



State Title V Block Grant Narrative

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Sections 5.4 – 5.7, containing standard forms and detailed descriptions of national and State performance and outcome measures, are not included in this PDF. Data from these sections can be viewed in interactive formats on the Title V Information System Web site (<http://www.mchdata.net>).

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I. COMMON REQUIREMENTS FOR APPLICATION AND ANNUAL REPORT

1.4 Overview of the State

The State of Hawai`i is composed of seven populated islands located in four major counties (Appendix A). Our population experiences special problems accessing health care because of the island topography of the state. Approximately 80% of the adult population and 70% of children reside in the City and County of Honolulu on the island of O`ahu. The neighbor island counties are Hawai`i, Kaua`i (includes Ni`ihau) and Maui (includes Moloka`i and Lana`i). Only 10% of the state's total area is classified as urban. The City and County of Honolulu is the most urbanized with a third of its land area and 96% of its population in urban communities. The majority of tertiary health care facilities, specialty and subspecialty services are located on O`ahu. Consequently, neighbor island and rural O`ahu residents often must travel to Honolulu for these services. This creates a financial barrier for neighbor island residents as round-trip airfare is about \$120. Geographic access is further limited because public transportation is inadequate in all areas of the state except for the city of Honolulu. Residents in rural communities, especially on the neighbor islands, need an automobile in order to travel to major population centers where hospital, speciality, and subspecialty services are available. Access to emergency care on neighbor islands often requires the use of helicopters or fixed-wing aircraft.

The ethnic composition of the state's population is very heterogeneous and no single ethnic majority emerges. Caucasian, Japanese, Filipino, and Part-Hawaiian are the largest ethnic groups and their proportions differ by county. These four ethnic groups combined represent about 83% of the state's population. Because of this ethnic diversity, there are a number of people who speak English as a second language (ESL). In 1997, approximately 7.2% of the state's public elementary school children were enrolled in the Students with Limited English Proficiency Program, an increase from 5.2% in 1993. According to a 1999 report of the Governor's Council on Literacy, 154,000 or more than 20% of Hawaii's adults are functionally illiterate.

While the rest of the nation has enjoyed a booming economy, Hawai`i has been in an economic slump for almost a decade, at least partially due to the Asian economic crisis. It is only now showing tentative signs of recovery with higher tax revenues and increased tourism numbers. However, many families have already moved to other states

in their search of improved economic opportunities. The National Governors' Association reported in a 1999 survey conducted with the National Association of State Budget Officers that Hawai'i and Alaska were the only states to cut their state budgets. This poor economic environment has significantly impacted families since Hawaii's cost of living is 30% to 40% higher than that of the rest of the nation. Unfortunately, the state legislative session ended in May 2000 with no significant progress in addressing the state's economy. The Felix v. Cayetano consent decree relating to mental health services for children and adolescents continues to take priority in the Department of Health budget. Over the past five years, the Title V program has been negatively affected by decreased funding and loss of positions. The effects are detailed in the section on program capacity.

Another indicator of these poor economic conditions can be seen in the increased numbers of children enrolled in Hawaii's public schools' free lunch program. In 1999, 49% of the public elementary students and 37% of the intermediate and high school students received free or reduced-price lunches. These were significant increases over rates during the 1993 school year, which were 38% and 20% respectively.

The full impact of welfare reform has not yet been felt for low-income populations. The First-to-Work (FTW) Program serving parents receiving Temporary Assistance to Needy Families (TANF) has been active with 14,610 clients entering the FTW program over the past five years. In FY 1999 alone, 405 FTW participants exited TANF due to employment. Hawai'i responded to the federal Welfare Reform Initiative passed in August of 1996 by creating a TANF waiver referred to as PONO (Pursuit of New Opportunities). One of the objectives of PONO is to cut welfare grants and to increase the earnings ceiling. Of the approximately 20,825 cases in the TANF system, 14,227 clients are expected to be able to enter the work force. All "able-bodied" TANF recipients experienced a 20% reduction in their cash benefits in the first year of the PONO program. Those individuals who are currently employed while in the program (about 10,018 individuals) have been able to earn back this 20% reduction, as well as an additional amount of allowed income, and are therefore in improved economic shape. An additional group of over 1,000 recipients are obtaining job experience with volunteer placements. However, they do not have supplemental income to offset the decrease in cash assistance and have experienced a degree of economic hardship. Anecdotal reports

from Hawai'i Food Bank and other philanthropic organizations indicated an increase in requests for emergency assistance from low-income families. The public-private non-profit organization Good Beginnings Alliance is working actively to develop increased availability of early childhood education and care in both center-based and family-centered settings throughout the state.

Hawai'i has historically had a large proportion of its population covered by some form of health insurance. According to provisional data from the 1999 Hawai'i Health Survey conducted by the DOH Office of Health Status Monitoring, 6.2% of the state's population is uninsured. There has been a major trend toward managed health care both in the public and private sectors. However, economic changes have led to a tightening of the eligibility within the QUEST program (1115 waiver managed care demonstration project) which began in August 1994. The result has been a major fall in enrollment from the high of 160,000 in January 1996 to the current level of 124,000 individuals. Changes in eligibility, increases in the premium cost share, establishment of an assets test, and cuts in benefits occurred in 1995 and 1996.

A Phase II waiver amendment request has been submitted by the Med-QUEST Division of the Department of Human Services to the Health Care Financing Administration. The amendment will incorporate some of the Medicaid Aged, Blind, and Disabled (ABD) beneficiaries into the existing QUEST program. Disabled and blind children under the age of 19, persons residing in institutions, and persons out-of-state will be enrolled later. Persons who are dually-eligible for both Medicare and Medicaid will have the option of enrolling. When Phase II is implemented, all adult members (including those who are aged, blind, and disabled) will be enrolled into separate medical, dental, and behavioral health managed care plans.

The Department of Human Services (DHS) is the lead agency in Hawai'i for the State Child Health Insurance Program (SCHIP). Hawaii's SCHIP plan requesting a Medicaid managed care expansion program was approved in 1998 by the Health Care Financing Agency with a proposed implementation date of February 2000. A plan amendment was subsequently submitted but has not been approved. Despite this, Hawaii's SCHIP program began on July 1, 2000, and covers all children under 19 years of age with family incomes up to 200% of the Federal Poverty Level (FPL) for Hawai'i. There is no waiting period for SCHIP eligibility. Hawaii's economic recession

negatively affected the SCHIP program, as the 1998 Hawai'i State Legislature did not allocate state match monies earmarked specifically for SCHIP. The state match is funded by a portion of Hawaii's share of the Tobacco Settlement.

Under the QUEST program, infants under one year were eligible up to 185% FPL; children under 6 years up to 133% FPL; 6 to 16 years up to 100% FPL; and 17 to 18 years up to 62.5% FPL. There is no assets test for those children born after September 30, 1983. Children who are legal immigrants arriving after August 1996, refugees and those born in the Marshall Islands and Federated States of Micronesia and Palau are also eligible under both SCHIP and QUEST effective July 1, 2000.

1.5 The State Title V Agency

1.5.1 The State Agency Capacity

1.5.1.1 Organizational Structure

Family Health Services Division continues to anticipate reorganization within the Department of Health. In November 1998, Governor Benjamin Cayetano was re-elected for a second four-year term. He appointed Dr. Bruce Anderson, an environmentally-trained public health administrator, as his Director of Health and Dr. Virginia Pressler, a physician with wide-ranging experience including health plan administration and leadership in the Coalition for a Tobacco Free Hawai'i, as Deputy Director of Health Resources.

Drs. Anderson and Pressler have committed to reorganizing the Department of Health in a manner that will support their vision of Hawai'i as the leading health and wellness center of the Pacific and to support accomplishing Hawaii's goals related to improving the health status of Hawaii's population. It is clear at this point that there will not be a department-wide reorganization. It is anticipated that by the end of the calendar year, the Family Health Services Division will complete its reorganization. Attached are the current DOH and State of Hawai'i organizational charts (Appendix B and C).

1.5.1.2 Program Capacity

Family Health Services Division has worked vigorously to gather timely, reliable data regarding the health of our state's families to assure that needs are met by effective communication to the state legislature and by obtaining additional federal and private resources to supplement available state funds. The State of Hawai'i has health statistics that are reasonable by comparison to national standards; however, significant disparities exist between geographic regions within the state and between different ethnic groups. FHSD has accepted responsibility for identifying and addressing these disparities as they relate to the health of our women, children, and families.

The current administration has placed a priority on data and the tracking of health outcomes. Tobacco Settlement funds will be used to fund an Outcomes Institute in conjunction with the School of Medicine. Similarly, FHSD has tried to enhance program efficiency and effectiveness by:

- **Enhancing Data Capacity** through increased partnerships with our Office of Health Status Monitoring; investing SSDI and Title V resources into the Hawai'i Health Survey, the Middle School Youth Behavior Risk Survey, and others; maximizing use of our CDC-Title V funded MCH epidemiologist; obtaining additional training and skill development through participation in the CityMatCH Data Use Institute and Periods of Risk Analysis with the National Working Group on Urban Maternal and Child Health Assessment. The division has contracted with a private firm to develop its Early Intervention Data Management System.
- **Partnering within FHSD and DOH** for maximum impact in such areas as adolescent and school health (with Community Health Nursing Division and Alcohol and Drug Abuse Division, Injury Prevention Program, Communicable Disease Division) and early intervention services (with Community Health Nursing Division).
- **Partnering across department lines** within such activities as *Partnering to Improve Children's Outcomes* and our *Perinatal Consortium*. *Partnering to Improve Children's Outcomes* is developing

a system to collect data related to school readiness and childhood asthma.

Dr. Cheryl Prince, an MCH epidemiologist who is field-deployed by CDC Division of Reproductive Health to Hawai`i, is working with FHSD to implement several projects including Child Death Review, PRAMS (Pregnancy Risk Assessment Monitoring System), and Periods of Risk Fetal and Infant Mortality Analysis. Dr. Prince also contributed significantly to development of our state's grant proposal in response to the Healthy Start Initiative Eliminating Racial/Ethnic Disparities in Perinatal Health and Perinatal Integrated Data Utilization grant applications.

Hawaii's Women, Infant and Children (WIC) program has flourished in recent years under the leadership of Ms. Fay Nakamoto who has been acknowledged for her capable program administration by being granted the 1999 National Governor's Association Award for Distinguished Service to State Government. Under her leadership, the WIC program continues to increase in capacity. Contract services to primary care/community health centers have provided increased integrated health center services capacity. Participation of eligible low-income women, infants, and children increased by 30% to over 35,000 participants at the end of fiscal year 1999. Because of this increase and because Hawai`i is a "under fair share" state, we have received increased federal funding as a priority Western Region WIC Program. The additional financial resources have assisted Hawai`i to move toward its goal of providing nutritional services to an estimated 41,000 eligible persons statewide. The increased penetration and stability of the WIC program, as well as its newly implemented statewide automated data processing and client tracking system, will increasingly allow collaboration between the WIC program and other MCH programs to forward objectives relating to childhood immunizations, breastfeeding, oral health, and assuring health insurance for low income children and mothers.

During the past year, Hawaii's WIC program has increased capacity with two new initiatives. The Paraprofessional Competent Professional Authority (PCPA) training program will certify a mid-level nutrition assistant staff to do participant certifications once reserved only for Public Health Nutritionists.

WIC is developing a new State/Federal partnership with the Department of Defense (NAVY) for a pilot Electronic Benefits/Electronic Service Delivery System for its active personnel and dependents. Some of the partners include the State, Western Governor's Association, General Services Administration, United States Department of Agriculture and Defense Commissary Agency. This project will show the interoperability and integration of services using a new card technology which could be transferred to the community at large.

Partnering to Improve Children's Outcomes is a grant from the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services. FHSD Chief is the principal investigator on this grant which provided resources for collaboration between the Departments of Health, Human Services, Education; the Governor's Office; the University of Hawai'i Center on the Family, and the Good Beginnings Alliance (a 501C organization dedicated to improving early childhood education and care). The objectives of this grant and the activities spawned by this collaboration are discussed in more detail under Section 1.5.1.3 Other Capacity.

The 1999 Session of the Hawai'i State Legislature provided level funding for most maternal and child health programs. Notable exceptions were the \$1.7 million in additional funding provided to augment existing funds for safety net ambulatory care services to uninsured persons statewide and \$1.6 million in supplemental funds to provide additional, mandated early intervention services under IDEA Part C to infants and children up to three years of age. However, anticipated budgetary shortfalls resulted in a restriction of half of these funds only to be reinstated in June when tax revenues improved. FHSD has worked to maximize federal cost share for EPSDT-related services to Medicaid eligible children. Approximately \$300,000 in state infrastructure funds were obtained to support this process. Since September 1997, the State of Hawai'i has received \$3.7 million in federal reimbursements under the Medicaid Early Intervention Carve Out. This resource has been a critical support in light of increasing needs and limitations to increases in state funding related to the prolonged recession.

1.5.1.3 Other Capacity

Availability of fiscal and administrative resources for Title V programs continue to be challenged by the mandatory investment of resources directed toward settlement of two separate federal court suits against the Hawai`i State Government for failure to provide adequate mental health services: the Department of Justice suit against the Adult Mental Health Division relating to inadequate services at Hawai`i State Hospital and an IDEA lawsuit settled by the Felix v. Cayetano consent decree for failure to provide adequate mental health supports to children with disabilities. The Department of Health has proposed formal closure of the Hawai`i State Hospital in order to provide adequate resources for a statewide system of community-based mental health services with necessary inpatient services being provided by existing resources within the private sector. Regarding the Felix v. Cayetano consent decree, the new Superintendent of Education and Director of Health are collaborating to create system changes which will provide school-based services for the majority of children who require mental health or behavioral supports in order to benefit from their education. In June, the State was found in contempt as it did not meet the June 30, 2000, compliance deadline. A revised implementation plan has been submitted to the court which includes an additional \$2.7 million for Early Intervention Services.

The *Partnering to Improve Children's Outcomes* grant has several objectives:

- to identify a common set of indicators (which have the endorsement and commitment of key public and private entities in Hawai`i) on the health and early childhood education and care of children from birth to five years of age, with special focus on those who receive or have left welfare or are homeless.
- to establish a data collection and reporting system on the common indicators that will have long-term sustainability.
- to develop a mechanism for affecting social policy through the use of indicator-based data to improve the health and educational outcomes of Hawaii's poorest young children.

A process which included building on previous public and private efforts that had wide community input and consensus has produced the following goals and indicators for this project. The unifying goal has been established as:

All of Hawaii's children will be safe, healthy, and ready to succeed in school.

The core indicators that will be tracked to assess progress toward this goal are:

- rate of unintentional injuries for which emergency room treatment is received
- rate of child abuse and neglect (reported and confirmed)
- percent of children covered by health insurance
- percent of properly immunized two year olds
- percent of children in early childhood education and care settings who receive a nutritious breakfast
- child poverty rates
- teen birth rate
- school readiness

Clearly, there has been significant contribution from our national Title V performance measures. However, there are other pertinent issues included here which are relevant to assuring overall health (in its broadest definition). The dialogue and networking provided by meeting of the Partner's Council has allowed efficiencies of data collection to occur (use of Hawai'i Health Survey to obtain statewide data on health insurance coverage for children benefitting both Departments of Health and Human Services; Hawai'i Health Survey to obtain data on child care and hunger) and spawned other collaborative projects such as Hawaii's successful National Partnership for Reinventing Government Boost 4 Kids proposal and Breakfast Program. The Breakfast Program (whose goal is to assure that all children under five years of age in group early childhood education and care settings receive a nutritious breakfast) is a pilot program which has provided a synergistic forum for multiple agencies to collaborate and identify/bust bureaucratic barriers. New Initiatives under the partnership include:

- the development of school readiness indicators
- the development of a core set of indicators to rank communities by school districts
- asthma public education and data collection system

Hawaii's families will have one important resource for health promotion over the next decade. SB 1034, 1999 State Legislative Session, stipulates management of funds received from the national tobacco settlement and will provide critical resources for tobacco control and public health measures. A full 60% of the tobacco settlement monies received by the State of Hawai'i will be used for public health purposes with the rest of the money to be used by the state government as a "rainy day fund." Placed under the administration of a public non-profit coalition for statewide tobacco control activities will be 25% of the receipts. Another 10% of the receipts will be made available for the required state match for implementation and expansion of the SCHIP program. A final 25% of the receipts will be provided to the Department of Health for strengthening of programs supporting improved nutrition, physical fitness, and maternal and child health. Our department's Deputy Director of Health Resources will be leading a community-based strategic planning effort to assure effective and appropriate management of these funds. Child Abuse Prevention has been a focus of Tobacco Settlement Funds for this 2000 fiscal year. Hawai'i Children's Trust Fund will receive \$250,000 and \$3.1 million has been appropriated to the state's Healthy Start Program. Receipt of money from the national tobacco settlement is anticipated to begin in 2001 pending settlement of ongoing appeals. Clearly, these funds will be a critical, potential resource toward assuring maternal and child health in our state.

