Puerto Rico Department of Health. SAPEESI

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health.

June 2005

Figure II - 12

Trends on Infant Mortality Rates Puerto Rico, 1992-2004*



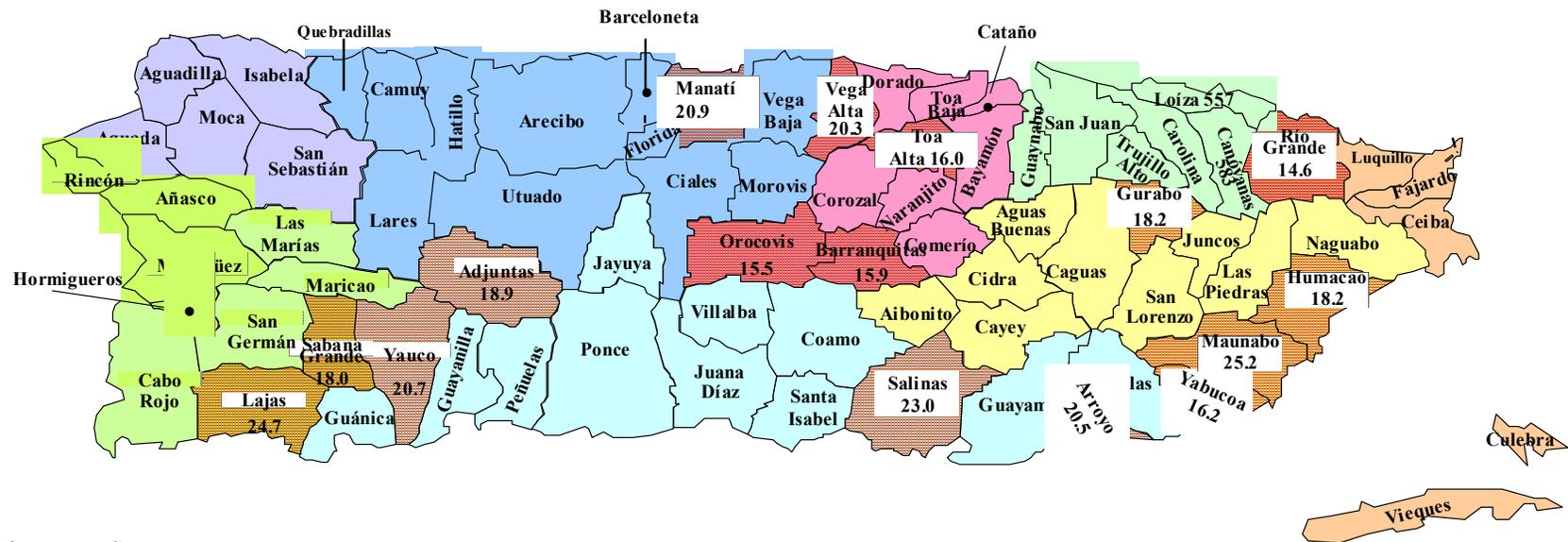
Data for year 2004 is preliminary.

Source: Puerto Rico Department of Health, SAPEESI

Prepared by: Monitoring and Evaluation Unit. Division of Maternal and Child Health.

Figure II - 13

Municipalities with Highest Infant Mortality Rates. Puerto Rico 2001-2003



Legend:

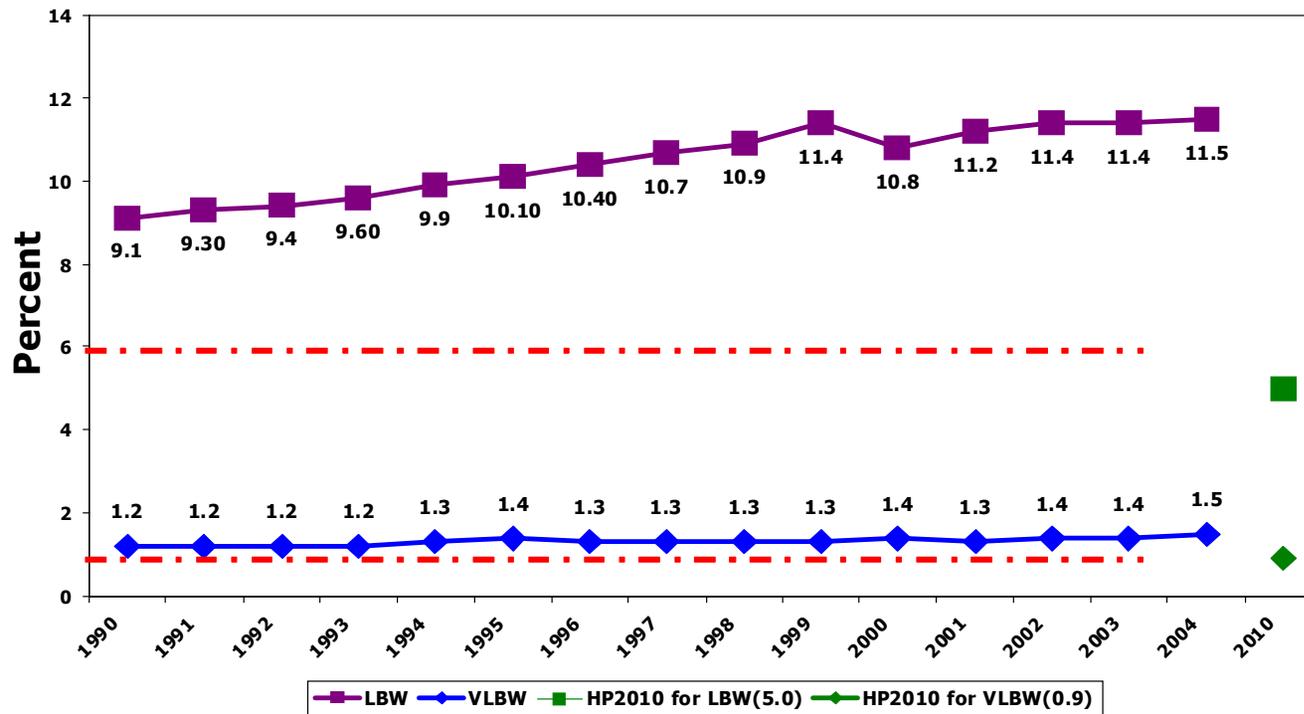
Municipalities with higher infant mortality rates (> 14/1,000 LB)

Source: PR Department of Health. Vital Statistics. 2001-2003

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health. June 2005.

Figure II - 14

Low Birth Weight (LBW) and Very Low Birth Weight (VLBW) in Puerto Rico: 1990-2004*



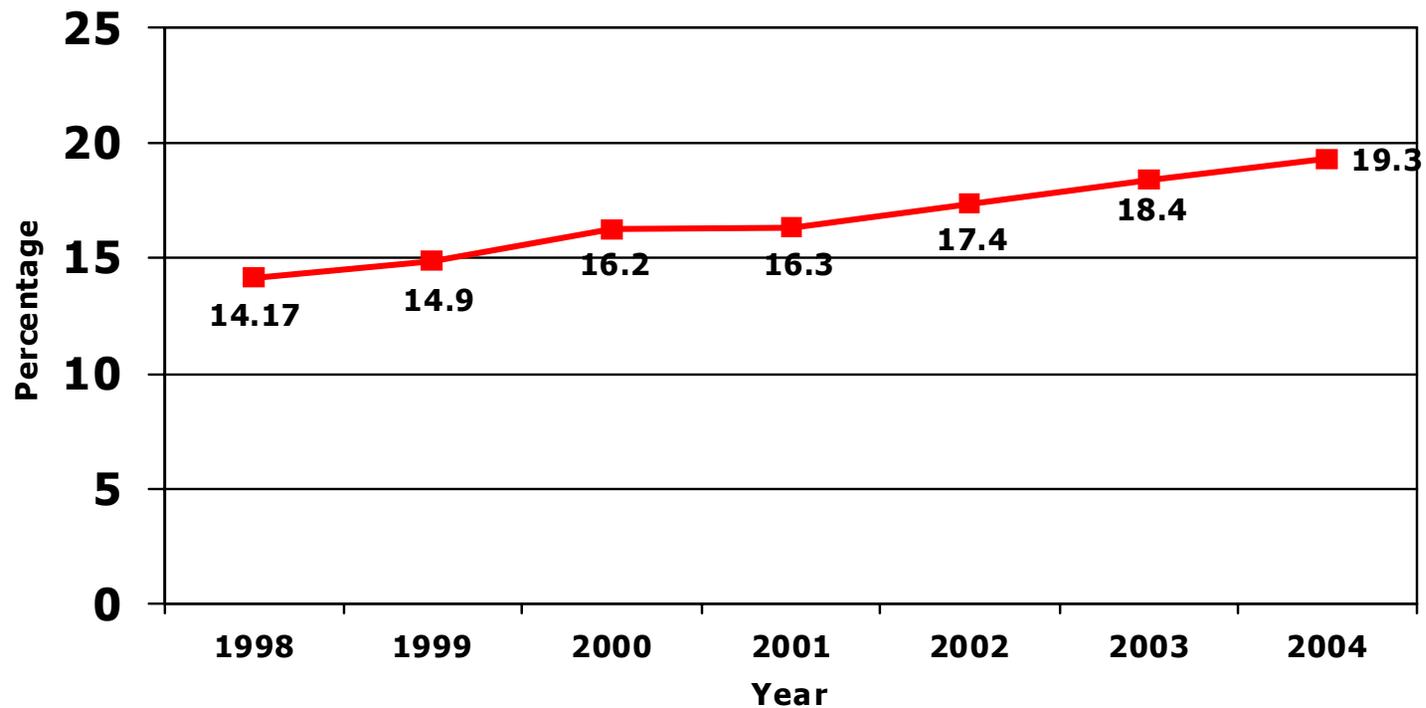
*2004 preliminary data.

Source: Puerto Rico Department of Health. SAPEESI. Vital Statistics Report.

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health. June 2005.

Figure II - 15

Percent of Premature Births Puerto Rico: 1998 – 2004*



*2004 preliminary data.

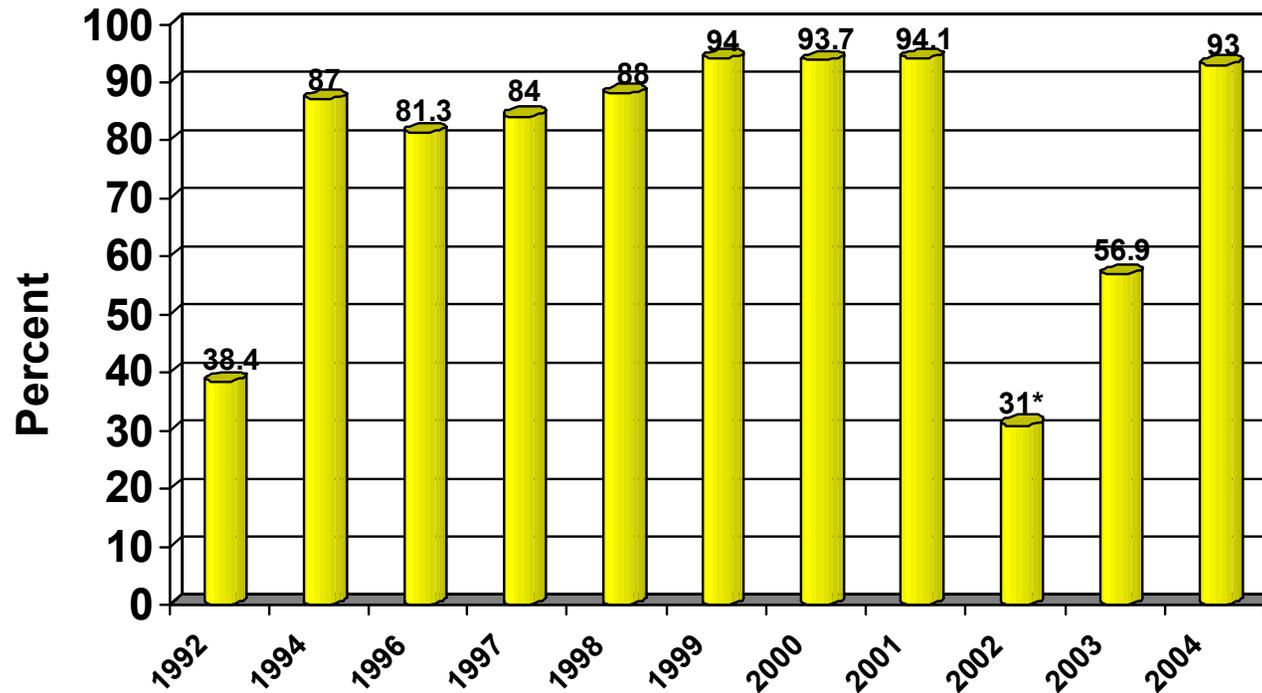
Source: Puerto Rico Department of Health. SAPEESI.

Prepared by: Monitoring and Evaluation Section.
Division of Maternal and Child Health. June 2005

Figure II - 16

Immunization Coverage Puerto Rico 1992-2004

Percentage of Immunized Children 19 to 35 months of age (4DTP, 30PV, and 1MMR)



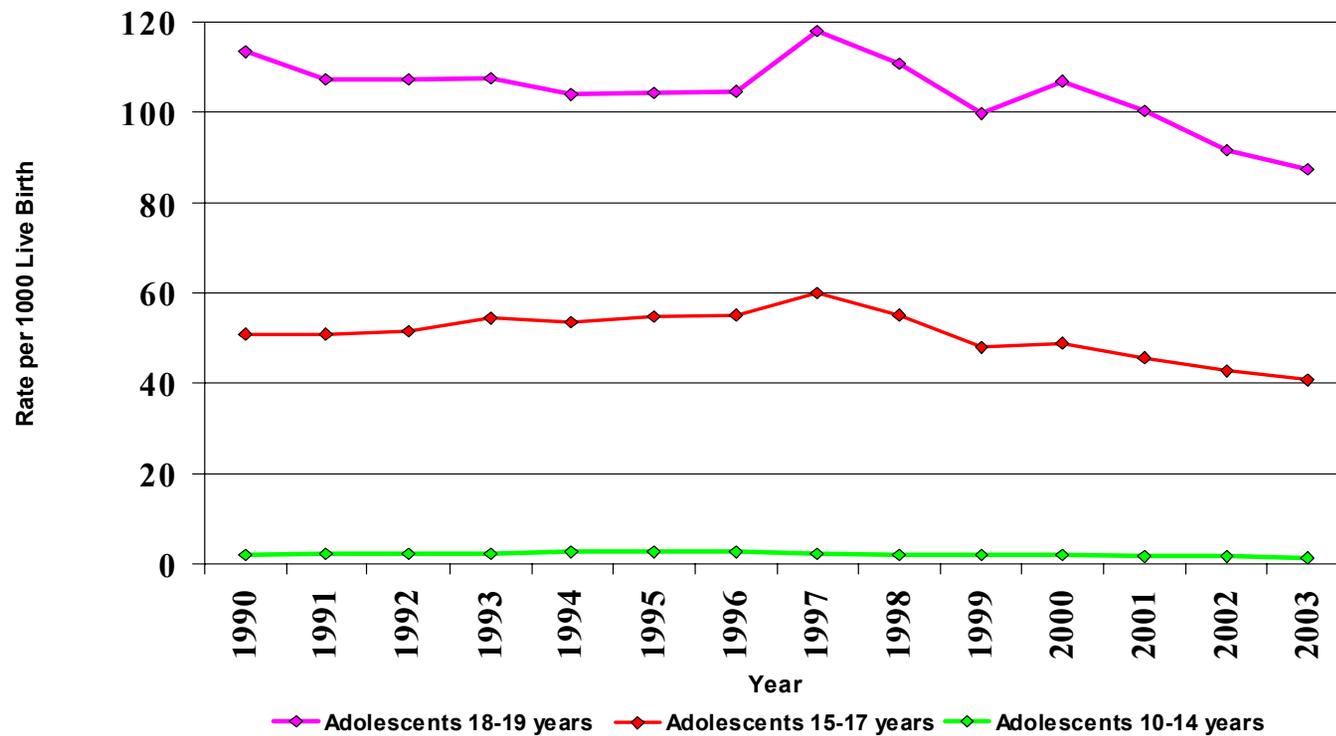
*Due to vaccine shortage, the fourth dose of DTaP was postponed for children at 15 months of age.