1.5.2 State Agency Coordination

The Title V program participates in a network of coalitions, advisory groups and planning efforts throughout the state. The majority of these planning efforts include input between different Departments of state government as well as between various Divisions and Branches within the Department of Health. For example, the Title V program collaborates with the Department of Education, Department of Human Services, Judiciary, Office of Youth Services, and the Children and Youth Services personnel in

the Governor's Office, as well as working with the District Health Offices and various Divisions (Community Health Nursing, Child and Adolescent Mental Health, Alcohol and Drug Abuse, Communicable Disease, Emergency Medical Services, Office of Health Status Monitoring, and State Health Planning Agency) within the Department of Health. The Title V program will work toward consolidation of these groups over the next year. Examples of public and private collaboration follow:

- The **Hawai'i Early Intervention Coordinating Council (HEICC)** advises the Director of Health on issues related to the planning, implementation, evaluation, and monitoring of the statewide system of early intervention services, and assists the Department of Health in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the state. Council functions include: 1) to advise and assist the Department of Health in planning a statewide system of early intervention services, identifying sources of fiscal and other support for services, assigning financial responsibility to the appropriate agency, and promoting interagency agreements; 2) to advise and assist the Department of Health in the preparation of applications and amendments; and 3) to prepare and submit an annual report to the Governor and to the Secretary of the U.S. Department of Education on the status of early intervention programs for handicapped infants and toddlers and their families within the state. Members are appointed by the Governor and include: parents of children with disabilities under age 6 years, providers of early intervention services, legislator, pediatrician, Governor's Special Assistant on Children and Families, and representatives from the Department of Education, Department of Human Services, University of Hawai'i College of Education, and a health insurance company. In addition, a member of the Federal Intervention Coordinating Council serves as an ex-officio member on the HEICC.
- The **Special Education Advisory Council (SEAC)** is an advisory committee to the Superintendent of Education for policies on any issues in the education of students with disabilities. Appointed membership as specified in the Individuals with Disabilities Education Act includes representative of consumer advocate groups, parents, individuals with disabilities, regular and special education personnel, Departments of Health and Human Services, and University of

Hawai`i. The Council has been actively working with the Department of Education (DOE) and voicing its concerns about enhancing the work environment and in the recruitment and retention of qualified special education teachers and other support staff. The Council is working with the DOE in its implementation plan for comprehensive student support system (CSSS) and of school-based mental health services, training initiatives, and assuring that educational needs of special education students within the Justice System are being addressed.

- The **Screening Instrument Task Force** is an ad hoc committee that is exploring and identifying developmental and behavioral-social-emotional screening tools that may fit the various needs of Hawaii's zero through five-year-old population and agencies serving them and allow the largest number of children access to screening. It is comprised of representatives from the Department of Education, Department of Health, Good Beginnings Alliance, Head Start, Parents and Children Together, Kamehameha Schools/Bishop Estate (a system of more than 30 preschools for children of Hawaiian ancestry statewide), and Tripler Army Medical Center Department of Pediatrics. The committee is reviewing various tools and selecting tools for closer review, trialing, and evaluation. Recommendations are presented to the **Early Childhood Screening Instrument Steering Committee** for discussion and decision making.
- The **Newborn Metabolic Screening Advisory Committee** consists of consumers and professionals (physicians, laboratory personnel, nurses from various birthing facilities, medical insurance plan representatives, parents, and other Department of Health representatives) from the private and public sectors who are involved with or have an interest in newborn metabolic screening. The committee serves in an advisory capacity to the Hawai`i Newborn Metabolic Screening Program. The committee's purposes are to improve coordination and communication among the DOH programs, health care providers, birthing facilities, laboratories, medical insurance plans, and parents; provide support, guidance, and feedback to DOH about newborn screening; disseminate information about newborn screening to colleagues and the community; monitor accountability and quality of the newborn screening program; and discuss ideas

and issues relevant to newborn screening. The committee played an integral role in the planning and development of expanded newborn screening which was implemented in July 1997. It will continue to have an important role with future changes which may include the development of national standards, new technology, or more cost-effective methods for screening for additional disorders.

- The **Hawai'i Birth Defects Program (HBDP) Advisory Committee** is composed of twenty professionals whose members include representatives from the community, medical, university, and public and private sectors. These members offer scientific guidance and input into the program and have expertise in the areas of children with special health needs, direct delivery of service to the community, epidemiology and research, family health services, fetal diagnosis, genetics, health information management, maternal and child health, neonatology, nursing, pediatrics, perinatology, public health, and fetal/pediatric ultrasonography. Members of the HBDP Advisory Committee have served as principal investigators for HBDP programs, grants and awards, and have represented the University of Hawai'i, a non-profit research entity, a community birth defects education and outreach program, and the Department of Health.
- The **Folic Acid Committee** includes the Department of Health, March of Dimes, University of Hawai'i, Kapiolani Medical Center, Queen's Medical Center, Shriners Hospital for Children, and other agencies to collaboratively provide folic acid education.
- The **State Genetics Advisory Committee** consists of representatives from public health, health care organizations, consumers, laboratories, March of Dimes, and

the insurance industry. The Advisory Committee advises the Department of Health about new genetics activities and help disseminate information about these activities.

- The **Pacific Southwest Regional Genetics Network (PSRGN)** represents California, Hawai`i, and Nevada. The goal of PSRGN is to enhance and promote genetics activities in the region and each of the states. PSRGN has enabled Hawai`i to provide genetics education to primary care providers, public health professionals, judges, legislative staff, and the general public. PSRGN has also allowed Hawai`i to participate in more broad-based educational campaigns such as development and distribution of the regional folic acid poster and brochure and the annual regional genetics conference. PSRGN supported a Hawai`i conference “The Impact of Genetics on Public Health - Putting the Pieces Together” in July 2000 for public health professionals and others interested in public health practice. Information was presented on the Human Genome Project and impact on public health practice, genetic testing, genetics legislation at the state and national level, ethical and social issues with genetic testing, and resources for genetic information, referral, and testing.
- The **State Nutrition Advisory Committee** focuses on improving access and availability of quality, coordinated nutrition services to CSHCN by promoting communication and collaboration among public and private providers of these services, identifying gaps/weaknesses in the delivery of nutrition services, developing and implementing coordinated intervention strategies, and identifying training needs for parents/caregivers, health providers, and school staff related to nutrition and feeding problems among CSHCN. Members include representatives from the Department of Health, Department of Education, hospitals/medical centers, University of Hawai`i School of Public Health, University Affiliated Program, a community health center, and a parent. The committee revised a Department of Education form for children in need of special/modified meals from the School Food Service Program; assisted with planning, coordinating, and

distribution of information regarding nutrition/feeding workshops, teleconferences, parent conferences; and promoted and supported inservice training to health care providers.

- The **School Health Advisory Council (SHAC)** was developed to be an advisory committee to the Superintendent of Education and Director of Health for policies relating to school health and child and adolescent health. With a change in Branch structure, efforts are being taken to re-evaluate the structure and functions of SHAC with its recommendations of early identification/risk assessment, K-12 health education curricula, and comprehensive school health programming as key strategies.
- The **Weed and Seed Project** (a project to expel crime and develop protective, support factors for the Kalihi Palama Community) was supported through a youth mapping project providing a Comprehensive Student Support System resource directory (within the Weed and Seed Project area) and supporting a School Health Advisory Council recommendation to “maximize existing resources to support prevention-based enhancement of CSSS.”
- The **Hawai'i Teen Pregnancy, Prevention and Parenting Council (HTPPC)** has continued since 1980 to meet quarterly as a network of public and private agencies and individuals (Collaborators) dedicated to improving public information and interagency communication around issues of teen pregnancy prevention and parenting. Efforts are being taken in HTPPC activities (meetings, trainings) to be inclusive of Laulima In Action (and Healthy People 2000 and 2010) in state and community-based efforts.
- An interagency Team of **Collaborators** continues to focus on coordinated public/private partnerships to support adolescent wellness and teen pregnancy prevention through statewide technical assistance workshops, CityMatCH workgroup, HTPPC, and community teams in May Teen Pregnancy Month and development of products/activities to be used beyond this time frame (public service announcements, book covers, legislative fact sheets, calendar of events).
- **Harm Reduction Hawai'i** (a coalition made up of public and private agencies focusing on a continuum of prevention and intervention regarding substance abuse, sexually transmitted diseases, and family planning) continued to meet

quarterly, as well as to hold statewide trainings both to orient service providers to the concepts of harm reduction and to further educate those already implementing them.

- The Adolescent Survey Committee also coordinates with some of the interests of Hawai'i Net - **HINET**, a group of Hawai'i agencies that administer federal grants and are concerned with integrated adolescent data sources.
- The “**Basic Concepts In Identifying the Health Needs of Adolescents**” **trainers** continue to be available throughout three of the counties. A variety of activities support the continuation of the Basic Concepts including trainer, agency efforts and grant integration. The Community Adolescent Program will continue to seek partnerships to support the expansion of trainers and trainings, as it is one of the strategies of the Hawai'i Adolescent Wellness Plan, “Laulima In Action.”
- **Early and Periodic Screening Diagnosis and Treatment (EPSDT)** - Family Health Services Division (FHSD) continues to collaborate with other agencies regarding child health issues in common, including immunizations, utilization of services, and lead screening. Recent agreement between the Medicaid Agency, the Department of Health, Environmental Management personnel, and Maternal and Child Health Branch personnel resulted in a coordinated statewide response to children with elevated lead levels. The EPSDT Coordinators of the various managed care plans are also partners in this endeavor.
- **Hawai'i State Child Death Review Council** is a voluntary public-private partnership formulated in 1996 through the leadership of the Department of Health (DOH), Family Health Services Division, to establish a comprehensive, statewide, multidisciplinary child death review system to reduce preventable child deaths from birth to age 18. In 1997, Act 369 of the Hawai'i Revised Statutes, authorized the DOH to conduct child death reviews through standardized procedures to identify causes of death and recommend policies and strategies to prevent future deaths. The Child Death Review Council with broad representation from the private and public sector oversees the development and implementation of this system of services.

C **Hawai'i Children's Trust Fund (HCTF)** established by the Legislature (Chapter 350B, Hawai'i Revised Statutes) is a public-private partnership committed to establishing a permanent endowment fund to provide grants towards efforts to strengthen families, prevent child abuse and neglect, and promote healthy child development.

The HCTF is composed of three entities. The Coalition consists of over 90 individuals, which includes parents, public and private agencies, and other groups with an interest in child abuse prevention. The Advisory Committee is comprised of public and private sector representation, which includes the Department of Human Services, the Department of Health, Department of Education, Office of Youth Services, and the Judiciary. Also sitting on the Advisory Committee are parents, attorneys, and private non-profit organizations such as Prevent Child Abuse Hawai'i and Parents and Children Together. The Advisory Board is made up of private and public representatives appointed by the Governor.

- **Keiki Injury Prevention Coalition (KIPC)** is an organization of over 60 private and public partners in the community, including KIPC chapters on Kaua'i, Maui, and Hawai'i. Title V staff continue to provide leadership and participate in statewide activities to address issues related to childhood injury prevention. KIPC supports networking with agencies and community organizations to effect legislation, policy, and educational measures to reduce both unintentional and intentional injuries. Establishing car safety restraint training and checkup sites at community health centers, sharing pedestrian safety data to increase awareness and link educational resources to targeted schools, and collaborating with the Department of Education to provide a comprehensive integrated injury prevention curriculum to school-aged children are examples of on-going projects.

KIPC is also the Hawai'i Safe Kid's affiliate and participates with the Department of Transportation in the Safe Communities Initiative.

- **Region IX Injury Prevention Network** includes representatives from Title V, Emergency Medical Services, and National Highway Traffic Safety Administration from four states to identify regional injury prevention issues and

develop and implement cooperative prevention strategies. State and local data systems have identified the need for consistent indicators to determine trends and patterns on a regional level. Current national resources and training information are available on the website. As a result of networking amongst the administrations, resources for the promotion of injury prevention have been a cooperative effort.

- **Keiki Booster Coalition** is a statewide, community-based coalition of public and private agencies which ensures that all of Hawaii's children are appropriately immunized against vaccine-preventable diseases. Activities include sharing information and resources, educational materials, and policies that affect immunizations. Training for health professionals and organizations on current immunization information and issues is an important function. Immunization practices to address access issues and barriers for at-risk populations and data information systems continue to be priorities.
- The **Hawaii Perinatal Consortium (HPC)** is a statewide leaders' forum organized to share information and data, define the unique needs of our state, and promote strategies to improve perinatal health. As the united voice for perinatal health issues, the Hawaii Perinatal Consortium will utilize members' expertise to advance changes in health policy and public awareness through interaction with government, corporate, and community decision makers. HPC will organize members' strengths to affect systems-oriented change through both the sharing of information and data and through support of members' legislative efforts. HPC is an advisory group for policy development to interface with related coalitions and groups involved in perinatal health, and will provide a bridge for newly emerging issues and assist organizations in data collection and presentation to maximize impact. The goal is to assemble a strong perinatal leadership voice through integrated data, better information sharing, and to speak about perinatal health issues from a common platform.

Receipt of a Healthy Start Initiative Grant to eliminate racial and ethnic disparities through the reduction of infant mortality and morbidity has allowed us to establish a Big Island Coalition to look at community-based perinatal issues. We have organizationally assured that this island/community-based

coalition is linked to HPC. The hope for the future is to establish other community-based or island-based coalitions which will truly provide statewide input for HPC.

- The **Substance Abuse Free Environment (S.A.F.E.) Council** is a statewide organization of community and agency representatives who meet to address issues and needs, and to advocate for substance using pregnant women. This council has met for a number of years and provides leadership and direction for the service delivery needs of the substance using pregnant women population. The council has testified at the legislature, co-sponsored training sessions for professionals, and worked closely with the Alcohol and Drug Abuse Division of the Department of Health and the Department of Human Services, Child Welfare Program Development Division, to coordinate advocacy and program planning efforts.

II. REQUIREMENTS FOR THE ANNUAL REPORT

The following progress report on the National and State Performance Measures is presented by Types of Service as shown in the pyramid in Figure 2 which organizes Maternal and Child Health Services hierarchically from direct health care services through infrastructure building.

Figure 3 presents schematically the Title V Block Grant Performance Measurement System that begins with the identification of priorities and culminates in improved outcomes for the Title V population. After choosing a set of priority needs from a needs assessment, resource allocation is assigned and programs designed and implemented to specifically address these priorities.

The program activities are described and categorized by the four levels of service described in the pyramid. Imbedded within the levels of service are performance measures (a set of National “core” performance measures and up to ten State “negotiated” performance measures) that are categorized into three types: capacity, process, or risk factor. Figure 4 lists the National “core” performance measures and Hawaii’s 10 State “negotiated” performance measures by category and type.

The program activities, as measured by the “core” and “negotiated” performance measures, should positively impact the National outcome measures for the Title V population. While improvement in outcome measures is the long-term goal, more immediate success may be realized by a positive impact on the capacity, process, and risk factor performance measures which are considered shorter term, intermediate, and precursors for the outcome measures. This is particularly important since there may be other significant factors outside of Title V programs that affect the outcome measures.

The performance measure system ensures fiscal accountability in three ways:

- 1) by having budget and expenditure figures for the four levels of service represented in the pyramid (Form 5);
- 2) by measuring the progress towards successful achievement of each individual performance measure;
- 3) by having a positive impact on the outcome measures.

Figure 2

**CORE PUBLIC HEALTH SERVICES
DELIVERED BY MCH AGENCIES**

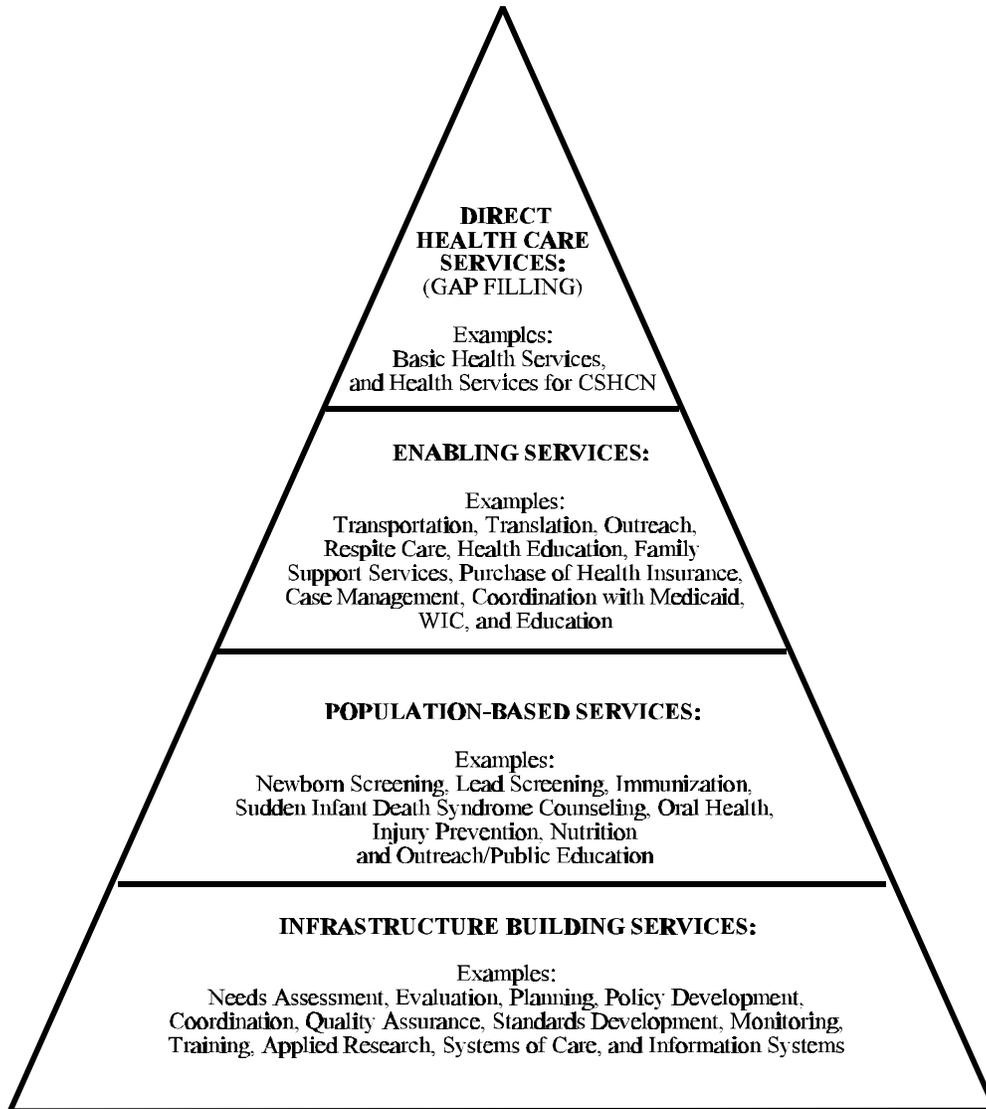
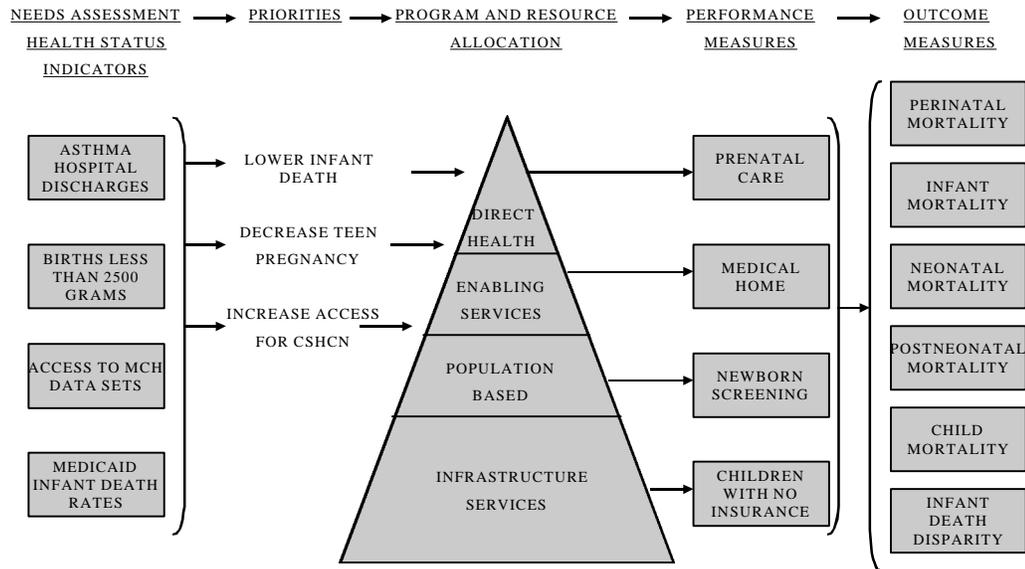


Figure 3 TITLE V BLOCK GRANT PERFORMANCE MEASUREMENT SYSTEM



**FIGURE 4
PERFORMANCE MEASURES SUMMARY SHEET**

Core Performance Measure	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.	X				X		
2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients.	X				X		
3) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a “medical/health home”		X			X		
4) Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g. the sickle cell diseases) (combined).			X				X
5) Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.			X				X
6) The birth rate (per 1,000) for teenagers aged 15 through 17 years.			X				X
7) Percent of third grade children who have received protective sealants on at least one permanent molar tooth.			X				X
8) The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children.			X				X
9) Percentage of mothers who breastfeed their infants at hospital discharge.			X				X
10) Percentage of newborns who have been screened for hearing impairment before hospital discharge.			X				X
11) Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN program with a source of insurance for primary and specialty care.				X	X		
12) Percent of children without health insurance.				X	X		
13) Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program				X		X	

Core Performance Measure	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
14) The degree to which the State assures family participation in program and policy activities in the State CSHCN program				X		X	
15) Percent of very low birth weight live births				X			X
16) The rate (per 100,000) of suicide deaths among youths 15-19.				X			X
17) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates				X			X
18) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester				X			X

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services
 IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

Negotiated Performance Measures	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1) % of sexually active women aged 18-44 who do not wish to be pregnant at this time and are using any contraceptive method including sterilization to prevent pregnancy.	X						X
2) % of WIC parents and caregivers who use feeding practices that prevent early childhood caries/baby bottle tooth decay.		X					X
3) % of pregnant women who report use of alcohol or illegal drugs (cocaine, marijuana, heroin, methamphetamine) during pregnancy.			X		X		
4) % of teenagers aged 12-17 attending public schools who report alcohol use within the last 30 days.			X				X
5) % of teenagers 12-17 attending public schools who report smoking tobacco within the last 30 days.			X				X
6) Rate of adults (aged 18-64 years, per 1,000) who have been physically injured by another household member.			X				X
7) Rate of confirmed child abuse/neglect reports per 1,000 for children aged 0-5 years			X				X
8) % of youths aged 15-17 attending public schools who report being involved in a physical fight within the last 12 months.			X				X
9) Incidence of neural tube defects per 10,000 live births plus fetal deaths.			X				X
10) Mean number of school days absent per public school student aged 5-18 who is diagnosed with severe asthma.				X			X

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services
 IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

2.1 Annual Expenditures

(See Form 5)

2.2 Annual Number of Individuals Served

(See Form 7)

2.3 State Summary Profile

(See Form 10)

2.4 Progress on Annual Performance Measures

2.4.1 Direct Health Care Services

National Performance Measure #1: The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.

Data for fiscal year 1999 show that 38.7% of State SSI beneficiaries less than 16 years old received rehabilitative services from the State CSHCN program. The target was met. The 1999 indicator of 38.7% helps meet the Healthy People 2000 objective that all 50 states have service systems for children with or at risk of chronic and disabling conditions.

Medically eligible SSI children less than 16 years old referred by the Disability Determination Branch (DDB) of the State Department of Human Services were provided outreach and rehabilitative services by the Children with Special Health Needs Program (CSHNP) social workers. Other CSHNP health professionals provided direct services to child SSI beneficiaries referred by other community resources.

The State CSHCN's Title V role mandated by OBRA 1989 is implemented by a service delivery system which assures children with disabilities access to medical speciality and related services. The delivery system is based upon the continuation of the SSI-Disabled Children's Program model established nationwide in 1977.

DDB works cooperatively with CSHNP to refer SSI children by providing DDB's hard copies of disability reports and determinations to CSHNP. DDB's commitment to the Title V agency effort is illustrated by inclusion of the SSI children's referral process in DDB policies, and by maintaining communication with CSHNP.

National Performance Measure #2: The degree to which the State CSHCN program provides or pays for specialty and subspecialty services, including care coordination not otherwise accessible or affordable to its clients.

In fiscal year 1999, the degree to which the State CSHCN program provided or paid for specialty and subspecialty services remained unchanged from the previous year. The target was met. Services were provided by the Children with Special Health Needs Program (CSHNP), Early Intervention Services Section (EIS), Early Childhood Services Unit (ECSU), Preschool Development Screening Program (PDSP), and the School Health Support Services Section (SHSSS). The following table shows the services provided or paid for by each of the programs:

SERVICE	CSHNP	EIS/ ECSU	PDSP	SHSSS
1. Medical and surgical subspecialty services	x	x ¹		
2. OT, PT services		x	x ¹	x
3. Speech, hearing, and language services	x ²	x	x ¹	
4. Respiratory services				
5. Durable medical equipment and supplies	x ³			
6. Home health care				
7. Nutrition services	x	x		
8. Care coordination	x	x		
9. Early intervention services		x		

¹Limited to evaluation and recommendations.

²Limited to speech therapy for children aged 3-5 years with craniofacial conditions who are not in Department of Education (DOE) special education preschool or Head Start, and to aural habilitation for children aged 0-5 years who are hearing impaired and do not qualify for DOE services.

³Limited to hearing aids and related services for low income children not covered by QUEST, Medicaid, and TriCare, who are either uninsured or whose health insurance does not cover the cost of hearing aids.

State Performance Measure #1: The percent of sexually active women aged 18-44 who do not wish to be pregnant at this time and are using any method, including sterilization, to prevent pregnancy.

Since 1998, contraceptive use in Hawai'i has been estimated from the Behavioral Risk Factor Surveillance System (BRFSS) using the CDC designed family planning

question module. The question is included in the BRFSS on alternate years. Thus, the indicator for 1999 is the same as 1998: 75% of sexually active women who were not seeking pregnancy were using some method of contraception. This did not meet the state negotiated objective of 78% and falls well below the national baseline of 93% (National Survey of Family Growth, 1995).

The goal of increasing contraception use through family planning services is crucial to the prevention of unintended pregnancy and improvement of the quality of life for women of child-bearing age and their children. The Healthy People 2010 goal for the nation is to reduce unintended pregnancy to 30% of all pregnancies. Although there is no standard measure for unintended pregnancy, the 1995 national baseline in HP 2010 is 49%. BRFSS 1998 data for Hawai'i estimates that only 43% of pregnancies to women age 18-44 in Hawai'i are unintended. Substantial cuts in State and Title V funding for family planning services over the past five years may deter efforts to achieve the national goal.

During the fiscal year 1999, Title V provided direct health services in the form of clinical family planning (FP) services to sexually active women between the ages of 14-44. Comprehensive services include thorough health histories and risk assessment, screening for sexually transmitted diseases, breast and cervical cancer, hypertension, obesity, and anemia. Health education, risk reduction messages, and contraceptives, including condoms, are integral parts of each visit. Clients with positive pregnancy tests are given specific health information relating to care during the first trimester and appointments for immediate medical follow-up are encouraged. Title V provided these services to 489 clients in 758 visits at three clinics in Hawai'i (two neighbor island clinics and one rural O`ahu clinic).

Enabling services were provided during comprehensive FP visits, including health education and translation services, case management and referrals for prenatal care, WIC and social services, Medicaid/Med-QUEST health insurance, and other similar services. Enabling services and population-based services, which include outreach and community education programs, were funded by Title X funds. Infrastructure building services, in the way of state needs assessment and planning and policy development, were provided to the Family Planning Services Section by Title V-funded Family Health Services Division staff.

In June 1999, Act 267 became law requiring all Hawai'i insurance plans offering coverage for pregnancy to cover family planning visits and all FDA approved contraceptive methods. The Title V agency, in collaboration with the Hawai'i Women's Coalition and other key community stakeholders, worked for six years with the state's major health insurance companies to ensure full contraceptive coverage for women with pregnancy coverage. Implementation of Act 267 began on January 1, 2000, and is occurring in phases with the final insurance plans coming on board by July 2001. Hawai'i is the 9th state to pass such legislation.

Although this is a significant achievement for women in Hawai'i, there is still an estimated 149,000 women, including 15,000 teenagers, in need of subsidized family planning services. Title V has contributed to meeting this need.

2.4.2 Enabling Services

National Performance Measure #3: The percent of Children with Special Health Care Needs (CSHCN) in the State who have a medical/health home.

For fiscal year 1999, it is estimated that approximately 91% of CSHCN in the state have a medical/health home. The increase from fiscal year 1998 reflects a change in methodology. Previous estimates were based on a proxy measure of receipt of EPSDT periodic screening service with an adjustment for uninsured CSHCN.

The current estimate of 91% is based on data from a survey of families of CSHCN that was conducted by the Children with Special Health Needs Branch during January-February 2000. Surveys were distributed to approximately 2,561 families, with the sample weighted toward those who used public services for CSHCN. Approximately 49% completed and returned the survey. The medical home survey question was based on the American Academy of Pediatrics' (AAP) definition and was developed with Dr. Calvin Sia of the AAP, the "Malama Pono" Medical Home and Integrated Services Project, and other members of the Title V CSHCN Planning Committee.

In response to the survey question: "A 'medical home' is a way of providing services in which doctors and parents act as partners to identify and get medical and other needed services. Do you have a doctor who knows about your child's health?" 91.7% of respondents said that their children had a doctor who knew about their child's health. Comments from families sharing why they did not have a doctor who knew about their child included: doctors were too busy to take on new patients; doctors did not have

enough knowledge about their child's condition; child sees different doctors in the clinic; family just moved to a new area; their doctor moved away; child switched medical plans and now has a different doctor; child just started seeing a new health provider; child had no insurance.

Of the respondents who said their children had a doctor who knew about their child's health, over 80% of families said their child's doctor listens carefully to them; provides information about their child's condition and care; includes the family in making decisions about their child's health care; talks about growth, behavior, injury prevention, and immunizations; and are available at all times when their child was sick. 70-75% of families said their child's doctor arranged or coordinated the services for their child provided by different doctors, therapists, or other persons; that the family received reassurance and support about the care they provided for their child; and that their family's cultural background is recognized and respected. 56.6% of families said they get information about educational and other support services in the community from their child's doctor.

"Malama Pono," funded by the federal MCH Bureau, is a collaborative project between the Hawai'i Medical Association, Department of Health, and Department of Education. It promotes accessible community-based, family-centered culturally competent medical homes which provide comprehensive coordinated services for CSHCN. The project works at the state level with managed care organizations and public agencies, and at the community level to build family-professional partnerships. The CSHNB Chief is a member of the Advisory Committee.

The 1999 indicator of 91% helps meet the Healthy People 2000 objective that all 50 states have service systems for children with or at risk of chronic and disabling conditions.

State Performance Measure #2: Percent of WIC parents and caregivers who use feeding practices that prevent early childhood caries (ECC)/baby bottle tooth decay (BBTD).