Source: Puerto Rico Department of Health. Immunization Program
Revised: June 2005

Figure II - 17

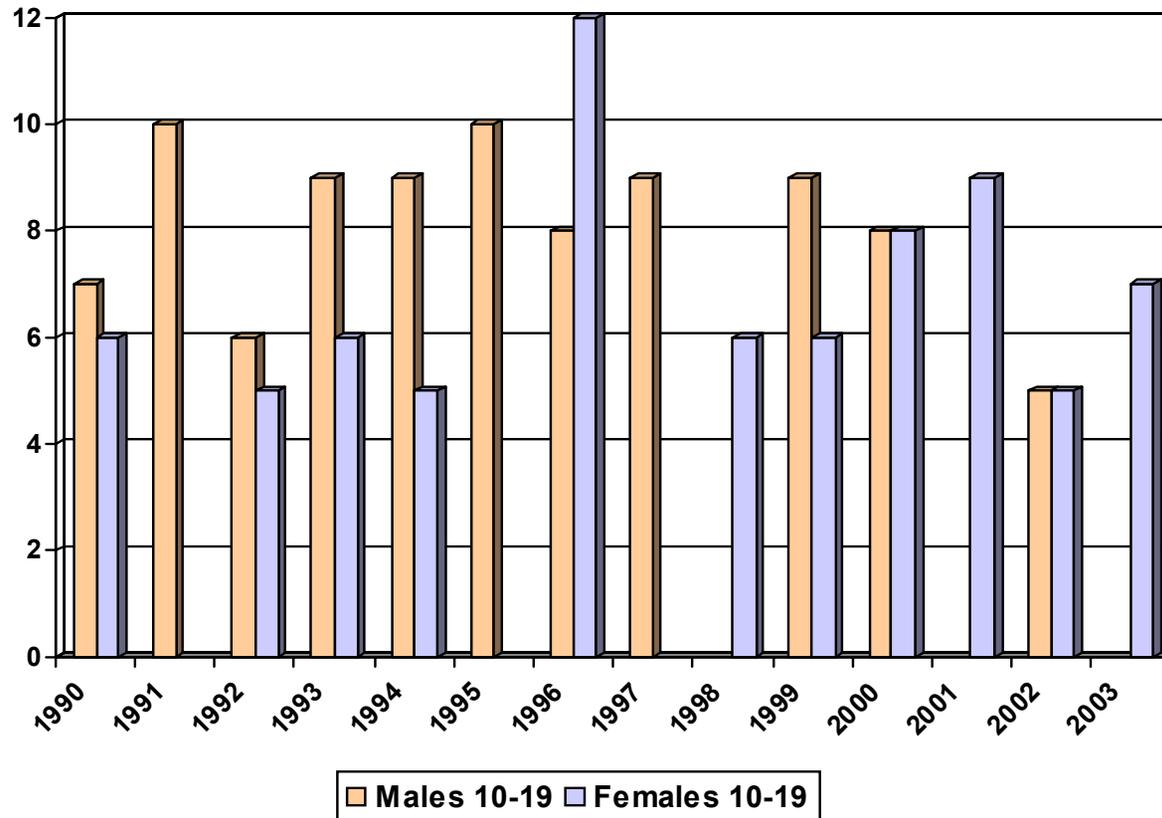
Birth Rates among Adolescents

Puerto Rico: 1990-2003



Sources: Population Data for 1997, 1998, and 2002: US Census.
Puerto Rico Department of Health. Vital Statistics Report. 1990-2002.
Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health. Program of Comprehensive Health Services for Adolescents.
June 2005.

Figure II - 18
**HIV/AIDS Cases in Puerto Rico by Sex
1990-2004**



Note: Cases in the female group in 1991, 1995, 1997, and 2004 are less than 5 and were not reported. .
Cases in the male group in 1998, 2001, 2003, and 2004 are less than 5 and were not reported.

Source: PR Dept. of Health. HIV/AIDS Surveillance System.

Figure II - 19

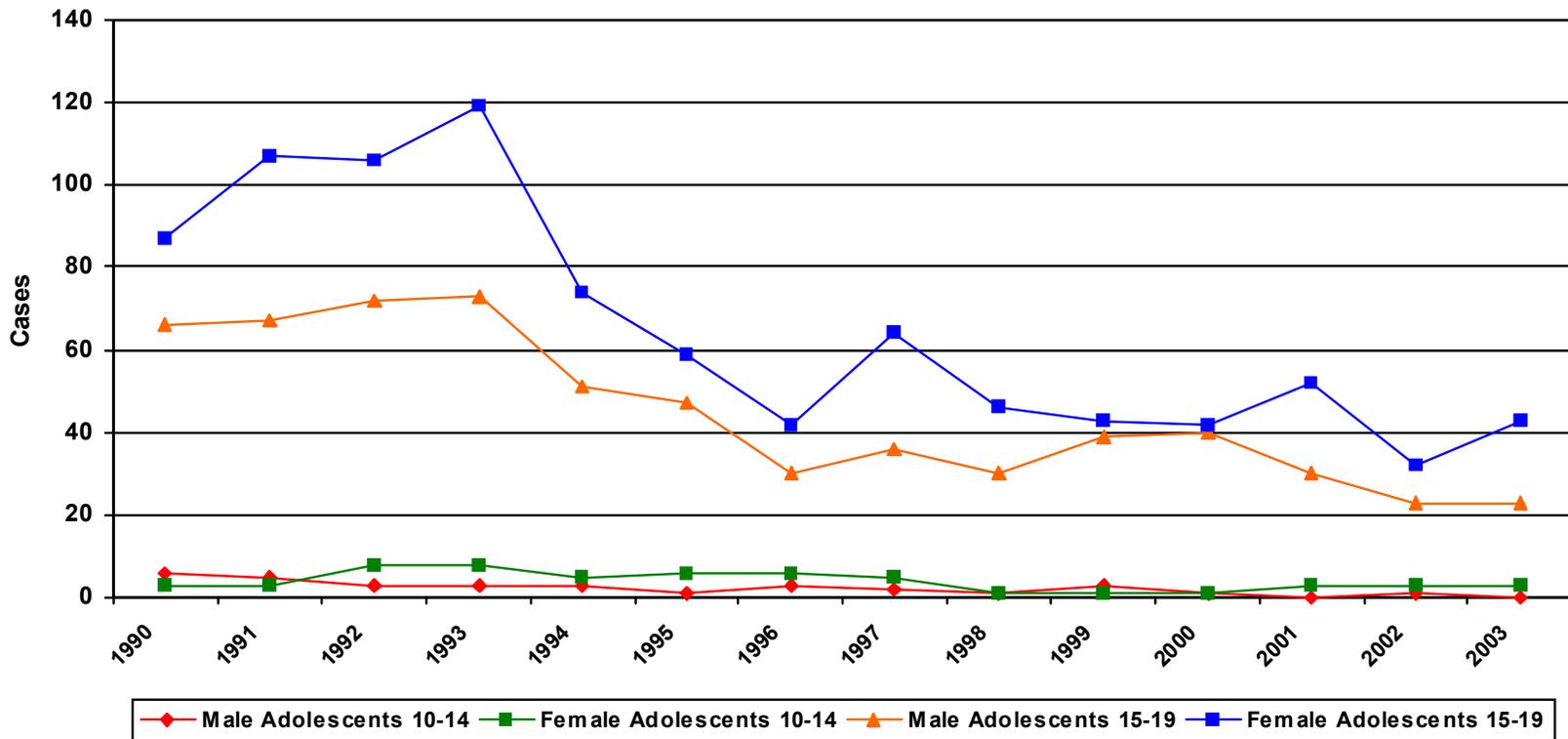
Rates of Chlamydia Infections among Adolescents in Puerto Rico 1996-2003



Source: Puerto Rico Department of Health. STD Prevention Program. Surveillance Office.
Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health.
June 2005.