The data for this measure was provided by WIC's new automated computer system. All previous data was generated from manual chart reviews. It was discovered during data retrieval that past WIC data had been incorrectly reported. Indicators for previous years measured the number of parents who were not using feeding practices

appropriate to prevent BBTD versus those who use preventive feeding practices as described in the measure. Thus, new data and objectives are provided for 1996-2000 on Form 11.

The indicator for 1999 is 82% which is above the Healthy People 2000 objective of 75% of parents and caregivers who use feeding practices that prevent BBTD and ECC. However, WIC data is self-reported and may not reflect actual feeding practices of families. Also, WIC parents receive ongoing education and support which may account for the high performance. Although it is not statistically significant, the data from 1996-1999 does show a slight decline in preventive feeding practices among WIC clients.

WIC clinics statewide continue to follow ECC/BBTD educational protocols at 6-9 months of age to review appropriate feeding practices to prevent dental caries. At one year of age, WIC parents and caregivers are surveyed to determine the efficacy of the educational information. The data is used for this performance measure.

Oral health education, including information on feeding practices to prevent ECC/BBTD and nutritional information, has been provided to health care providers and community groups throughout the State. The Dental Health Division (DHD) of the Department of Health has provided training for program staff and produced informational brochures for dissemination to clients. DHD information/training also emphasizes the need to follow the EPSDT guidelines for dental visits by two years of age and the importance of fluoride supplements for children from six months up to 16 years of age.

The Title V agency is partnered with DHD to identify appropriate early childhood programs to receive training and disseminate information. The programs included the community health centers, pregnant and parenting teen classes, Early Head Start and

Healthy Tomorrows clients, and Native Hawaiian health care providers. Title V also provided free sippy cups for distribution with educational materials to many of these agencies.

The Title V program also continued to collaborate with DHD on the progress of a Federal CDC Fluoride systems development grant which will assess the readiness of Hawaii's water system for fluoridation and determine public awareness and educational activities for the community.

2.4.3 Population-Based Services

National Performance Measure #4: Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g., the sickle cell disease).

Data for fiscal year 1999 indicate that the objective was essentially met with the screening of 99.8% of infants born in Hawai'i who did not expire before testing for phenylketonuria, congenital hypothyroidism, galactosemia, hemoglobinopathies, congenital adrenal hyperplasia, biotinidase deficiency, and maple syrup urine disease.

The 1999 indicator of 99.8% exceeds the Healthy People 2000 objective of 95% newborns screened for genetic disorders and other disabling conditions.

The Newborn Metabolic Screening Program (NBMS) staff worked closely with the contracted testing laboratory and medical consultants regarding streamlining procedures of notification and follow-up of test results. In-service education sessions were held for practitioners, nurses, laboratories, and birthing facilities involved with newborn screening.

Monthly screening practice profiles were sent regularly to birthing facilities and submitters in an effort to improve the transit time, specimen age of collection, quality of the specimens, and to improve the feeding history information. Many of the birthing facilities used these monthly screening practice profiles as a quality assurance tool, did more in-service sessions, and reduced the number of specimen errors. In FY 98, the average number of newborn screening specimens submitted without errors was 82.26%. In FY 99, the average number of newborn screening specimens submitted without errors was 90.93%.

The parent brochure, "Testing Your New Baby for Hidden Birth Defects," continues to be disseminated to parents through the birthing facilities, childbirth

educators, and through perinatal agencies, which are part of the Perinatal Advocacy Network coordinated by the Healthy Mothers/Healthy Babies Coalition.

All infants identified with the above disorders through screening received appropriate treatment. NBMSP staff tracked all children diagnosed with metabolic and other disorders to ensure that they received appropriate follow-up. The staff also identified and tracked infants who were not screened, based on information on home births from the Office of Health Status Monitoring, "Specimen Not Obtained" forms, and monthly reports from birthing facilities. To assure satisfactory testing, the staff also tracked and followed-up on infants with abnormal and unsatisfactory screening results and infants who were transferred from one facility to another.

One effort to assess the care and the education given to families of newborns identified with Bart's hemoglobin and other hemoglobinopathy traits/diseases was to send out a Hemoglobinopathy Follow-Up Survey to primary care providers. In July 1999, 466 surveys for individual patients were sent out to 119 physicians. A total of 329 surveys were returned. Approximately 95% of the physicians received the newborn screening results. The other 5% of the physicians were not the initial primary care physicians and did not receive any forwarded newborn screening results. Approximately 91% of the families were informed of the hemoglobinopathy results. The results showed that only 64% of the infants with hemoglobinopathies were referred for further testing. Most physicians who provided education or "genetic counseling" to families did it themselves. Approximately 15% of the families needed but did not receive genetic services.

National Performance Measure #5: The percent of children age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.

Hawai'i did not achieve its target of 83% in 1999 according to the results of the National Immunization Survey (NIS), but the 1999 indicator 76.2% immunizations for children 19-35 months of age is higher than the 1998 national baseline of 73%. The indicator for 1998 was incorrect and has been changed to 79.3%. Despite this correction, the 1999 indicator did drop from previous years. The percentage decrease is likely due to a change in the NIS reporting format. The Hepatitis B vaccine was first included in the immunization schedule in 1999. In previous years, the NIS did not report Hepatitis B

as part of the vaccination schedule, thus past indicators were somewhat higher. If we compare the immunization percentage of vaccination schedules without Hep B, the indicator is 79.4%, roughly unchanged from 1998 at 79.3%. Both figures are very close to the HP 2010 goal of 80% immunization.

Continued partnership with the Hawai'i Immunization Program and the Hawai'i Immunization Coalition (HIC), which is comprised of public and private stakeholders, addresses population-based services related to accessibility, education, and advocacy. Title V staff also continues to monitor primary care purchase-of-service contracts that provide immunizations to uninsured populations to improve compliance with the guidelines from the Advisory Committee on Immunization Practices (ACIP). Technical assistance is also provided to early childhood programs within the Maternal and Child Health Branch (MCHB).

National Performance Measure #6: The rate of birth (1,000) for teenagers aged 15 through 17 years.

Preliminary data reported in prior years 1996-98 for this measure was updated to final/published data from the vital statistics program and is reported by calendar year as are most vital statistics measures for Hawai'i. The 1999 data is preliminary and indicates a rate of 25.5 live births per 1,000 teenagers aged 15-17, a slight decrease since 1998. The target of 25.0 was nearly met. Relative to national standards, Hawai'i compares well. The 1999 indicator of 27 is far better than the national baseline of 72 per 1,000 and meets the Healthy People 2000 goal of 50 per 1,000. Note that the national measures are for teen *pregnancy* rates versus birth rates, thus the national rates are higher since many youth do not carry their fetus to term.

As teen pregnancy is known to be embedded in larger issues, teen pregnancy prevention is addressed through a holistic adolescent wellness approach as described in Hawaii's Adolescent Wellness Plan. Working with its many partners, the Title V agency's accomplishments in 1998 focused on continued service provision emphasizing: education; early identification and intervention; peer-helping-peer models; youth involvement in program development and implementation; parent and caring adult involvement; after school programs; technical assistance to support community-based adolescent wellness team efforts; and training of health care providers/advocates working with young people.

The Peer Education Program (PEP) at 26 public schools provided adolescent health prevention education on tobacco, alcohol, and substance abuse; teenage pregnancy; STD/AIDS; suicide; sexual assault; and personal/social skills development. Activities included peer counseling/support, formal classroom presentations, wellness events and special promotional activities, and referral to student support services. Outreach was provided to over 265,000 students.

The Abstinence Only Education Program contracted to the Boys and Girls Club of Hawai'i was conducted in all four counties as an after-school program targeting ages 9 to 12 through a curricula for healthy youth development. Evaluation is showing that the program is reaching a higher proportion of ethnic groups with high teen birth rates through peer mentoring, parent/adult involvement, counseling/education, and community activities. The evaluation conducted by the School of Public Health demonstrated that a higher proportion of youth going through the program understood that abstinence outside of marriage is the expected standard than the control group.

The number of School Based Health Service Centers (SBHSC) increased from three to four secondary schools. All SBHSCs conduct risk assessments and education and care coordination related to at-risk behaviors. SBHSCs actively assess if a child has health insurance or a medical home and take efforts to link program youth with these resources. Case management outcomes were piloted, including one for sexual activity, which demonstrated improvement through intervention or coordination.

Title V Family Planning Services Section provided school and community presentations on puberty, abstinence-based family planning, and self-esteem for students and youth at-risk. Educational outreach included use of mass-based media, as well as health fair exhibits and publication of printed materials.

IT CAN HAPPEN TO YOU, a high school drama regarding teen pregnancy, sexually transmitted diseases (STD), and HIV/AIDS Prevention, was created and performed by high school and college students at many of the public schools. The play promoted communication, abstinence, sexually responsible behavior, and positive healthy relationships for teens and was presented by an ethnically diverse group of youth actors.

National Performance Measure #7: The percent of third grade children who have received protective sealants on at least one permanent molar tooth.

Hawai'i has exceeded the target for 1999 of 21% by 21.3%. The data for this measure was collected from a representative sample of public school 3rd grade children from the state. The Dental Health Division (DHD) completed screening on an increased number of children statewide in the 2nd and 3rd grades. Fluoride applications were done only in Honolulu schools. Education and information were provided to students and parents to promote better awareness of basic oral health practices. The Title V program supported travel and per diem costs for DHD staff to increase the number of children screened.

National Performance Measure #8: The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children.

As with other vital statistics measures, the data for previous reporting years 1996-98 was revised to reflect final published data from the vital statistics branch. Moreover, the federal Maternal Child Branch has revised this measure to include all children 0-14 years (versus 1-14 years of age) killed in motor vehicle crashes. The 1999 data is preliminary and will be revised in next year's report when final figures are released. The indicator for 1999 is 0.8 deaths to children aged 0-14 per 100,000 caused by motor vehicle crashes. This meets the target of 5.0. Over the past four years, the indicator shows a steady decline; however, the numbers for this measure are so small for the state that they may vary tremendously given 1 or 2 car accidents.

In 1999, continued partnership with the Keiki Injury Prevention Coalition (KIPC), Injury Prevention and Control Program (IPCP), and the Hawai'i Department of Transportation's Safe Communities Initiative provided increased awareness of traffic and pedestrian safety. Child safety seat training and check-up sites are being integrated into primary care health centers, medical care facilities, and car dealerships throughout the state. Efforts to integrate comprehensive injury prevention education through the "Risk Watch" curriculum was piloted in one elementary school. Training for staff included traffic and pedestrian safety education for students at appropriate ages and activities to meet the health education performance standards.

The Title V staff on the neighbor islands continue to build capacity in their community for their local coalitions. IPCP has conducted assessment, education and training, advocacy, and legislation related to child safety seats and pedestrian safety. Injury prevention resource information continues to be distributed through a variety of

community networking activities. The Region IX Injury Prevention Network meets regularly to partner and share legislation, educational information, data, and resources among representatives from the Emergency Medical Services for Children, Department of Transportation, Maternal and Child Health Branch, and Injury Prevention and Control Program.

National Performance Measure #9: The percentage of mothers who breastfeed their infants at hospital discharge.

The 1999 fiscal year target of 73% was exceeded as 78% of mothers breastfed their infants at hospital discharge. The 1999 calendar year indicator of 78% brings Hawaii's performance in excess of the Healthy People 2000 objective of 75%.

The Newborn Metabolic Screening Program provided an improved, population-based data source for this performance measure through the feeding histories on their screening form completed by the hospitals. Although the increase in the percentage of women who were breastfeeding at hospital discharge may be attributed to a more accurate source of data, credit must also be given to the perinatal programs, WIC, and all of the hospitals in the state.

The Title V program contracts with ten sites statewide to provide Perinatal Support Services to high-risk pregnant women. On the island of Hawai'i, Title V program staff provide similar services. All of these programs provide comprehensive breastfeeding education and support to all of their pregnant moms. Other community-based programs that promote breastfeeding include: Pulama I Na Keiki, Alu Like, Inc., a statewide program focusing on Hawaiian families; Malama Na Wahine Hapai, a demonstration project providing culturally competent prenatal and postpartum care to Hawaiian, Japanese, and Filipino women on the island of Hawai'i; and programs under the Native Hawaiian Health Systems on each island.

The WIC program has purchased several electric breast pumps which it lends to clients on an as needed basis. It also provides comprehensive breastfeeding promotion and education to all of their clients. Their Breastfeeding and Support Clinic Environment Policy prohibits pictures, samples, or logos of formula to be visible in the clinic setting. In their breastfeeding incentives program, women are given a certificate, picture, and a gift (washable nursing pads, infant t-shirt, and canvas bag with a picture of

multi-cultural babies) if they are breastfeeding at 6 weeks, 6-8 months, and 1-year postpartum.

All of the delivering hospitals in the state have employed lactation consultants or utilize the services of nurse midwives to provide outstanding support to their breastfeeding moms! Kaiser Permanente Hospital, Moanalua, was the second of only 11 U.S. hospitals to receive the designation of “Baby Friendly” Hospital by the U.S. Committee for UNICEF. As of July 1998, Kapiolani Medical Center for Women and Children received its Certificate of Intent to be a “Baby Friendly” Hospital.

The Breastfeeding Promotion Council of Hawai`i has continued to provide leadership in the breastfeeding arena by linking the programs, activities, and policy changes related to breastfeeding support and promotion. The Council has a new web site (www.breastfeedinghawaii.org) upon which it posts local meeting information, services for breastfeeding mothers, and links to other breastfeeding support sites. The Healthy Mothers/Healthy Babies Coalition and the MothersCare for Tomorrow’s Children also have provided support to the Council.

With the passage of the “New Mothers Breastfeeding Promotion and Protection Act,” it is hoped that women feel supported to express breastmilk at their workplace and to continue to breastfeed their babies for at least 6 months. Under Hawai`i House Bill 266: 1) employers are not allowed to prohibit an employee from expressing breastmilk during any meal period or break period; 2) it is unlawful for any employer to refuse to hire or employ, or to bar or discharge from employment, or withhold pay, demote, or penalize an employee who expresses milk at the workplace; 3) allows employers to establish internal rules and guidelines for employees who may wish to breastfeed or express milk in the workplace.

National Performance Measure #10: Percentage of newborns who have been screened for hearing impairment before hospital discharge.

In 1999, an estimated 97.8% of newborns were screened for hearing impairment before hospital discharge. The annual objective was met.

The 1999 indicator of 97.8% addresses the Healthy People 2000 objective to reduce the average age at which children with significant hearing impairment are identified to no more than 12 months.

Hawaii's Newborn Hearing Screening Program (NHSP) is supported by a 1990 law which mandates that the Department of Health has the responsibility to develop methodology to establish, implement, and evaluate a statewide program and develop guidelines for screening, identification, diagnosis, and monitoring of infants and children to age 3 years with hearing impairment. Screening began in two Honolulu hospitals in 1992; and by the end of 1999, all birthing facilities in Hawai'i were providing newborn hearing screening. Newborn hearing screening is now standard medical practice for newborn care in Hawai'i.

NHSP is responsible for the planning, development, and implementation of statewide newborn hearing screening program services; identification and assessment of needs and resources; promotion of collaboration with national experts, the state agency, physicians, and service providers in the development of screening programs at community-based sites throughout the state; and development, evaluation, and implementation of methods and procedures to be use in screening. NHSP provides training, technical assistance, and assistance with follow-up for infants who need rescreening or referrals for audiological assessments. NHSP maintains the central computer data system from which data files are transferred monthly from most hospitals.

State Performance Measure #3: The percent of pregnant women who report use of alcohol or illegal drugs (cocaine, marijuana, heroin, methamphetamine) during pregnancy.

Population-based data is currently not available for this performance measure. The Alcohol and Drug Abuse Division (ADAD) of the Department of Health conducts a blind study periodically which is the Department's best data source for this measure. The study has been completed but has not been officially released at this time. Data will be available for next year's report.

Statewide law enforcement/criminal justice data indicate an increase in drug use. Child abuse, prison, and mental health programs all identify substance use as a major reason for increases in case load or as a primary problem of those in their system of services.

As the need for drug prevention and treatment increases in Hawaii's ninth year of economic slump, existing service programs must coordinate to maximize resource utilization.