Figure II -20

Trends in Syphilis Infections among Adolescents by Age Group and Sex. Puerto Rico: 1990-2003

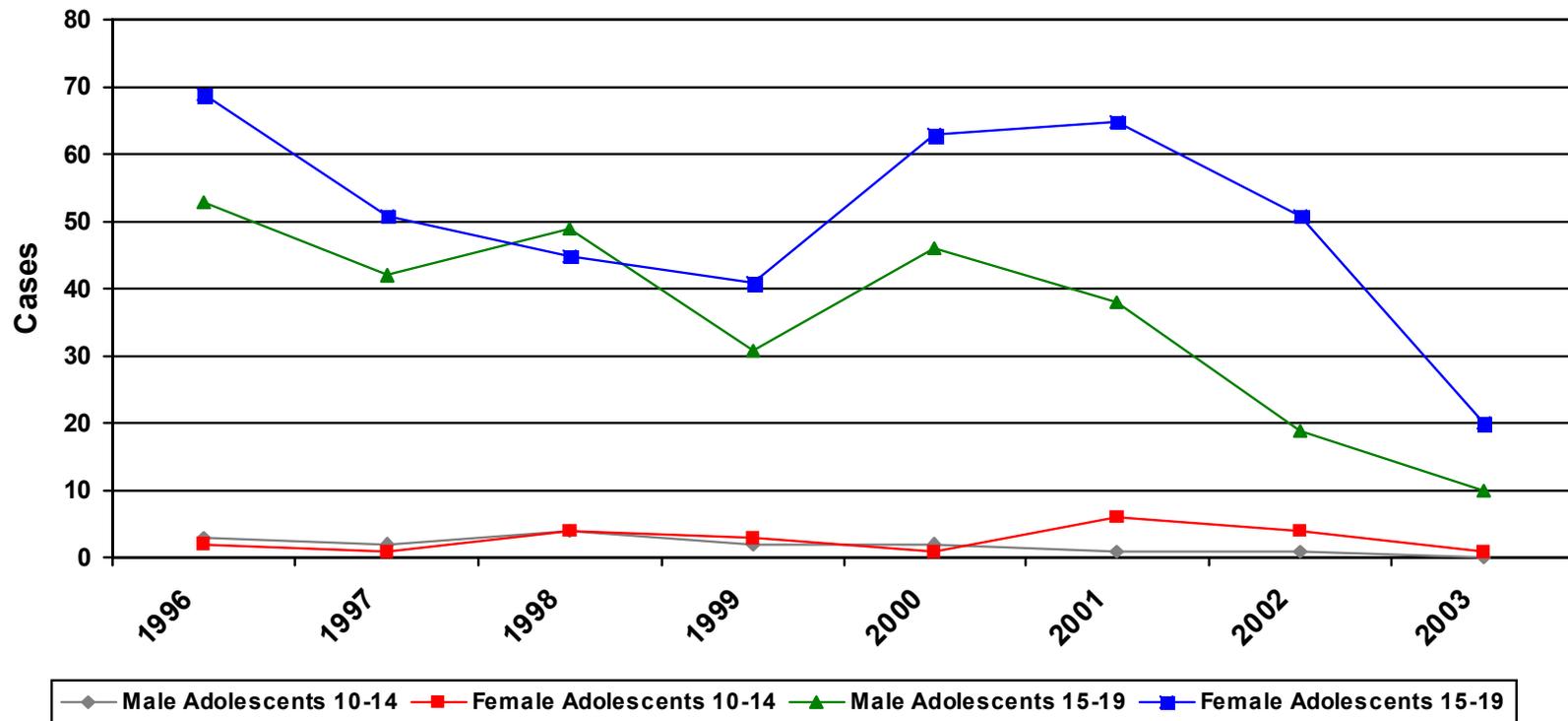


Source: PR Department of Health. STD Surveillance System.

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health. June 2005.

Figure II - 21

Trends in Gonorrhea Infections among Adolescents by Age Group and Sex. Puerto Rico: 1996-2003

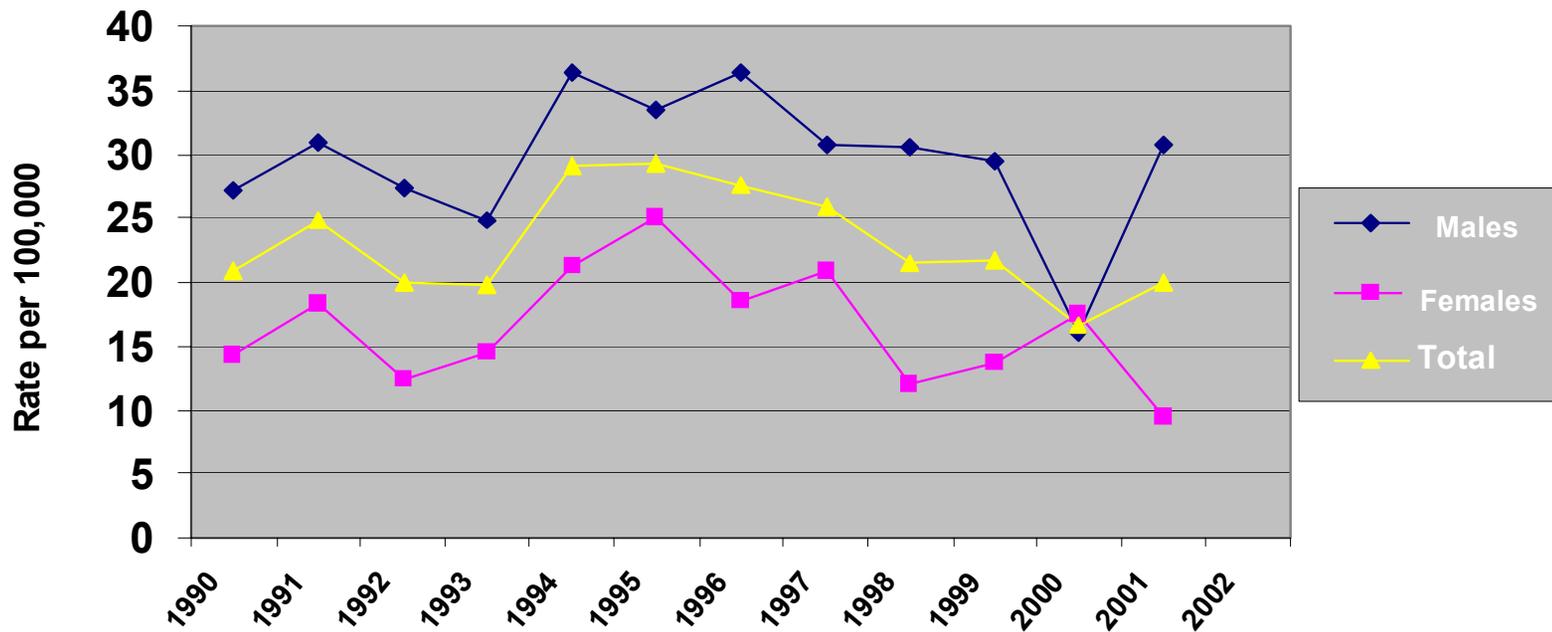


Source: PR Department of Health. STD Surveillance System.

Prepared by: Monitoring and Evaluation Section. Division of Maternal and Child Health. June 2005.