Strengthening the partnership with ADAD and service providers continued to be a priority. Another partner is the March of Dimes. Training for physicians throughout the state was provided in partnership with the March of Dimes. Dr. Janet Michell, Chair of the committee which developed the treatment protocols for SAMSA, provided the training. In addition, the Title V program participated on a committee focused on Fetal Alcohol Syndrome and Fetal Alcohol Effect sponsored by the Foster Parents Association and the Junior League of Hawaii.

State Performance Measure #4: The percent of teenagers in 9th-12th grades attending public schools who report alcohol use (within last 30 days).

State Performance Measure #5: The percent of teenagers in 9th-12th grades attending public schools who report smoking tobacco (within last 30 days).

Since performance measures 4 and 5 are related to prevention of substance use, the program activities will be discussed together.

For fiscal year 1999, data from the high school YRBS indicated 44.6% of 9th-12th public school respondents reported alcohol use in the past 30 days, not meeting the objective of 39.0% and higher than the 1998 indicator of 40.3%. For fiscal year 1999, data from the high school YRBS indicated 27.9% had smoked tobacco in the past 30 days, meeting the objective of 28.0%, a lower percentage than reported in 1997. Thus, alcohol use may be increasing among Hawaii's youth, while smoking may be in slight decline.

School programs are considered the most effective avenue for intervention to prevent substance abuse. Population-based activities include the Peer Education Program (PEP) and the Community Adolescent Program. PEP continued its school-based primary prevention education and early identification and referral efforts on critical public health issues. This included more specific smoking and alcohol

prevention activities, such as participation in the Great American Smokeout and Drug Awareness Month. PEP worked in collaboration with community partners like the American Lung Association, American Cancer Association, American Cancer Research Institute, The Underage Drinking Task Force, The Tobacco Prevention and Control Program, Tobacco Free Coalition, and the Drug Free Coalition of Hawai`i to organize other drug awareness events and activities throughout the year.

The existing School Based Health Service Centers also provide risk assessments for substance use and develop appropriate educational interventions and care coordination for substance use services.

Title V continued to support the development of infrastructure services to promote adolescent health and wellness. The Healthy Hawai`i Initiative, supported by Tobacco Settlement funds, proposes to support interventions which promote healthy lifestyles through tobacco prevention and cessation, proper diet, exercise, and body weight. Plans developed will focus efforts on children through integrated school, community, and family-based approaches.

The National Center for Leadership Enhancement in Adolescent Programs (LEAP) assisted Title V with the facilitation of a workshop on “Developing Integrated Coordinated Programs for Children and Youth.” The workshop led to the development of a key recommendation adopted by Departments of Health and Education to implement the Centers for Disease Control’s Coordinated School Health Approach. The model is being integrated into the Department of Education’s existing Comprehensive Student Support System (CSSS) which would create school and community-based health promotion programs on tobacco control, nutrition, and physical activity classes, and encourage the formation of health coalitions.

The Adolescent Survey Committee (ASC) is developing a product for parents to help improve communication with their children. The information packet will contain facts about different substances, data on substance use, and strategies and resources for additional information and support.

State Performance Measure #6: The rate of adults (aged 18-64 years, per 1,000) who have been physically injured by another household member.

There were several problems discovered with this measure. First, data reported for previous years was incorrect. A review of the Hawai`i Health survey results in 1996

show the indicator is 3.0 per 1,000 adults physically injured by an intimate partner (not 55 per 1,000 as reported). The survey did not ask respondents whether their partners were household members, thus the measure will be reworded to “The rate of adults (aged 18-64 years, per 1,000) who have been physically injured by an intimate partner.”

In 1999, the Hawai`i Behavioral Risk Factor Surveillance Survey (BRFSS) included a module on Sexual Assault and another on Intimate Partner Violence. Preliminary data from the 1999 BRFSS indicates 7.2 per 1000 adults were injured by intimate partners. The indicator is well below the HP 2000 objective of 27 per 1,000 for physical abuse directed at women by male partners. This may be largely due to survey participants’ reluctance to answer the questions or unwillingness to report honestly. A high percentage of respondents refused to respond to the BRFSS intimate partner violence questions.

The 1996 and 1999 indicators are not comparable because the survey questions were worded differently. Thus, it cannot be inferred that violence among intimate partners has declined. After a review of the BRFSS questions, the Title V staff decided to pilot a new survey measure that has been included in the 2000 Hawai`i Health Survey, an annual random digit dialing phone survey of over 4,000 households. The number of questions regarding intimate partner violence has been reduced and reworded to minimize offending survey participants.

During fiscal year 1999, Title V programs continued to provide services, planning, and advocacy to prevent domestic violence through its Sexual Assault Prevention Program. Title V staff participated in the State Planning Committee on Violence Against Women Act (VAWA) led by the State Attorney General’s office and the Ad Hoc Committee on Domestic and Sexual Violence to work toward the reduction of violent crimes against women.

Preventive Health & Health Services Block Grant funding to the Kapi`olani Medical Center, Sex Abuse Treatment Center, and sexual assault treatment centers on the Wai`anae Coast, Maui, Hawai`i, and Kaua`i supported continuance of:

- 1) school/community-based sexual assault prevention education presentations, and
- 2) other outreach initiatives to increase public awareness of the community-based sexual assault centers and services provided.

The Preventive Health Block Grant funded sexual assault curriculum development and training for coordinators and peer educators for the Peer Education Program which is located in 26 public schools statewide. Presentations were made to over 27,000 students during the 1998-1999 school year.

Infrastructure building activities advanced with expansion of the Coalition for the Prevention of Sexual Assault. Policy activities included the monitoring of pertinent legislation. Planning continued with the development of a statewide outreach plan, review of the system of sexual assault prevention and response services, improved coordination with other violence programs (domestic violence, school violence, child abuse and neglect), and analysis of existing data.

The Sexual Assault Prevention program continued to work with the Hawai'i State Commission on the Status of Women and other community groups to assure a continuum of services for the prevention of violence against women.

State Performance Measure #7: The rate of confirmed child abuse/neglect report per 1,000 for children aged 0-5.

The past year's data for this measure was updated from preliminary to final/published data from the State Department of Human Services. The preliminary data for 1999 indicates 12.3 child abuse/neglect cases per 1,000 children aged 0-5 were confirmed. Data from 1996 shows a small, but steady increase in the rate. Title V will continue to monitor this measure closely in the future.

Title V addressed the goal of reducing overall incidences of child abuse and neglect in children aged zero-to-five (0-5) through implementation of new initiatives and strengthening of current contract performance. Staff wrote a request-for-proposals to serve children aged 10 and under who have been witnesses to family violence to provide therapeutic services to the children and their families, as well as outreach presentations on violence prevention to community groups. Two agencies were each awarded contracts, one serving children in rural O'ahu and the other in urban Honolulu. Also during 1999, the section provided statewide training workshops for parents and other caregivers on a variety of children's psychosocial-behavioral issues with a special emphasis on the issue of Sexual Development of the Young Child: 0-5. Mobile family outreach units (play mornings) to serve homeless and isolated families is being replicated statewide with assistance from many community organizations.

Title V oversees another successful program, Hawai'i Healthy Start. Healthy Start is a nationally recognized home visitation program which provides support to families identified as high-risk using para-professional personnel. All new parents at infant's birth are screened in the hospitals and identified for follow-up services. Based on its success, the program has been replicated nationally at Healthy Families America.

The Parent Line, a free statewide telephone "warm line" providing support, encouragement, informal counseling, and information and referral to over 5,000 callers a year, has seen its numbers served increased by 400 during 1999. Reducing incidences of family destabilization and inappropriate guidance techniques continue to be a goal of the HomeReach home-visiting program. Two statewide home visiting staff meetings were organized and held in 1999 to increase service cohesion and provide peer consultation and support.

Infrastructure-building activities of the section include continued administration of the Early Head Start grant, which provides comprehensive infant/toddler services to 50 children and their families in the Ko'olauloa area of O'ahu. The reduction to serving 50 children from 75 is a negotiated change this year.

The Hawai'i Children's Trust Fund (HCTF) established by the Legislature (Chapter 350B, Hawai'i Revised Statutes) is a public-private partnership committed to establishing a permanent endowment fund to provide grants to strengthen families, prevent child abuse and neglect, and promote healthy child and family development. Title V continues to partner with the Hawai'i Community Foundation to administer the Community-Based Family Resource Supports Grant which provides funds for the development of a continuum of family strengthening and child abuse preventive services for children and families.

Title V personnel provided staffing for this public-private partnership (which consists of the HCTF Coalition with over 120 individuals representing parents, public and private agencies, and other groups interested in child abuse prevention) and the HCTF Advisory Committee (which includes representation from public and private sector, private non-profit organizations, parents and businesses).

Title V personnel also participate in the Never Shake a Child Task Force and various Child Abuse and Neglect Prevention activities in the state.

State Performance Measure #8: The percent of teenagers in 9th -12th grades attending public schools who report being involved in a physical fight (within the past 12 months).

For fiscal year 1999, data from the high school YRBS indicated 30.6% of 9th-12th public school teenagers had been in a physical fight within the past 12 months, meeting the objective of 31% and somewhat less than the 31.7% percent reported in 1997. The 1999 middle school YRBS of public school 6th-8th graders had 39%, a significantly higher percent than the high school respondents reporting involvement in a physical fight within the past 12 months.

As with teen pregnancy and substance use, a holistic approach is being taken to address physical violence along with other risk-taking behaviors. Therefore, activities for this population-based measure fall within a system of strategies to address healthy adolescent development similar to those discussed under Performance Measures #4 and #5.

The Hawai'i State Peer Education Program delivered 528 formal classroom presentations on the topic of sexual assault and violence prevention. Partnerships were also formed with the Sex Assault Treatment Center, Domestic Violence Clearing House, Honolulu Police Department's Juvenile Crime Division, and Attorney General's Office to provide support and in-service training for PEP on youth violence issues.

The University of Hawai'i, Department of Social Sciences Youth Research, also provided PEP with an evaluation of the three-year PEP Sexual Assault Prevention effort. The study showed statistically significant gain of knowledge of PEP Educators and the students they taught and compared the gains with non-PEP site students.

The Department of Health contracted with the Hawai'i State Commission on the Status of Women to partner with the Violence Prevention Consortium to develop and implement a comprehensive, age-appropriate, culturally-diverse and gender-equal integrated violence prevention curriculum in the public schools—kindergarten through grade twelve. Performance measures to evaluate the effectiveness of the integrated violence prevention curriculum will also be developed.

State Performance Measure #9: The incidence of neural tube defects (NTDs) per 10,000 live births plus fetal deaths plus medical terminations.

The preliminary incidence of NTDs for 1999 is 7.2. The target was met. The indicator exceeds the Healthy People 2000 objective to reduce the cases of NTDs to 10 per 10,000 live births.

In January 1999, public and private sector representatives from Hawai`i participated in the “Preventing Neural Tube Defects with Folic Acid: Working Together for Healthier Babies” premiere national prevention campaign sponsored by the Centers for Disease Control and Prevention and the March of Dimes in Arlington, Virginia. By mid-March 1999, the Folic Acid Committee had been re-established in Hawai`i with broad community participation in quarterly planning meetings that explored educational efforts, outreach activities, free vitamin distribution, funding opportunities, etc. Between February 1, 1999, and September 30, 1999, the Committee documented 63 statewide activities directly related to folic acid and neural tube defects.

A key component has been the continuation of the Hawai`i Birth Defects Program (HBDP) which has been tracking the number of birth defects, including neural tube defects, statewide. With loss of state general funds in 1998, HBDP continued initially with Title V and State Systems Development Initiative (SSDI) funds, followed by grant funding from the Centers for Disease Control and Prevention beginning February 1999 to enhance state-based birth defect surveillance and used this surveillance data to guide prevention and intervention programs.

2.4.4 Infrastructure Building Services

National Performance Measure #11: The percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN program with a source of insurance for primary and specialty care.

It is estimated that approximately 95% of CSHCN in the State CSHCN programs have a source of insurance for primary and specialty care, and the target was met. This is based on: 1) 5% (45/959) children in the Children with Special Health Needs Program were uninsured. Data on insurance coverage for children served in the other CSHCN programs was not available. 2) The rate of uninsured children from the population-based Hawai`i Health Survey 1998 is approximately 5%. The State CSHCN programs probably have a similar rate.

The 1999 indicator of 95% helps the Healthy People 2010 objective that all 50 states have service systems for children with or at risk of chronic and disabling conditions.

A January 1999 survey of CSHNP uninsured children indicated that the most common reasons for being uninsured were not being eligible for QUEST/Medicaid because of family income, assets, or immigration status, and the inability of the family to afford the high cost of premiums.

The Children with Special Health Needs Branch conducted a survey of families of CSHCN during January-February 2000. Surveys were distributed to approximately 2,561 families with the sample weighted toward those who used public services for CSHCN. The return rate was approximately 49%. Data on health insurance showed: 96.5% of children had health insurance coverage; 91% had drug coverage; 87% had dental coverage; and 74.2% had vision coverage. For families who did not have insurance, reasons included: 46.2% - cost was too much; 35.9% - they worked but did not have a family plan; 38.5% - child did not qualify for QUEST or Medicaid; 15.4% - too difficult to apply for Medicaid or QUEST; and 20.5% - other reason.

Assistance is given to families in applying for Medicaid/QUEST. The Children with Special Health Needs Branch was involved in the initial planning efforts for the State Child Health Insurance Program (SCHIP) for Hawai`i, for which the Department of Human Services is the lead agency. Implementation of the Hawai`i SCHIP begins July 1, 2000.

National Performance Measure #12: The percent of children without health insurance.

The target for FY 1999 was 4.5% and the percent of children without health insurance in FY 1999 was 3.7% (indicator). The target was met, and the improvement over the FY 1998 indicator of 5% is statistically significant. There is no Healthy People 2000 objective for this measure.

The Title V program collaborates with the Department of Health, Office of Health Status Monitoring (OHSM), which administers the population-based Hawai`i Health Survey to obtain the data for this measure. The health insurance questions are funded by the Title V program and an improved set of questions was initiated with the 1998 Hawai`i Health Survey. Therefore, only the FY 1998 and FY 1999 indicators can

be compared. The data from the Hawai`i Health Survey also provides estimates of uninsured Medicaid-eligible and SCHIP-eligible children. Since the Hawai`i Health Survey is administered by telephone, the data may not adequately measure the uninsured population. For example, they may not have a telephone or may refuse to participate in such a survey due to cultural and language barriers. Because of the limitations of the Hawai`i Health Survey, the Title V program is collaborating with other stakeholders such as the DOH Public Health Nursing Branch which collects uninsured data on public school children, in order to gain a better understanding of this measure. Another Title V program partner, Hawaii's Covering Kids Initiative was funded in June 1999 by the Robert Wood Johnson Foundation and focuses on outreach and enrollment of uninsured children. The project will soon be carrying out its evaluation process which should provide further insight into the actual numbers of uninsured children. The Title V program will continue to work to improve the data for this performance measure.

The target for this measure was met because of increased activities and networking among stakeholders related to uninsured children. Stakeholders have met regularly to plan for the implementation of Hawaii's SCHIP program which is scheduled to begin on July 1, 2000. These efforts have placed increased emphasis on outreach and enrollment of Medicaid-eligible, as well as SCHIP-eligible children. Hawaii's Covering Kids Initiative and the Medicaid agency have sponsored statewide outreach and enrollment training sessions for all stakeholders. These two agencies have also established a statewide hotline to provide information and application forms for Medicaid-eligible children. The Covering Kids Initiative has also sponsored media and networking activities and special outreach and enrollment projects. The Title V program has been an active participant in all of these activities and has assured that all Title V stakeholders are informed of and can benefit from these efforts. In addition, all of the Title V program's purchase-of-service contracts require that uninsured Medicaid-eligible children be referred for Medicaid assistance.

National Performance Measure #13: The percent of potentially Medicaid-eligible children who have received a service paid by the Medicaid program.

The indicator for fiscal year 1999 was 61.9%. The target of 60% was exceeded. The numerator was obtained from service data collected by the Department of Human Services (DHS) Medicaid program, and the denominator is the total of DHS Medicaid

enrollment numbers and 1999 Hawai'i Health Survey data on uninsured Medicaid-eligible children. Limitations of the Hawai'i Health Survey are explained under National Performance Measure #12. There is no Health People 2010 objective for this measure.

This performance measure builds on National Performance Measure #12, which focuses on increasing insurance coverage for children and emphasizes outreach and enrollment of uninsured Medicaid-eligible children. The activities under Performance Measure #12 affect the denominator in Performance Measure #13—the number of potentially Medicaid-eligible children which has increased from 94,465 in FY 1998 to 102,135 in FY 1999. The major activities under Performance Measure #13 affect the numerator—the number of Medicaid-eligible children who have received a service paid by the Medicaid program. These activities have focused on improving access to and utilization of services. The Title V program has collaborated with the DHS Medicaid and EPSDT programs and the health plans contracted by the DHS QUEST program to promote EPSDT as the standard of care. This information has been given to stakeholders with special emphasis targeted to providers of care and Medicaid clients. In addition, the Title V program's purchase-of-service (POS) contracts to community-based providers require enabling services which promote appropriate utilization of all health services, including Medicaid services. These contracts promote a system of care for vulnerable populations which include transportation, translation, and case management services.

National Performance Measure #14: The degree to which the State assures family participation in program and policy activities in the State CSHCN program.

For fiscal year 1999, the target for the performance indicator was met. The indicator helps meet the Healthy People 2000 objective that all 50 states have service systems for children with or at risk of chronic and disabling conditions.

The CSHCN programs involve parents of children with special needs in various ways, including the following:

- C For the Title V Block Grant Application process, parents of children with special needs were involved in Title V CSHCN planning committee meetings, and developing, critiquing, and field-testing questions for the survey of families of children with special health care needs.

- C As required by state law, the Hawai'i Early Intervention Coordination Council (HEICC) includes at least 20% (3/15) of members who are parents of infants, toddlers, or children with disabilities aged 12 or younger, and one member who is a parent with a child with a disability aged 6 or younger. In addition several other members have older children with disabilities. The HEICC Chairperson is a parent of a teenager with disabilities. The Early Intervention Section (EIS) involves parents in training and mentoring on all committees and on interview panels for EIS positions. Parents participate both as trainers and as receivers of training. Parents are invited to all training activities sponsored by EIS at no cost. Parents review all brochures and other written materials developed by EIS to ensure they are family-friendly, readable, and understandable. To support parent participation, EIS provides a parent stipend to cover the cost of child care for parents to participate in training and other early intervention activities. In addition, parents from neighbor islands are provided with airline coupons and ground transportation for meeting and training activities on behalf of both HEICC and EIS. EIS includes "parent of a child with special needs" as a desired qualification in each staff position description. Staff members who are parents of children with special needs are involved in the parent panel session of the EIS two-day orientation for all new Early Intervention staff both at EIS and at community programs.
- C For the Early Childhood Services Unit, families are offered services in a family-friendly, natural environment. This includes the home setting or a community-based program or activity where other family members or friends can participate.
- C Five parents of children receiving services from the Children with Special Health Needs Program were selected from island communities to provide their input on proposed policy changes. A detailed information packet was prepared for each participant, and staff members worked directly with the parents to provide an understanding of the proposed changes and obtain their feedback. Parents were paid for their services on an hourly rate.
- C There is a parent member on the State Nutrition Advisory Committee. Stipends are provided for committee meetings. Assistance with inter-island travel is provided to neighbor island participants at the Children with Special Health

Needs Branch nutrition conferences for parents and caregivers. Private grants were obtained to support parent conferences by reducing registration fees. Nutrition conferences/trainings include parents as presenters. The advocacy and initiative of families were key elements in passage of a legislative bill in 1999 mandating insurance coverage for medical foods for children with inborn errors of metabolism.

- C Parents of children with disabilities, as well as students with disabilities, are members of the Special Education Advisory Council which advises the Superintendent of Education on issues related to the education and related therapy of students with disabilities. Family members take a very active leadership role.
 - C Parents of children with phenylketonuria, congenital hypothyroidism, and hemoglobinopathies served on the Community Panel for Newborn Metabolic Screening and on the Newborn Screening Advisory Committee.
 - C The State Genetics Advisory Committee includes consumer representation by having at least one person with a genetic disorder and one person who is a parent of a child with a genetic disorder. The Pacific Southwest Regional Genetics Network--Hawai'i Advisory Committee has three consumer representatives on the committee. One consumer is a parent of a child with a genetic disorder, and another consumer is affected and has a child with a genetic disorder. For the genetics education activity for primary care physicians, consumers were represented on the planning committee and participated on a plenary panel.
 - C The Hawai'i CHOICES Transition Project Planning Committee included individuals with disabilities and parents of children and adults with special needs.
 - C A new Children and Youth Task Force of the State Traumatic Brain Injury Advisory Board of the DOH includes parents of children with special needs.
 - C The family participants are of diverse ethnic and cultural backgrounds, including: Filipino, Japanese, Caucasian, African-American, and Hawaiian.
- National Performance Measure #15: The percent of very low birth weight births.
Data reported for previous years for this measure was changed from preliminary data to final/published figures from the vital statistics division. The new data does not

result in any substantial changes in the percentage of very low birth weight births. The percent of very low weight births for fiscal year 1999 is preliminary and will be updated in next year's report when final data is made available. The percentage for 1999 was 1.2, a decrease from 1.5% in fiscal year 1998 and closer to the Healthy People 2000 target of not more than 1%.

In order to decrease very low weight births, efforts have focused on maternal health. The Title V program continued to fund and monitor purchase-of-service contracts to provide perinatal support services to high-risk women statewide. In addition to promoting early entry into prenatal care to identify medical risks, the women are assessed for psycho-social risks such as depression/mental illness, substance use, and domestic violence. Funding also continued for Baby S.A.F.E. (Substance Abuse Free Environment) services. These services include early identification and outreach/pretreatment services for substance using pregnant women.

Hawai'i was awarded a Healthy Start Initiative Grant to decrease infant mortality and morbidity on the island of Hawai'i which reports some of the highest infant mortality rates in the state. Planning for the grant began in FY 1999. The program will target Hawaiian and Pacific Island women. Services will identify women's stressors as they relate to their pregnancy and provide culturally competent support services.

Because substance use during pregnancy has been linked to very low weight births, training was provided through the March of Dimes to physicians and perinatal support providers statewide regarding this issue. Efforts to design culturally competent interventions for mothers who smoke during pregnancy are in progress. Handbooks, brochures, and posters were reproduced in preparation for further provider training.

The Title V program also received a Pregnancy Risk Assessment Monitoring (PRAMS) grant, which will provide population-based information on maternal behaviors. The data will be used for future program planning and policy development.

A partnership continues with the Healthy Mothers/Healthy Babies Coalition to provide advocacy for women to assure ready access to insurance coverage during pregnancy and to liaison with third party insurers and legislators.

National Performance Measure #16: The rate per 100,000 of suicide deaths among youths aged 15-19.

For fiscal year 1999, the rate of suicides per 100,000 15-19 year old youth was 7.25, not meeting the objective of 5.0. The 1999 high and middle school YRBS provides data on self reports of suicide thoughts, plans and attempts for 6th-8th and 9th-12th grade public school students as follows:

	<u>High YRBS last 12 months</u>	<u>Middle YRBS Ever Considered</u>
Seriously considered	23.3%	30.0%
Made a plan	18.5%	14.8%
Made an attempt	10.1%	11.1%

The Adolescent Survey Committee continues to support the ongoing assessment of reports of suicide thoughts and actions of Hawaii's public school youth through the implementation of the Middle and High School surveys and disseminate this to support program planning and development.

A comprehensive approach is required to address healthy youth development and mental health issues including early identification and interventions. There are a variety of programs and partnerships addressing this measure.

School Based Health Service Centers continued to provide services including risk assessments, education and care coordination to youth who report or express emotions, behaviors related to feelings of sadness, depression, hopelessness and anger.

The Department of Education's Comprehensive Student Support System (CSSS) focus is prevention and early identification. Through CSSS, efforts are being taken to provide social, emotional, and physical environments to ensure students and families connectedness to resources based on a child's needs. The Departments of Health and Education have workgroups meeting to determine how the CDC Coordinated School Health Approach can support CSSS through a public health perspective.

The Hawai'i State Peer Education Program (PEP) collaborated on an Emergency Medical Services Children's Grant with the Injury Prevention and Control Program and the University of Hawai'i to develop a Native Hawaiian Youth Suicide Prevention Project, A Gate Keeper Training Manual, and a pilot demonstration project model. The Gatekeeper Training Conference involved three public school PEP sites with plans to implement the pilot project during the 1999-2000 school year. PEP, in 23 high schools and three middle schools, provides suicide prevention education and personal development skills.

The Basic Concepts In Identifying Health Needs of Adolescents training on Kaua'i assisted with broadening practitioners, advocates for youth, and trainers in understanding the range of normal growth and development (normal and abnormal adolescent behaviors), and in improving communication with adolescents in appropriate interventions and care coordination for emotions and behaviors related to hopelessness and/or anger at self and the world.

The First National Suicide Prevention Conference resulted in the Surgeon General's Call to Action To Prevent Suicide Report in 1999. Title V staff convened a Suicide Planning Group in collaboration with the Injury Prevention and Control Program to assess the needs, data, reports, and resources within the Department of Health. A broader community representation in addition to the DOH has partnered to formulate the Suicide Prevention Task Force which plans to develop a Statewide Strategic Plan for Suicide Prevention for all ages.

National Performance Measure #17: The percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

The previous year's data reported for this measure has been revised. One of the hospital facilities was mistakenly identified as a Level III facility when in fact it was a High Level II. The indicator for 1999 is preliminary and will be revised in next year's report upon release of final data from the vital statistics division.

The percent of very low birth weight infants delivered at facilities for high-risk deliveries has decreased slightly from 73.3% in fiscal year 1998 to 72% in fiscal year 1999. The 1998 indicator was revised from the previously reported 91.5%.

The tertiary care facilities in Hawai'i are Kapiolani Medical Center for Women and Children and Tripler Army Medical Center/Hospital, both located on the island of O'ahu.

Due to the geographical make up of the state, high-risk pregnant women on the neighbor islands and the rural communities on O'ahu are of concern. On the island of Lana'i, OB services are available once a month and all deliveries are on the islands of O'ahu or Maui. On the island of Moloka'i, OB services are provided by certified nurse midwives. Low-risk deliveries occur on-island and high-risk deliveries are flown to O'ahu. In order to assist in identifying high-risk pregnancies, the Title V program has

continued to fund and monitor purchase-of-service contracts to provide perinatal support services to high-risk women statewide.

National Performance Measure #18: The percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

As in other vital statistics measures, the previous year's data was revised to reflect final/published data from the vital statistics division. The indicator for 1999 is preliminary and will be revised next year when final data is available.

The percent of infants born to women receiving prenatal care in the first trimester for fiscal year 1999 was 76.6%. The target of 83% was not met and the percentage is a decrease from the 1998 indicator of 81.3%. The difference is statistically significant. The Title V program will continue to monitor this performance measure and conduct further analysis to identify disparate populations for targeted intervention.

The Title V program has continued to address barriers to accessing prenatal care through the following purchase-of-service contracts: 1) Perinatal Support Services, 2) MothersCare for Tomorrow's Children, a statewide prenatal phone line and incentive program, 3) Healthy Mothers/Healthy Babies (HMHB) perinatal coalition, and 4) Primary Care services for uninsured pregnant women.

Lack of medical insurance is often identified as a barrier to entering early prenatal care. HMHB and the Title V program staff hold quarterly meetings to assess waiting periods for accessing QUEST (Hawaii's Medicaid Waiver program). Through HMHB's advocacy efforts at the legislature, 37 positions with the QUEST program were converted from limited term to permanent status. It was hoped that this would provide a more stable staff who are knowledgeable of the policies and procedures to enroll pregnant women into the QUEST program. In the past, frequent staff turnover contributed to longer eligibility processes for pregnant women, thus delaying entry into prenatal care. Despite improvements in the personnel status, providers have continued to encounter barriers to enrollment. HMHB will continue to work with the QUEST staff to identify the barriers and to facilitate QUEST enrollment.

HMHB, as well as the Title V program, was also involved in a collaborative effort with community health center staff in developing a new QUEST brochure for pregnant women.

The Hawai'i Perinatal Consortium (H.C.) has been developed with the assistance of Maternal Child Health - American College of Nurse Midwife Partnership grant. Its Communication subcommittee will be working towards developing an ongoing effort to provide perinatal information in a way that is friendly and relevant to target audiences. It will promote the importance of early prenatal care.

State Performance Measure #10: Mean number of school days absent per public school student aged 5-18 who is diagnosed with severe asthma.

In 1999, the mean number of school days absent per public school student was 11.5. This number is a slight decrease over the 1998 figure. The 1998 and 1999 data only include absences for children who have severe asthma and have an Emergency Action Plan in place, while the 1997 data measured mean days absent for all children diagnosed with asthma.

Asthma continues to be the most prevalent chronic disease in public school students. The Public Health Nursing Branch organized a Partnership Committee in collaboration with the Department of Education (DOE), American Academy of Pediatrics, American Lung Association, and Title V providers and personnel to address these issues. As a result, a standardized Emergency Action Plan protocol for students with severe asthma was initiated, as well as a process to identify and monitor the students. The DOE's Emergency card was revised and training was provided to health aides to update their knowledge and increase early identification of students with asthma. Emergency Action Plans are developed with the parent/caregiver and include teacher follow-up. Attendance record reviews have been initiated for planning.

The Family Health Services Division, in collaboration with the University of Hawaii's Center on the Family, was successful in its application to the Hawai'i Medical Services Association Foundation for a "Partners Against Asthma" project which has the goal of reducing the prevalence and negative consequences of asthma among children from birth to 12 years of age. Objectives are: 1) to increase early identification of childhood asthma through family education; 2) to reduce the severity of asthmatic episodes and the impact on overall child well-being through the promotion of disease management education; and 3) to improve the data collection and reporting system relating to asthma among Hawaii's children. Strategies will include a statewide campaign that targets children who are most vulnerable to asthma, namely the poor and

children of Hawaiian heritage; a collaborative initiative that builds on successful efforts in Hawai`i and other communities; a strong focus on a common outcome, monitored by measurable indicators; and an emphasis on prevention and control of asthma.

Data from the Hawai`i Health Information Corporation on hospital discharges per 10,000 children less than age 5 years showed a 1998 rate (45.2) that was similar to rates for 1996 (44.6) and 1997 (46.8). These rates decreased from 1995 (55.6).

Data from the 1998 Hawai`i Health Survey showed a statewide asthma prevalence of 137 per 1,000 children 0-17 years of age. Prevalence was higher for children aged 0-14 years (141) compared to older children aged 15-17 years (111). The statewide prevalence of asthma per 1,000 persons of all ages was greatest in Hawaiians (148.2), compared to Caucasian (63.7), Chinese (78.2), Filipino (80.0), Japanese (78.6), and others (73.4).

2.5 Progress on Outcome Measures

The National Outcome Measures address fetal, infant and child fatalities. Activities that address services for pregnant women, mothers and infants are addressed in Outcome Measures 1, 2, 3, 4, and 5. Activities dealing with services for children aged 1-22 are addressed in Outcome Measure 6. Note that the outcome measures are per calendar year, not fiscal year.

The block grant guidance asks the Title V agency to describe the relationship between the degree to which the National and State performance measures were met in the State and their collective contributory positive impact on the outcome measures for the MCH population. This type of data analysis capability will be strengthened over the next fiscal year. Staff will review the performance measures and determine the impact the measures have on the outcomes.

Outcome Measure #1: The infant mortality rate per 1,000 live births.

Data collected from Hawai'i Vital Statistics indicated that the infant mortality rate for calendar year 1999 was 6.9 per 1,000 live births--higher than the infant mortality rates for 1996, 1997, and 1998, 5.3, 6.0, and 6.7, respectively; but still lower than the infant mortality rates of the early 1990*s; and lower than the HP 2000 Objective of 7 infant deaths per 1,000 live births. This was accomplished through direct service activities such as prenatal care through the Comprehensive Primary Health Care contracts.

Outcome Measure #2: The ratio of Black infant mortality rate to the White infant mortality rate.