Figure II - 22

Adolescent Mortality Rates 10-14 Year Old by Sex: 1990-2002

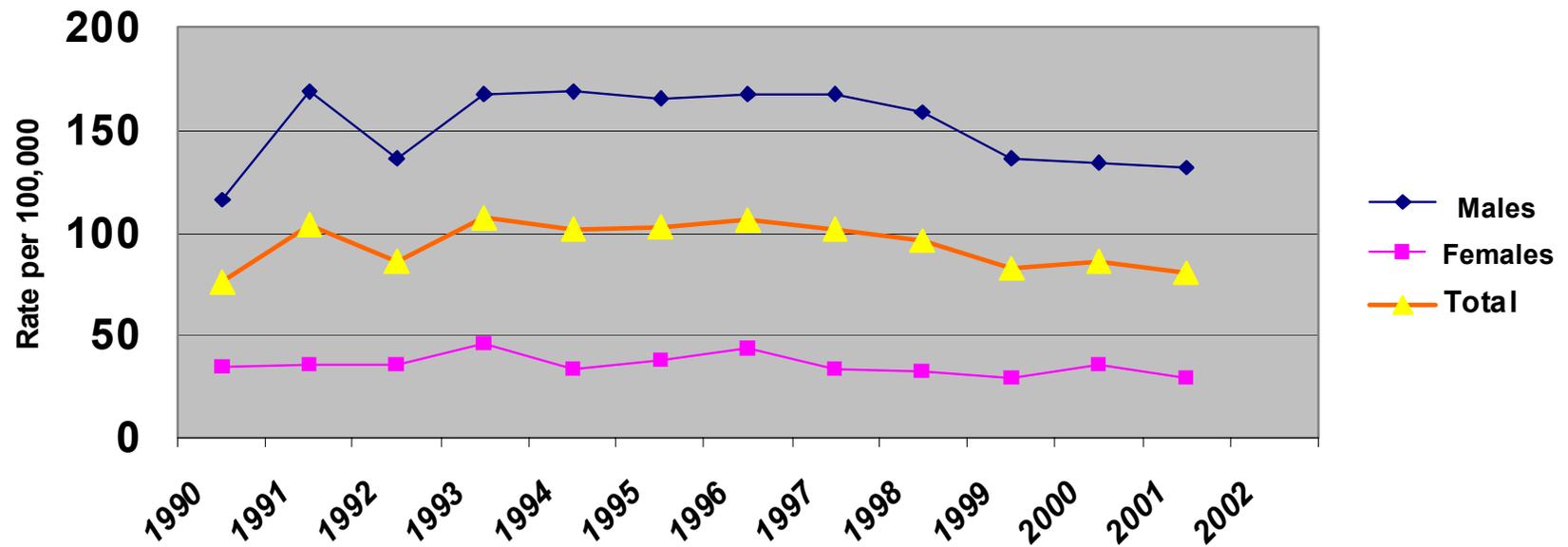


Source: Puerto Rico Department of Health. Vital Statistics Report. Prepared by:
Monitoring and Evaluation Section. Division of Maternal and Child Health.
June 2005

Figure II - 23

Adolescent Mortality Rates

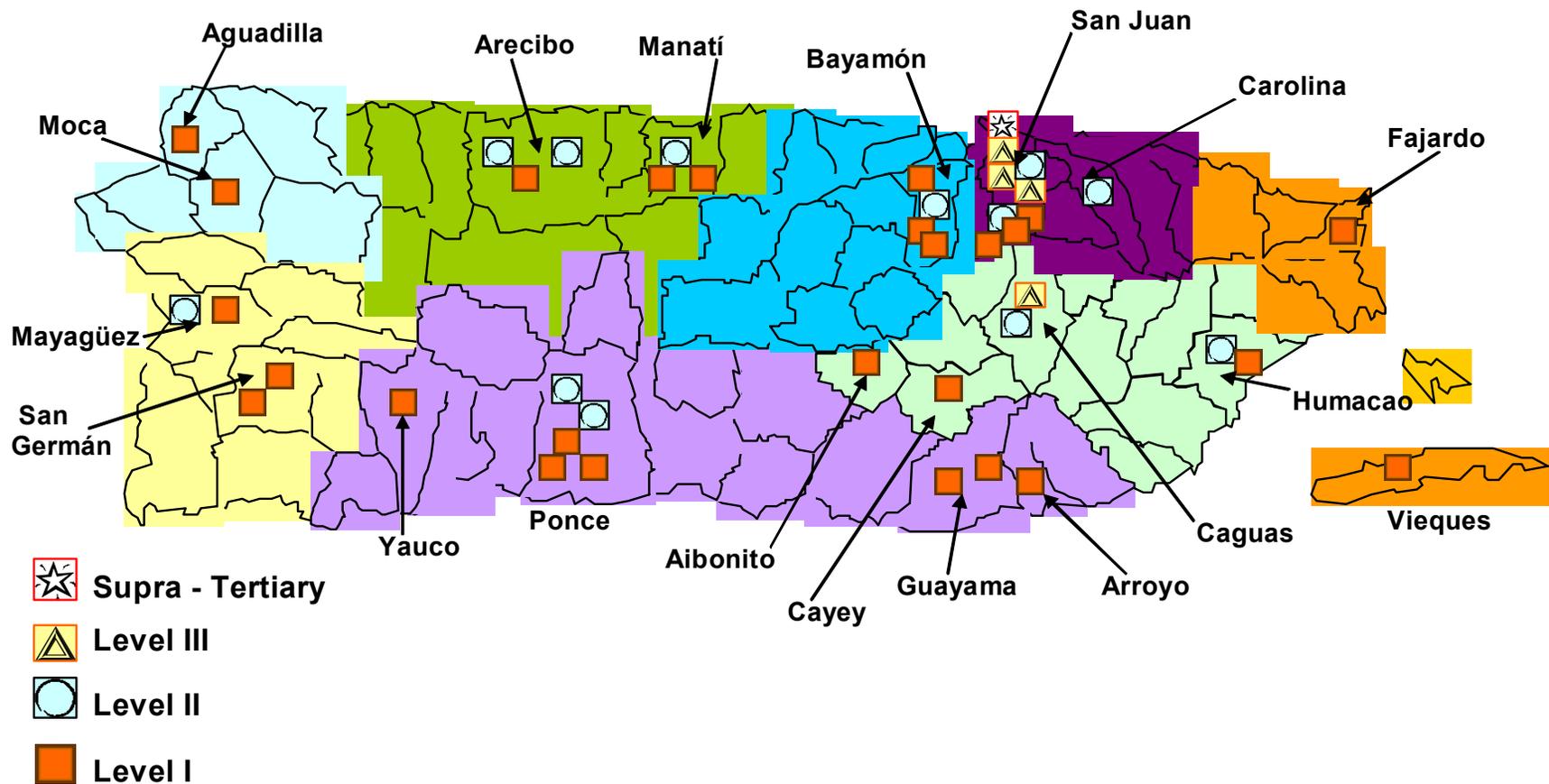
15-19 Year Old by Sex: 1990-2002



Source: Puerto Rico Department of Health. Vital Statistics Report.
Prepared by: Monitoring and Evaluation Section.
Division of Maternal and Child Health. June 2005

Figure II - 24

Distribution of Hospital Facilities by Level of Care – Puerto Rico 2004



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Table II - 1

Municipio	Posición Nacimientos	Población ²	Tasa Bruta de Natalidad	Posición (1)	Por ciento Madres Solteras y en unión consensual	Posición (2)	Por ciento de Madres	Posición (3)	Por ciento Madres Adolescentes	Posición (4)	Por ciento Madres menos de 4to año	Posición (5)	Por ciento 1er Trimestre	Posición (6)	Indice de Kotelchuck	Posición (7)	Por ciento Muy Bajo Peso	Posición (8)	Por ciento Bajo Peso	Posición (9)	Por ciento Prematurez	Posición (10)	Tasa de Mortalidad Neonatal	Posición (11)	Tasa de Mortalidad Posneonatal	Posición (12)	Tasa de Mortalidad Infantil	Posición (13)	Tasa de Natimueertos ³	Posición (14)	Tasa de Perinatales ³	Posición (15)	IISMI	Posición	
Moca	1	555	41,589	13.3	26	31.2	1	13.3	4	55.4	7	18.9	13	89.2	3	87.7	4	0.7	7	10.1	13	20.2	38	3.6	10	1.8	9	5.4	15	5.4	7	5.4	14	171	1
Camuy	2	426	37,042	11.5	9	31.9	2	15.0	11	48.4	2	19.2	15	88.3	6	82.8	22	0.7	7	12.4	31	19.5	35	2.3	3	2.3	12	4.7	11	7.0	16	4.7	12	194	2
Isabela	3	582	45,930	12.7	21	35.9	5	13.9	7	51.9	4	21.0	22	84.9	23	86.5	8	1.0	10	9.3	7	16.3	13	5.2	18	1.7	8	6.9	22	10.2	35	6.8	20	223	3
San Sebastián	4	573	45,707	12.5	19	38.2	9	18.5	32	56.6	9	24.8	38	86.4	14	87.8	3	0.3	3	11.3	22	19.2	32	3.5	9	0.0	1	3.5	7	8.7	27	3.5	9	234	4
Aguas Buenas	5	410	30,007	13.7	29	52.7	34	18.3	31	76.0	32	20.0	18	84.1	24	78.3	41	0.2	2	9.5	9	15.4	9	0.0	1	0.0	1	0.0	1	2.4	2	2.4	4	238	5
Aguada	6	474	43,724	10.8	4	39.9	10	15.0	11	64.8	14	21.1	23	88.2	7	84.4	17	1.5	15	7.6	1	17.3	19	10.5	40	0.0	1	10.5	39	6.3	11	10.5	37	249	6
Utua	7	418	35,270	11.9	13	46.2	20	21.3	41	74.2	28	23.4	35	89.5	2	83.5	20	1.2	12	9.8	11	21.8	44	2.4	4	0.0	1	2.4	2	9.5	33	2.4	4	270	7
Ceiba	8	239	18,168	13.2	25	35.1	4	16.3	18	71.8	20	12.6	2	74.5	53	72.0	57	0.4	4	10.5	16	16.3	13	4.2	12	0.0	1	4.2	9	8.3	24	8.3	26	284	8
Culebra	9	23	1,970	11.7	11	52.2	33	21.7	43	100.0	71	26.1	45	73.9	54	82.6	23	0.0	1	8.7	3	13.0	1	0.0	1	0.0	1	0.0	1	0.0	1	0.0	1	290	9
Añasco	10	348	29,190	11.9	13	44.3	15	15.8	14	67.3	15	25.6	42	83.0	32	86.5	8	0.9	9	14.4	41	23.9	49	2.9	7	0.0	1	2.9	4	14.2	48	0.0	1	299	10
Hormigueros	11	180	17,016	10.6	3	43.3	12	8.3	1	73.3	24	12.2	1	87.8	8	86.7	6	1.7	17	12.2	29	19.4	34	0.0	1	5.6	32	5.6	17	21.7	61	16.4	55	301	11
Barceloneta	12	320	22,627	14.1	33	47.2	22	15.9	15	72.5	23	21.3	24	85.6	18	75.3	52	1.9	19	9.1	6	19.1	31	0.0	1	3.1	18	3.1	5	9.3	31	3.1	7	305	12
Las Piedras	13	565	36,375	15.5	45	49.9	26	16.6	20	81.9	48	17.3	7	83.4	30	75.2	53	1.1	11	10.8	19	13.6	3	3.5	9	0.0	1	3.5	7	7.0	16	5.3	13	308	13
San Germán	14	435	37,633	11.6	10	48.0	25	18.2	30	62.0	12	19.1	14	86.0	16	86.4	9	1.6	16	13.3	36	26.2	55	2.3	3	2.3	12	4.6	10	20.3	60	2.3	3	311	14
Toa Alta	15	874	69,779	12.5	19	43.7	13	12.1	2	78.3	38	15.1	3	88.4	5	85.0	14	2.3	22	11.0	21	15.1	7	10.3	38	5.7	33	16.0	53	10.2	35	4.6	11	314	15
Trujillo Alto	15	971	79,906	12.2	16	47.5	24	13.1	3	78.7	40	17.3	7	83.9	26	80.0	36	0.8	8	10.1	13	17.6	20	6.2	23	4.1	25	10.3	37	7.2	18	6.2	18	314	15
Bayamón	16	2933	224,131	13.1	24	54.3	41	14.6	9	80.4	42	17.2	6	86.4	14	84.5	16	1.6	16	10.4	15	15.4	9	5.5	19	2.7	15	8.2	31	10.8	38	7.8	24	319	16
Hatillo	17	481	40,711	11.8	12	36.8	6	15.6	13	53.3	5	19.5	16	86.3	15	78.3	41	0.6	6	11.0	21	22.9	47	4.2	12	4.2	26	8.3	32	12.3	42	8.3	26	320	17
San Lorenzo	18	516	42,613	12.1	15	53.1	36	17.4	26	74.4	29	20.3	19	87.2	10	86.6	7	1.4	14	14.3	40	20.3	39	7.8	32	0.0	1	7.8	28	5.8	9	5.8	17	322	18
Quebradillas	19	407	26,577	15.3	43	32.7	3	16.0	16	49.2	3	22.1	27	88.9	4	85.4	12	1.7	17	13.8	38	23.3	48	7.4	29	0.0	1	7.4	26	9.7	34	7.4	22	323	19
Aguadilla	20	814	66,027	12.3	17	37.8	8	16.7	21	60.3	11	25.9	44	87.7	9	86.0	10	1.4	14	11.3	22	19.9	37	6.1	22	1.2	3	7.4	26	12.1	41	11.0	39	324	20
Cabo Rojo	21	549	49,413	11.1	6	40.1	11	13.3	4	56.2	8	18.6	11	86.0	16	90.0	1	1.5	15	11.5	24	22.2	46	9.1	36	1.8	9	10.9	43	24.9	62	12.7	45	337	21
Naranjito	22	422	30,078	14.0	32	55.9	49	15.9	15	77.6	36	25.4	41	88.4	5	85.3	13	0.7	7	9.0	5	16.8	15	7.1	27	0.0	1	7.1	24	9.4	32	11.8	40	342	22
Guaynabo	23	1221	101,837	12.0	14	46.6	21	13.8	6	81.0	44	17.3	7	87.7	9	84.1	18	1.9	19	10.1	13	16.9	16	9.0	35	3.3	20	12.3	45	12.9	45	9.8	31	343	23
Florida	24	195	13,470	14.5	36	37.4	7	16.9	22	57.6	10	18.5	10	75.4	51	76.8	48	0.5	5	8.7	3	19.0	30	5.1	17	0.0	1	5.1	13	15.2	50	15.2	52	355	24
Carolina	25	2305	187,781	12.3	17	54.8	44	13.4	5	81.9	48	17.0	5	77.6	45	75.4	51	1.5	15	11.3	22	17.2	18	4.3	13	3.0	17	7.4	26	8.2	23	5.6	16	365	25
Toa Baja	26	1253	94,931	13.2	25	57.7	57	18.1	29	81.5	46	23.0	33	83.0	32	81.8	26	0.6	6	9.5	9	15.3	8	4.8	15	3.2	19	8.0	30	7.9	21	4.0	10	366	26
Caguas	27	1975	142,010	13.9	31	54.0	38	17.2	25	83.8	53	17.8	8	85.2	21	80.9	29	1.5	15	12.6	32	18.1	25	5.1	17	2.5	14	7.6	27	7.5	20	5.6	16	371	27
Dorado	28	575	34,826	16.5	46	47.3	23	14.3	8	82.9	51	22.4	29	77.2	46	80.7	31	0.5	5	8.9	4	15.3	8	5.2	18	5.2	30	10.4	38	6.9	15	6.9	21	373	28
Villalba	29	362	29,106	12.4	18	55.0	45	24.3	51	84.1	54	21.0	22	81.5	39	80.9	29	1.9	19	9.7	10	18.8	28	2.8	6	2.8	16	5.5	16	5.5	8	5.5	15	376	29
Arecibo	30	1179	101,806	11.6	10	46.6	21	19.7	35	72.0	21	22.1	27	85.4	20	80.3	33	1.4	14	12.0	27	21.8	44	5.9	20	2.5	14	8.5	33	9.2	30	10.1	33	382	30
Sabana Grande	30	334	26,778	12.5	19	45.8	18	15.0	11	54.0	6	15.9	4	86.5	13	87.1	5	2.1	21	14.4	41	24.6	51	15.0	52	3.0	17	18.0	55	8.9	28	11.9	41	382	30
Corozal	31	511	37,847	13.5	28	58.9	59	16.2	17	77.1	34	22.9	32	86.7	12	84.8	15	1.6	16	10.6	17	15.5	10	7.8	32	5.9	34	13.7	49	3.9	6	7.8	24	385	31
Cidra	32	578	44,745	12.9	23	54.2	40	17.5	27	86.1	56	17.8	8	85.5	19	85.5	11	1.6	16	13.8	38	19.2	32	6.9	26	0.0	1	6.9	22	8.6	26	12.0	42	387	32
Naguabo	32	365	24,010	15.2	42	51.8	32	19.7	35	73.6	26	25.2	39	81.6	38	71.2	59	0.0	1	7.9	2	17.3	19	5.5	19	2.7	15	8.2	31	8.2	23	2.7	6	387	32