Because of Hawai'i*s varied ethnic representation, there are almost 20 different racial and ethnic groups listed in the Hawai'i Vital Statistics records. Data collected indicate that for calendar year 1999 the ratio of the Black infant mortality rate to the White infant mortality rate was 1.8. Although this ratio is increasing compared to the 1997 ratio of 0.594 and the 1998 ratio of 1.3, all years result from very few (<10) infant deaths for Black infants. Additionally, the Black infant mortality rate of 10.3 is less than the HP 2000 Objective of 11.0 and the White infant mortality rate of 5.7 is less than the HP 2000 Objective of 7.0.

Outcome Measure #3: The neonatal mortality rate per 1,000 live births.

Data collected from Hawai'i Vital Statistics indicate that the neonatal mortality rate per 1,000 live births was 4.9 for calendar year 1999. Although this rate is slightly lower than the rate of 5.1 for 1998, it is still higher than the HP 2000 Objective of 4.5.

Outcome Measure #4: The postneonatal mortality rate per 1,000 live births.

Data collected from Hawai'i Vital Statistics indicated that for calendar year 1999, there were 34 postneonatal deaths for a rate of 2.0 per 1,000 live births. Although we have exceeded our objective of having fewer than 1.8 postneonatal deaths per 1,000 live births, we have met the HP 2000 Objective of 2.5.

Outcome Measure #5: The perinatal mortality rate per 1,000 live births.

Data collected from Hawai'i Vital Statistics indicate that for fiscal year 1999, there were 113 perinatal deaths (fetal demise >28 weeks plus infant deaths <7 days) for a rate of 6.6 per 1,000 live births. This rate has been increasing slightly since 1996, though the increase is not statistically significant. The preliminary rates for 1996, 1997,

and 1998 rate were 5.2, 5.9, and 6.2 respectively. After final reports were generated by vital records, the final rates were 8.2, 8.9, and 9.3 respectively. If the preliminary rate for 1999 does not change, it will be significantly lower than the final rate of 9.3 in 1998.

Although there is no Objective 2000 measure for perinatal mortality, the 1999 indicator of 6.6 is above the HP 2010 Objective of 4.5.

Outcome Measure #6: The child death rate per 100,000 children aged 1-14.

The rate for child deaths for calendar year 1999 is 12.8 meeting the objective of 17 child deaths per 100,000 children aged 1-14. The data for 1999 is based on preliminary data and may change next year after death record files are reviewed and cleaned. The data reported for this measure for prior years has been changed from preliminary vital statistics data to final published data provided by the Office of Health Status Monitoring. The annual child death rates did not change dramatically despite the switch from reporting preliminary data.

MCHB is working to establish a nurse coordinator position to be responsible for the implementation of the Child Death Review system. A half-time Research Statistician is also being recruited to assist with the data collection and analysis. The start-up learning process for a quality Child Death Review program requires adequate Title V staff support with time-intensive training, coordination, and communication with public and private agencies. Another ongoing challenge is maintaining the long-term voluntary commitment of the multidisciplinary local Child Death Review team members.

Surveillance protocols and preliminary data analysis are being evaluated to identify systems and process issues that resulted from the pilot review project. Next steps include utilizing the aggregated information and recommendations to improve the retrospective statewide child death reviews to develop prevention strategies to address issues that will assist in reducing future child deaths. An annual report of the pilot project will be distributed to stakeholders to report the findings and recommendations.

III. REQUIREMENTS FOR THE APPLICATION

3.1 Needs Assessment of the Maternal and Child Health Population

3.1.1 Needs Assessment Process

Three needs assessment planning groups, including public and private stakeholders, were established to carry out the needs assessment. Required data was collected for the Title V performance and outcome measures, and the new health status indicators. The project collaborated with the Department of Health's Office of Health Status Monitoring (OHSM) and funded questions on the annual Hawai'i Health Survey (HHS) related to health insurance coverage. Insurance and demographic data from HHS assisted in fulfilling Title V data requirements. The Hawai'i Health Information Corporation was contracted to provide hospital discharge data on asthma. The Medicaid program was a major partner and provided Medicaid related data. Collaboration to address data linkage was initiated with OHSM which collects the birth and infant death files and with programs responsible for Medicaid, WIC, newborn screening, hospital discharge, and Healthy Start/early intervention data. Hawaii's CDC-assigned epidemiologist worked with the SSDI project and these partners to submit a SPRANS Data Utilization and Enhancement Grant to improve birth certificate data and to develop a plan for data linkage. New data was collected by carrying out surveys for two groups-- children and children with special health care needs. Although the children with special health needs survey data has been analyzed, the child health survey is still in progress. Several issue papers were developed for each population group. Methods for prioritizing health issues were identified, and five priorities were identified for each population group. The final determination of ten state priorities was made by the core staff for the Title V program. State performance measures were also developed.

3.1.2 Needs Assessment Content

3.1.2.1 Introduction

Capacity of Title V Program Staff:

Hawaii's Family Health Services Division (FHSD), the state Title V agency, spent considerable time and effort planning and starting the process of the Five-Year Needs Assessment. It was decided early in the process that Title V staff would conduct the assessment in-house using existing staff versus hiring a contractor to conduct the study. Title V Program would use this opportunity to

assess the capacity of the staff to compile and analyze data, review the system of services, and assess needs. It became evident through the process that Title V Program had limited capacity in many of the core functions, particularly in the area of assessment. Data information systems as well as epidemiological and statistical analysis and support were variable throughout the division.

Lessons Learned:

The experience helped identify important skill-development areas and training needs for the Title V staff to ensure the state agency is making sufficient progress in the transition from direct service provision to the practice of core public health functions.

The needs assessment process proved extremely beneficial for the Title V staff. People were excited to improve their data analysis skills. Staff reviewed available data with the assistance from newly hired agency statistician, MCH faculty from the University School of Public Health and CDC-assigned epidemiologist. Sources and limitations of the data were reviewed carefully so staff could evaluate the quality of the data and determine its reliability for program or policy decisions. The meaning, significance, and interpretation of the data was discussed. Oftentimes, this led to further questions regarding the data and requests for further analysis.

Another important area for improvement is in planning and evaluation. Once data and analysis is available how is the information applied to program and policy decisions. Key budget and resource allocation decisions are rarely linked to organizational mission, policies, priorities, or plans. Evaluation of programs, existing plans, and policies are not routinely conducted within the division. Policy development is another skill the staff identified as weak. Lastly, the need for organizational planning was characterized by Title V staff as critical as the scope of service is so broad. With the reduction of staff and the expanding scope, there is a need to prioritize Title V Program effort.

Cursory discussions began in the work teams regarding the assessment of available services in the community. However, Title V staff has a good sense of existing programs and has a basic sense of gaps, duplication of services, areas for integration and collaboration. However, additional training is needed to

identify the characteristics of a system, goals of the system, and to assess whether a system of services is in place.

The CSHCN work team began an analysis of the system of care for CSHN with the assistance of faculty from the University Affiliated Program. But, the discussion and initial analysis will require more much extensive work over the next year. A SPRANS CISS grant was submitted as a result of these discussions to continue the systems analysis and develop a community based network of family advocates.

Title V program hoped to use the technical assistance (T.A.) made available through HRSA's CompCare initiative to conduct a similar analysis of the system of care for children; however, the scope of work for the Hawai'i contract was canceled by the Region 9 office because of difficulty with the contractor. Thus, T.A. in this area has been specifically requested in Form 15.

Recognizing the deficit in data analysis skills amongst its staff, Title V Program did submit an application to the Association of Maternal and Child Health Program (AMCHP), Data and Assessment Technical Assistance (DATA) Program to provide training in data collection and analysis. The application is approved.

The needs assessment process did have many positive qualitative outcomes not readily apparent by the actual report submitted this year. Title V staff began to work in collaborative teams with colleagues both within Title V Program and other Department of Health divisions. The Team approach helped foster greater cross-program understanding, analysis, and a more comprehensive (versus categorical) approach to analyze issues and identify interventions. Staff were willing to tackle "messy" issues like violence and substance abuse, utilizing more comprehensive approaches. It became painfully clear to the staff (because of down sizing) that there is a critical need for greater and smarter collaboration across Title V programs, other divisions within the Department of Health, and with systems outside of health (such as education, social services, mental health).

Leaving behind categorical views of public health issues, the staff is now willing to conduct more thorough analysis of these complex problems (examine

the real causes), review more research and craft more innovative responses. The staff also understands their leadership role to help ensure effective systems of care are in place for the MCH population.

While there have been opportunities in the past to work across programs, the key to the teams success was the creation of a safe learning environment for the staff to reflect and discuss the nature of their work. From the outset, the Title V staff made it clear that the teams were designed to assist the staff to strengthen their program efforts and learn new skills. All questions and concerns were encouraged regarding all aspects of Title V block grant, the state Title V agency, and the transition to core public health functions.

The work teams were used extensively to review the purpose and rationale for Title V performance measure system with the staff. Thus, the process of working with data became more meaningful and began to inform their program efforts rather than being a bothersome yearly reporting requirement. The staff has committed to conduct further analysis of the Title V performance measure data during the year and improve the application of the data analysis to program decisions. Discussions also focused on defining and reviewing the level of services as described in the pyramid.

Title V program has documented data sources for all the Title V performance measures and new health status indicators. Each measure has a data sheet which explains in great detail the data collected, the data source (agency contact) for the numerator and denominator and the calculations required to develop each indicator. Limitations and validity/reliability issues are also identified for each source of data. The data information is shared and developed with the agency statistician and program staff.

The importance of building data infrastructure was reflected in the submission of a SPRANS Data Utilization Grant submitted to the Federal MCHB to create more linkages between databases and agencies as encouraged in the new Title V infrastructure health status indicators. Title V Program provided leadership in the collaborative grant effort between Title V Program, the Office of Health Status Monitoring (which manages the vital statistics data) and the state Medicaid agency.

Emphasis was also placed on the need to set priorities. Staff often believe they are required to do everything despite enormous reduction in resources over the past five years. The wisdom of targeting resources (including staff time) toward a few feasible priorities was a major lesson for state Title V personnel. It was stressed to the staff that the prioritization was not an academic exercise, but would reflect programmatic commitment to the identified state priorities. If new priorities were adopted, then resources devoted to current priorities may need to be reduced or new resources identified.

Status of Needs Assessment:

Despite the benefits engendered by the process, the meetings were protracted and time consuming and the needs assessment is far from complete nor as comprehensive as required. Further data collection from existing sources needs to be completed. Analysis of the data is also needed. Moreover, the primary data source for the child health assessment, a statewide child health survey, is not complete. Delays were experienced during the contract negotiations over the scope of work and budget, as well as the process to secure contract approval. The child health survey is currently underway to collect data on children 5-11 years of age. The random-digit dialing telephone survey of parents will yield a demographic profile of children 5-11 years for the state, household information, as well as information on insurance coverage, health service utilization, barriers to care, and satisfaction with the quality of care. Parents/caregivers will also be asked questions regarding their children's diet, physical activity, experience with school violence, behavioral problems, after school/child care and access to guns in the household. Furthermore, the survey is using the Foundation for Accountability (FACCT) screening questions to identify population-based numbers for Children with Special Health Needs in Hawai'i. The sample is large enough to generate county data which communities have been requesting. Data will not be available in time for this year's needs assessment and will be included in next year's report.

Needs Assessment Plan/Preliminary Report:

The assessment presented is an initial attempt by the Title V staff to conduct an in-house needs assessment. Title V staff recognize the preliminary

nature of this effort and is clearly committed to continue assessment work throughout the next year. The summary of findings to date will be strengthened over the next year as Title V staff build their ability to work with data and assess the system of care. Title V support for T.A. and training needs for the staff will be an essential component to the state agency's success. Thus, an extensive technical assistance request has been made through the Title V application in Form 15. A more complete and comprehensive needs assessment will be included in next year's Title V report.

Data which was ready to present is provided. A list of additional data has been identified for collection and analysis over the next year. The plan for work on the assessment as outlined in the state's SSDI grant is included to assure MCHB that work will be conducted on the needs assessment throughout the next year. The staff will review and update the plan in the next few weeks to identify achievable short term benchmarks for the year.

Title V Program understands the importance of the needs assessment. The assessment part of a cycle to produce planned change in the health status of the MCH population. The assessment will serve as a basis for the state Title V agency to set clear goals, objectives, action plans, implementation activities, evaluation of accomplishments and revisions based on evaluation findings.

3.1.2.2 Overview

This section provides an overview of the demographic and economic characteristics of the State, the health resources that are available in Hawai'i and availability of scope of health insurance in the State. More detailed data will be included in our discussion of each MCH population group.

General Population:

Hawaii's estimated population in 1999 was 1.2 million. The population of the state is generally slowing in growth. Between 1995 and 2000 the resident growth rate is projected to be 0.45 percent, the slowest growth since statehood in 1958. The slowing rate of growth is due in part to poor economic growth and declining job counts.

The proportion of elderly in the population increased from 5% in 1960 to 13% in 1997, giving Hawai'i an aged population comparable to the national

average. The numbers of “older old” are also increasing dramatically. Between 1990 and 1997, the number of residents ages 75 and older increased by 47%, and the number of those 65 to 74 years old increased 15%. This is due in part to Hawai`i’s high average life expectancy, one of the highest in the U.S.

Ethnic Diversity:

Hawai`i is unique in the U.S. with a multi-ethnic population in which no single ethnic group is a numerical majority. There are over ten different ethnic groups that have significant populations in the state. Based on the most recent information available from the Department of Health, the largest ethnic groups are Caucasian (22%), Hawaiian (21%), Mixed-except Hawaiian (21%), Japanese (20%), Filipino (10%), Chinese (3%), and Other (3%).

Geographic Distribution:

Approximately 75% of the residents live in the County of Honolulu which comprised the island of O`ahu. The “neighbor island” counties of Hawai`i and Maui both have 10% of the population and 5% of the population lives in the County of Kaua`i. Approximately one-third of residents on the islands of Hawai`i and Maui are living in rural areas. There has been only a minor shift of population toward the Neighbor Islands, primarily to Maui and Hawai`i islands. The islands of O`ahu and Kaua`i have extensive public transportation systems, while there is none in Maui County.

Financial Resources:

The average per capital income in Hawai`i is below the U.S. average. In 1999 it was \$27,842 in Hawai`i and \$28,518 for the U.S. This does not take into account the higher cost of living in Hawai`i due to the state’s isolation from the continent and dependence on transporting many essential goods and services. The median household income for 1998 was \$41,200 a substantial decline from \$48,526 in 1993 after adjusting for inflation.

Based on state data, 9.4% or 111,437 people in Hawai`i have incomes below the federal poverty level. About 28.4% or 336,681 people had incomes below 200% of the poverty level.

POVERTY LEVELS	TOTAL
Total Population	1,185,497
Percent Below: 50% of poverty	3.6%
100% of poverty	9.4%
200% of poverty	28.4%
Source: Hawai'i State. Department of Health. Office of Health Status Monitoring. Health Surveys & Disease Registry. Hawai'i Health Survey, 1999.	

MCH Population:

While the percentage of elderly is increasing, children and youth are a declining proportion of the entire state population. Since 1960, the proportion of youth to total population has decreased from 43% to 28% in 1997.

About 390,788 or 34% were women in their childbearing years, children and adolescents. Estimates of the Title V target groups are shown in table below.

Group	Number	% of All People
Total: All People All Ages ^a	1,185,497	100.0%
MCH Subgroups ^b	573,100	48.3%
Women in Childbearing Years (15-44) ^a	247,906	20.9%
Pregnant Women ^c	21,552	1.8%
Infants Under 1 Year ^a	16,742	1.4%
Children and Adolescents (1-19) ^a	308,452	26.0%
Children with Special Health Care Needs ^d	51,542	4.3%
^a U.S. Bureau of the Census. 1999 population estimates for the State of Hawai'i. ^b Does not include pregnant women, since they are counted among women in childbearing years. ^c Hawai'i State, Department of Health, vital records. ^d Hawai'i State, Department of Health, Children with Special Health Care Needs, estimation.		