Cayey	33	626	47,332	13.2	25	63.3	65	21.1	40	87.1	59	22.8	31	76.2	48	80.2	34	0.6	6	8.9	4	13.9	4	1.6	2	4.8	29	6.4	19	7.9	21	1.6	2	389	33
Mayagüez	33	1007	97,282	10.4	2	50.6	29	17.5	27	69.3	18	24.1	36	79.4	43	83.7	19	1.9	19	13.2	35	17.3	19	6.0	21	1.0	2	7.0	23	19.5	58	10.9	38	389	33
Las Marías	34	114	11,561	9.9	1	36.8	6	24.6	53	39.3	1	31.6	59	85.1	22	82.5	24	0.9	9	14.0	39	19.3	33	8.8	34	0.0	1	8.8	34	8.7	27	17.4	56	399	34
Lares	35	459	35,971	12.8	22	45.3	17	20.5	37	72.3	22	33.6	61	86.3	15	80.1	35	1.1	11	15.9	43	24.4	50	4.4	14	2.2	11	6.5	20	8.6	26	6.5	19	403	35
Santa Isabel	36	398	22,264	17.9	47	56.8	54	18.8	33	88.0	61	21.1	23	72.6	56	72.6	56	0.3	3	9.0	5	19.1	31	5.0	16	0.0	1	5.0	12	2.5	3	2.5	5	406	36
Rincón	37	194	15,515	12.5	19	44.8	16	14.9	10	89.7	64	28.4	53	89.2	3	81.8	26	2.1	21	17.0	45	18.0	24	5.2	18	0.0	1	5.2	14	20.2	59	10.2	34	407	37
Juncos	38	557	38,093	14.6	37	46.0	19	17.1	24	82.1	49	21.4	25	75.6	50	77.3	46	1.3	13	9.7	10	17.8	22	9.0	35	1.8	9	10.8	42	7.1	17	5.4	14	412	38
Fajardo	39	528	41,773	12.6	20	51.3	31	18.8	33	68.7	16	23.1	34	67.8	61	77.5	44	1.1	11	11.9	26	20.8	41	7.6	31	0.0	1	7.6	27	7.5	20	7.6	23	419	39
Coamo	40	505	38,586	13.1	24	56.4	51	23.0	48	81.9	48	22.2	28	83.6	28	78.5	40	0.8	8	10.9	20	20.2	38	5.9	20	2.0	10	7.9	29	7.9	21	4.0	10	423	40
Vieques	40	124	9,241	13.4	27	74.2	72	23.4	50	75.9	31	27.4	50	70.2	59	60.5	67	1.6	16	8.9	4	17.7	21	0.0	1	0.0	1	0.0	1	8.0	22	0.0	1	423	40
Jayuya	41	244	17,775	13.7	29	55.3	47	29.9	59	78.1	37	23.0	33	84.0	25	80.2	34	1.2	12	10.7	18	18.9	29	4.1	11	0.0	1	4.1	8	12.1	41	12.2	43	427	41
Guayanilla	42	320	23,426	13.7	29	54.7	43	18.1	29	81.0	44	26.3	46	73.8	55	76.4	49	1.6	16	9.7	10	18.4	27	6.3	24	0.0	1	6.3	18	6.2	10	9.3	28	429	42
Ciales	43	297	20,251	14.7	38	57.2	55	26.6	56	86.1	56	27.6	51	85.9	17	81.1	28	1.7	17	9.8	11	20.5	40	3.4	8	3.4	21	6.7	21	3.4	5	3.4	8	432	43
Vega Baja	44	968	63,480	15.2	42	58.2	58	22.9	47	83.8	53	27.4	50	84.1	24	77.7	43	0.7	7	9.4	8	17.6	20	5.2	18	0.0	1	5.2	14	9.2	30	6.2	18	433	44
Morovis	45	466	31,261	14.9	40	55.8	48	20.8	39	77.3	35	30.0	56	92.1	1	88.6	2	1.5	15	11.4	23	24.7	52	6.4	25	4.3	27	10.7	41	6.4	12	8.5	27	443	45
Aibonito	46	415	26,841	15.5	45	64.1	66	22.4	45	91.4	69	18.8	12	76.4	47	82.4	25	0.5	5	12.3	30	14.5	5	4.8	15	2.4	13	7.2	25	11.9	40	2.4	4	446	46
Guánica	47	299	22,371	13.4	27	55.2	46	15.4	12	73.9	27	25.4	41	83.9	26	80.6	32	2.0	20	14.4	41	22.1	45	13.4	46	0.0	1	13.4	47	6.6	13	10.0	32	456	47
Juana Díaz	48	709	51,898	13.7	29	56.7	53	18.3	31	86.2	57	19.6	17	82.4	34	77.4	45	1.1	11	13.4	37	18.8	28	8.5	33	1.4	5	9.9	36	7.0	16	9.8	31	463	48
Patillas	49	270	20,220	13.4	27	56.3	50	22.6	46	88.5	62	24.8	38	86.7	12	68.8	60	1.9	19	13.3	36	16.3	13	0.0	1	0.0	1	0.0	1	14.6	49	14.6	50	465	49
Gurabo	50	548	39,078	14.0	32	44.0	14	17.2	25	74.5	30	19.2	15	83.9	26	83.5	20	1.5	15	14.8	42	21.7	43	14.6	51	3.6	23	18.2	56	9.0	29	12.7	45	466	50
Luquillo	51	290	20,256	14.3	35	54.1	39	23.1	49	80.6	43	27.9	52	68.6	60	74.0	54	1.4	14	10.7	18	17.9	23	3.4	8	0.0	1	3.4	6	13.6	47	6.9	21	470	51
Río Grande	52	753	54,205	13.9	31	46.6	21	17.0	23	73.4	25	20.6	20	72.6	56	75.8	50	1.5	15	11.7	25	20.3	39	13.3	45	1.3	4	14.6	50	11.8	39	9.3	28	471	52
Lajas	53	283	27,105	10.4	2	51.2	30	13.8	6	69.2	17	27.2	49	82.0	35	80.6	32	2.5	23	12.4	31	19.8	36	21.2	56	3.5	22	24.7	63	10.5	36	14.1	48	486	53
Peñuelas	54	385	27,902	13.8	30	54.5	42	20.5	37	78.5	39	29.9	55	83.4	30	80.8	30	2.3	22	12.7	33	17.7	21	10.4	39	0.0	1	10.4	38	15.3	51	10.4	36	504	54
Yauco	55	581	47,516	12.2	16	50.1	28	17.9	28	76.9	33	21.3	24	81.8	37	79.0	39	1.9	19	13.4	37	19.3	33	17.2	55	3.4	21	20.7	60	8.5	25	15.4	53	508	55
San Juan	56	5492	430,942	12.7	21	62.2	62	16.6	20	87.0	58	27.1	48	79.8	42	76.9	47	1.4	14	11.9	26	18.0	24	7.1	27	3.5	22	10.6	40	10.6	37	10.3	35	523	56
Maricao	57	74	6,476	11.4	8	50.0	27	25.7	54	63.2	13	39.2	63	82.4	34	79.7	37	0.0	1	17.6	46	25.7	54	13.5	47	0.0	1	13.5	48	13.3	46	13.5	47	526	57
Vega Alta	58	542	38,757	14.0	32	56.6	52	19.2	34	82.7	50	22.5	30	74.5	53	77.8	42	1.8	18	10.3	14	16.2	12	16.6	54	3.7	24	20.3	58	7.3	19	11.0	39	531	58
Ponce	59	2529	185,009	13.7	29	57.3	56	18.5	32	81.2	45	25.2	39	80.0	41	76.4	49	1.7	17	13.0	34	22.1	45	7.5	30	1.6	7	9.1	35	12.5	43	9.8	31	533	59
Manatí	60	671	47,329	14.2	34	52.8	35	21.5	42	70.1	19	21.8	26	83.2	31	79.7	37	1.8	18	10.0	12	17.9	23	13.4	46	7.5	36	20.9	61	19.0	57	20.6	59	536	60
Barranquitas	61	441	29,742	14.8	39	67.8	69	22.2	44	90.8	68	26.1	45	86.8	11	83.0	21	1.4	14	9.8	11	13.6	3	13.6	48	2.3	12	15.9	52	17.8	54	15.8	54	545	61
Comerio	62	277	19,783	14.0	32	63.2	64	21.3	41	89.8	65	29.6	54	81.9	36	79.1	38	1.8	18	14.4	41	14.8	6	7.2	28	0.0	1	7.2	25	14.2	48	14.3	49	546	62
Orocovis	63	323	24,556	13.2	25	65.0	67	28.5	58	93.5	70	26.9	47	71.5	57	73.7	55	1.5	15	10.5	16	13.9	4	15.5	53	0.0	1	15.5	51	3.1	4	9.3	28	551	63
Loíza	64	366	33,334	11.0	5	70.2	70	27.3	57	89.0	63	30.9	57	66.9	62	66.4	62	2.5	23	16.7	44	21.6	42	2.7	5	0.0	1	2.7	3	10.8	38	8.2	25	557	64
Guayama	65	678	44,888	15.1	41	60.9	61	22.4	45	86.2	57	27.9	52	83.8	27	64.9	63	1.3	13	10.0	12	13.4	2	11.8	42	1.5	6	13.3	46	16.0	52	14.7	51	570	65
Cataño	66	419	28,396	14.8	39	74.2	72	21.7	43	90.1	66	35.8	62	75.9	49	76.4	49	1.4	14	11.9	26	16.7	14	2.4	4	4.8	29	7.2	25	16.4	53	9.5	30	575	66
Maunabo	67	159	12,808	12.4	18	72.3	71	24.5	52	87.2	60	18.2	9	71.1	58	64.2	65	2.5	23	10.1	13	17.0	17	12.6	44	12.6	39	25.2	64	0.0	1	12.6	44	578	67
Arroyo	68	292	19,071	15.3	43	63.0	63	24.3	51	83.1	52	25.7	43	80.8	40	67.1	61	1.7	17	10.6	17	16.1	11	10.3	38	10.3	38	20.5	59	6.8	14	10.2	34	581	68
Canóvanas	69	697	45,129	15.4	44	57.7	57	20.7	38	81.9	48	24.2	37	75.3	52	75.4	51	3.0	24	12.1	28	18.8	28	10.0	37	1.4	5	11.5	44	12.7	44	12.9	46	583	69
Adjuntas	70	212	18,935	11.2	7	53.3	37	23.1	49	79.6	41	31.1	58	83.5	29	81.6	27	1.9	19	17.0	45	25.0	53	14.2	50	4.7	28	18.9	57	18.5	56	9.4	29	585	70
Yabucoa	70	554	39,859	13.9	31	59.2	60	20.0	36	85.6	55	25.3	40	78.7	44	64.7	64	1.8	18	11.9	26	17.9	23	10.8	41	5.4	31	16.2	54	7.2	18	12.6	44	585	70
Humacao	71	825	59,897	13.8	30	57.7	57	16.5	19	81.6	47	20.8	21	82.8	33	71.7	58	1.2	12	12.7	33	18.3	26	12.1	43	6.1	35	18.2	56	20.2	59	18.0	57	586	71
Salinas	72	435	31,788	13.7	29	67.1	68	26.0	55	90.3	67	32.2	60	75.9	49	60.6	66	1.4	14	10.3	14	17.9	23	13.8</											

Table II-2

Number and Percent of Children of the Total Population by Age Groups

Ages	1970	1980	1990	2000⁽²⁾	2004⁽³⁾	Percent of Total Population (2004)
1 - 4 ⁽¹⁾	251,162	267,592	250,436	295,406	215,873	5.5
5 - 9	138,800	330,331	316,991	305,162	294,373	7.6
10 - 14	335,100	338,291	340,128	305,800	304,874	7.8
15 - 19	291,800	337,134	327,251	313,436	299,286	7.7
Total 1 – 19	1,216,682	1,273,348	1,234,806	1,219,804	1,114,406	28.6
Total Population	2,716,000	3,203,956	3,527,76	3,808,610	3,894,855	

Table II – 3. Number of patients 0-21 years old with a special condition reported by ASES, the Health Insurance Commissioner Office and PININES for 2004

Health Condition	ASES	HICO	PININES
Bronchial Asthma	35,326	4,961	9,646
Congenital Anomalies	26,539	6,503	983
Diabetes Mellitus	24,950	2,111*	360*
Mental Disorders	24,251	19,078	1,163

* According to HICO, Diabetes Mellitus (DM) was the sixth most frequent condition, while PININES data shows that DM was number eight in frequency.

** According to PININES sensorial disorders was the third most frequent condition in children 0-21.

Table II – 4. Estimated Prevalence of Mental Disorders in Children 4-17 years old in Puerto Rico

Type of Disorder	Estimated Prevalence
Any Diagnosis	16.4%
Attention Deficit/Hyperactivity Disorder	8.0%
Oppositional Defiant Disorder	5.5%
Separation Anxiety	3.1%
Major Depression	3.0%
Conduct Disorder	2.0%

Data Source: Canino Glorisa, et al. The DSM-IV Rates of Child and Adolescent Disorders in Puerto Rico. Arch Gen Psychiatry, 2001; 61: 85-93. The study was performed during the period of January 1999 and December 2000 with the 4-17 years old population, n=1,897. DSM=Diagnostic and Statistical Manual of Mental Disorders (diagnostic criteria).

Table II – 5. Developmental Disability Rates in Puerto Rico Distributed by Age Group.

Developmental Disability	Rate per 10,000 population					
	Children < 6 years old		6-16 years old		17-22 years old	
	Male	Female	Male	Female	Male	Female
Mental Retardation	4.9	2.6	101.8	37	140	41.1
Down Syndrome	14.6	0	1.9	8.7	0	0
Autism	7.5	0	14.9	26	0.4	0.6
Attention Deficit Disorder	28.8	14.1	173.3	24.8	3	0
Cerebral Palsy	0	6.1	2.3	9.2	6.6	8.8
Spina Bifida	3.3	8.8	3.1	7.3	0.5	3.1
Muscular Dystrophy	0	0	1.7	1.6	0	2.3

Data Source: PR Health Interview Survey, 2001, Collaborative Project between the PR Department of Health And the Graduate School of Public Health of the University of Puerto Rico.

Table II – 6. Summary of children 3-21 years with disabilities enrolled in the PR Special Education Program by impairment. Academic Year 2004-2005

Impairment	Number	Percent
Specific learning disabilities	46370	53
Speech and language disorders	19575	22
Mental Retardation	11910	14
Chronic health conditions	3868	4
Multiple disabilities	1378	2
Autism	1013	1
Emotional conditions	978	1
Hearing disabilities	933	1

Table II – 7. Pediatric Medical Specialists and Subspecialties Islandwide.

PROFESSIONAL	NUMBER
Pediatricians	952
Neonatologists	45
Pneumologists	76
Psychiatrists	47
Cardiologists	18
Endocrinologists	11
Nephrologists	8
Neurosurgeons	25
Orthopedists	97
Pediatric Surgeons	5

Table II – 8. Other programs and resources for CSHCN.

ORGANIZATION	SERVICES PROVIDED
D.A.R. Foundation	Helps in the rehabilitation of children in Puerto Rico. Provides assistance to receive medical services not available in PR.
I.N.S.E.C.: Community Services Institute	Mentoring services, eyeglasses, medicines, home improvement.
Spina Bifida and Hydrocephaly Association	For children and youth younger than 25 years. Physical and occupational therapy services, nursing, trainings and others.
San Juan Handicap Services Program	Mentoring and referrals to need areas to handicap children and adults living in San Juan.
Children’s Hospital in Guaynabo	Speech/ language and occupational therapies for children.
Muscular Dystrophy Association	Evaluation services of about 40 different neuromuscular conditions.
Nuestros Corazones Unidos	Equipments, medicines, laboratories and medical services for children under 18 years. This association provides financial assistance when surgeries can not be performed in Puerto Rico.
Office of the Ombudsman for Persons with Disabilities	Advocacy office for persons with disabilities; for filing of complaints of the public and private sectors.
Office of the Patients’ Ombudsman	Is responsible to ensure that patients’ rights and responsibilities under Law # 194 (Patients’ Bill of Rights and Responsibilities) are enforced.
Catastrophic Illnesses Funds	Legislative funds to address medically necessary services not available in PR.