3.1.2.3 Preventive and Primary Care Services for Pregnant Women, Mothers & Infant

Births:

In 1997, the Hawai'i birth rate, which had been higher than the national rate, essentially converged with the U.S birth rate. Much of the difference between 1970 and 1997 was attributable to the relatively high military birth rate. In Hawai'i, between 17% and 20% of all births are to military families. Overall, birth rates in both Hawai'i and the U.S., including military births, have been declining since 1990.

Hawai'i's birth rate declined dramatically between 1970 and 1997, from 21.2 births to 14.6 births per 1,000 population, a decrease of 31%. This decline is due in part to fewer women in child-bearing age groups (15-44), preference for fewer children and increasing delays in child bearing. Hawaii's decreasing birth rate is coupled with an increasing death rate which means that most of the population growth in the state is due largely to in-migration. Thus, the population is "reproducing" itself to a lesser degree.

The majority of births are to women 20-34 years of age (73%). The percentage of all births to women under 18 years has stayed fairly constant (3-4% of all births) from 1990-1999. Whereas, the percent of births to women over 35 years continues to increase from 11% in 1990 to 16.3% in 1999. Timing of births differ significantly by ethnicity in Hawai'i. The majority of Asian women are delaying childbirth to age 35. Of all the births to Japanese women in 1999, 31% were to women over 35. For Chinese, the percentage was 30 and for Koreans 26%. Hawaiian women on the other hand are choosing to have their children at a younger age. Of all births to Hawaiian women in 1999, 20% occur to women 19 years or younger. Hawaiian women account for 50% of teen births in 1999.

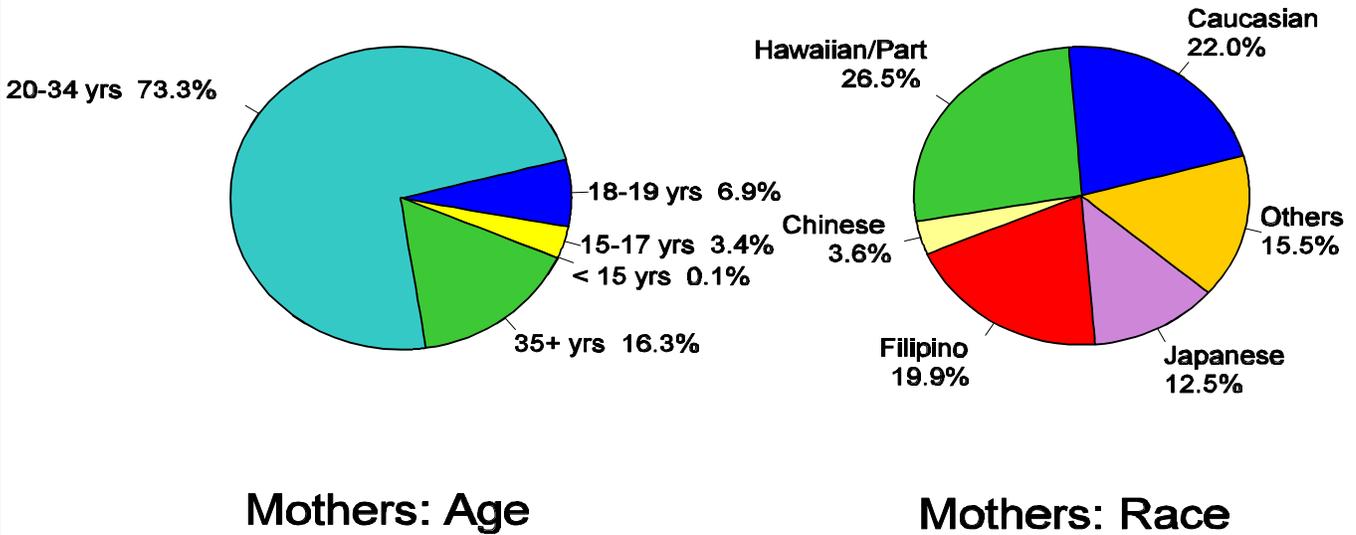
Health Status Indicator #07: Births to Women in Hawai'i by Age, 1999						
Category	< 15 years	15-17 yrs	18 and 19 yrs	20-34 yrs	35+ yrs	Women all ages
Caucasian	0	33	133	2,768	687	3,621
Hawaiian/Part-Hawn	7	303	591	3,209	394	4,504
Chinese	1	9	10	409	185	614
Filipino	5	125	216	2,537	506	3,389
Japanese	1	28	58	1,381	650	2,119
Puerto Rican	0	5	7	62	9	83
Korean	0	2	11	237	87	337
Samoaan	1	20	44	411	42	518
Portuguese	0	3	6	95	18	122
Guamanian	0	1	4	31	3	39
American Indian	0	7	16	139	41	203
Black	0	13	28	376	40	457
Vietnamese	0	3	2	127	23	155
Other Asian	0	5	6	95	21	127
Other Pacific Islanders . . .	0	15	36	430	44	525
Cuban	0	0	0	1	0	1
Mexican	0	4	10	116	13	143
Asian Indian	0	0	0	11	7	18
All Others	0	0	0	4	2	6
Unknown	0	0	0	8	4	13
Total	15	576	1,180	12,452	2,776	17,000

Birth rates in Hawai'i differ significantly by ethnicity. In 1995, the most recent year that reliable data is available, Hawaiians and Filipinos had the highest birth rates at 20.7 and 20.6 births per 1,000, respectively. In 1999, the majority of

births were to Hawaiian/Part Hawaiian women (26.5), followed by Caucasians (22%). The smallest percentage of births (3.6%) were to Chinese women. See the graph below.

Developmental Health Status Indicators #07A

Births to Mothers by Age, by Race: 1999



Infant Mortality:

Infant Mortality in Hawai'i for the last ten years has remained lower than the national average. Due to the small numbers involved (less than 130 deaths per year) relatively wide swings in the actual rate can occur each year and result in frequent shifts in Hawai'i's national ranking for infant mortality. The 2000 Kids Count, using 1997 data has Hawai'i ranked 18th down from 8th the year before. Since 1980, infant mortality rates for Caucasians and Japanese have

been consistently lower than the statewide rate, while the infant mortality rates for Hawaiians have been consistently higher.

Low-Birth Rate:

Hawai'i has a lower incidence of low and very low birth weight babies than the U.S. as a whole. The percent of low birth weight babies have begun to rise slightly since reaching a low of 6.5% in 1994. The percentage for 1999 was 7.4. However, there has been a slight increase in multiple births which may account for much of this increase. The percentage of very low birth weight babies has remained steady 1.2% in 1996 and 1999 as has the number of multiple births in this weight classification.

Prenatal Care:

Women who have no prenatal care are far more likely to have low birth weight babies. In the early 1990s the data showed the longer a women waited to have a first prenatal care visit, the more likely she was to have a low birth weight baby. That relationship no longer appears in the recent data, although women receiving prenatal care in the first trimester consistently have better birth outcomes than the statewide average. For 1999, there was a slight decrease in the entry to prenatal care in the first trimester from 81.1% in 1998 to 76.6% in 1999. This percentage is slightly below the national average of 83%. The percentage of pregnant women who made an adequate number of prenatal care visits also decreased slightly in 1999 from 71.9% in 1998 to 68.2% in 1999.

Data for 1997 shows women of Portuguese ancestry received the highest percentage of early prenatal care (91%), while African-American, Japanese and Caucasian mothers are approaching the Health People 2000 target of 90% (89%, 88%, 88% respectively). Disparities appear with 67% of Samoan mothers along with 76% for Hawaiian and Vietnamese women who received early prenatal care.

Chlamydia:

For 1999 Hawai'i reported at rate of 21.1 per 1,000 women aged 15-19 years with a reported case of chlamydia. The rate was significantly less (7.2) for women aged 20-44 years.

3.1.2.4 Preventive and Primary Care Services for Children

Location:

The numbers of children increased on the neighbor islands, but decreased on the main urban center of O`ahu. Nearly two-thirds of Hawaii's children and youth (70%) live in urbanized areas, while only 30% live in rural areas. Persons under 19 years of age are more likely to live in the urban fringe (suburbs), while adults are more likely to live in the central urban areas. There are no metropolitan or frontier areas in Hawai`i.

GEOGRAPHIC LIVING AREAS ^a	TOTAL
Living in urban areas	236,487
Living in rural areas	97,210
All children 0 through 19	333,697
^a Census Bureau's 1998 population estimates for the State of Hawai'i and geographic definitions.	

Children in Poverty:

The percentage of children in poverty has dramatically increased during this decade from 11.1% in 1990 to 20.7% in 1997. County data from 1995 show that the increase is in every county, with the rate in Hawai`i County being nearly double that of other areas. In the 2000 Kids Count report, Hawai`i is now ranked 27th in the percent of children in poverty, exceeding the national rate of child poverty. This report uses the federal poverty level (unadjusted for Hawai`i's higher cost of living) thereby understating the true poverty.

Insurance Coverage:

Despite the economic hardship experienced by many Hawai`i families, the data reveals that the percentage of children covered by health insurance is still relatively unchanged and relatively high compared to national averages. In 1990, the percentage of children covered was 92.1% according to the U.S. Census reports. Recent data from the 1999 Department of Health indicates

coverage to be as high as 96.3%. Many service providers have questioned the accuracy of this data, however. Although the percent of Hawai'i's children who are covered by health insurance has remained relatively constant, the type of coverage has changed. Private insurance coverage has declined more than 28% while Medicaid coverage has doubled since 1990.

Mortality:

For most of the leading causes of death children, including perinatal conditions, congenital anomalies, motor vehicle collisions and unintentional injuries, Hawai'i's death rates are lower than those of the U.S. as a whole.

3.1.2.5 Services for Children with Special Health Care Needs

Sources

The following sources were used to assess the need for direct health care, enabling, population-based, and infrastructure-building services for CSHCN:

- C List of needs and issues identified by Title V CSHCN Planning Committee in a series of meetings from August to September 1999.
- C CSHCN/family survey conducted by CSHNB in January-February 2000. The survey focused on some of the needs identified by Title V CSHCN Planning Committee. Surveys were distributed to 2,562 families with children enrolled in the CSHNB Children with Special Health Needs Program, Preschool Developmental Screening Program, Early Childhood Services Programs, Respite Program; Shriners Hospital for Children; and other families throughout the state. Forty-nine (49%) of families completed and returned the survey. A major limitation was that this survey was not population-based.
- C CSHNB study of need for vision and hearing screening in elementary and middle schools in two school districts on Oahu (January to June 2000), and study of vision screening in young children using a photoscreener (1997-1999). Both studies were conducted by the Audiologist with the Children with Special Health Needs Program.
- C Newborn Metabolic Screening Program study (1999) to assess the care and the education given to families of newborns identified with Bart's hemoglobin and other hemoglobinopathy traits/diseases.

- C CSHNB program data, including monthly and special reports, and information from interviews with key CSHNB staff. Programs included the Children with Special Health Needs, Early Intervention, Newborn Hearing Screening, Newborn Metabolic Screening, Hawaii Birth Defects, Preschool Developmental Screening, School Health Support Services, Genetics, and Nutrition.
- C Data from other federal, state, and community agencies, such as the Office of Health Status Monitoring (OHSM), Hawaii Health Information Corporation (HHIC), Hawaii Medical Services Association “Health Trends in Hawaii” (1999) (HMSA), Social Security Administration, and others.

Overview of the CSHCN Population’s Health Status

- C Using a 15% estimate of CSHCN (from R Stein, EJ Silver, “Operationalizing a Conceptually Based Noncategorical Definition”, Arch Pediatr Adolesc Med 1999;153:68-74), it is estimated that Hawaii has approximately 51,542 children with special health care needs. The number will be more precise when data is available from both the national CSHCN survey and the Department of Health’s Maternal and Child Health Branch’s child health survey which are in progress. There is currently no overall single source for information regarding the health conditions of CSHCN in Hawaii.
- C For children age 0-9 years requiring care on a regular basis, 1994 survey data from the FHSD/Maternal and Child Health Branch showed that 15% of Hawaii families have at least 1 child who requires care for a health condition on a regular basis. The majority of these children had asthma (46%), ear infections (9%), and allergies (7%).
- C Asthma is a major health problem for Hawaii children.
 - o Data from HHIC on hospital discharges per 10,000 children less than age 5 years showed a 1998 rate (45.2) that was similar to rates for 1996 (44.6) and 1997 (46.8). These rates decreased from 1995 (55.6).
 - o Data from the 1998 Hawaii Health Survey showed a statewide asthma prevalence of 137 per 1,000 children 0-17 years of age.

Prevalence was higher for children age 0-14 years (141) compared to older children age 15-17 years (111). The statewide prevalence of asthma per 1,000 persons of all ages was greatest in Hawaiians (148.2), compared to Caucasian (63.7), Chinese (78.2), Filipino (80.0), Japanese (78.6), and others (73.4).

- Data from HMSA for asthma prevalence by age group in 1996 showed that the greatest prevalence occurred in younger children: 0-3 years, 10%; 4-5 years, 11.3%; 6-12 years, 7.9%; 13-14 years, 5.4%; 15-17 years, 4.4%; 18-19 years, 2.6%. The overall prevalence for 0-19 years was 7.5%.

C The prevalence of diabetes in 1996 for children ages 0-19 years was 2.2/1,000 (data from HMSA).

C The incidence of cancer for children in 1996 was approximately 18 per 100,000 population, with leukemia as the most frequently occurring cancer in children, followed by nervous system cancers (data from HMSA).

C Birth defects are a major cause of infant mortality in Hawaii, with over 1,000 fetal deaths each year. Approximately 20% of all pregnancies result in spontaneous miscarriage and over 1,000 (5.3%) of all babies each year have some recognizable abnormality. Neural tube defects (NTDs) are common birth defects contributing to infant mortality and disability. The 1999 rate for NTDs in Hawaii was 7.2 per 10,000 live births/fetal deaths/medical terminations. (Data from the Hawaii Birth Defects Program, June 2000.)

C Mortality rates for children age 0-19 due to chronic conditions (rates per 100,000 population, 1997) (data from OHSM/HMSA):

Congenital anomalies	9.2
Malignant neoplasms	4.2
Heart disease	2.7
Cardiovascular diseases	0.9
Chronic obstructive pulmonary disease (including asthma)	0.6
Nephritis	0.3

C Data from the Newborn Metabolic Screening Program (June 2000) showed :

- From 1986 to present, there were 9 infants with classical PKU and 3 with hyperphenylalaninemia; and 159 cases of congenital hypothyroidism, 57 with primary hypothyroidism, 7 with secondary hypothyroidism, 67 with transient hypothyroidism, and 28 undetermined. The rates in Hawaii are similar in magnitude as reported nationally.
- From July 1997 to present, the following significant cases were identified: 1 congenital adrenal hyperplasia (male salt-waster), 1 profound biotinidase deficiency and 1 partial biotinidase deficiency, 2 classical maple syrup urine disease (MSUD), 2 galactosemia Duarte variant, 1 sickle cell (SS) disease, 1 sickle C (SC) disease, 1 F only, 5 probable Hemoglobin E disease cases, 41 Hemoglobin H disease, 1 Hemoglobin Lepore, and 1 New York variant. In addition, 235 S trait, 123 E trait, 67 C trait, 6 D or G trait, and 1,093 alpha thalassemia (Bart's) trait cases have been identified.

C Data from the Newborn Hearing Screening Program showed the following statewide rates for infants with confirmed hearing loss for the January 1998 to June 1999:

Permanent conductive hearing loss	0.9 per 1,000 births
Sensorineural hearing loss	3.4 per 1,000 births

C A CSHNB study to assess the accuracy and feasibility of the MTI Photoscreener in identifying vision problems in children ages 6 months to 5 years old showed that of a total of 710 children who were screened, 65 children were subsequently referred for further medical evaluation. Rates of referral were higher for children with special needs age 0-3 receiving early intervention services, compared to children age 0-5 not receiving early intervention services. Diagnosis information from medical follow-up of children showed: 12 (23.1%) children with ocular misalignment, 12 (23.1%) astigmatism, 10 (19.2%) hyperopia, 5 (9.6%) myopia, 1 (1.9%) ptosis, 1 (1.9%) anisometropia, 6 (11.5%) other, and 5 (9.6%) normal.

- C The CSHCN/family survey showed that for the 1,257 respondents:
- The largest ethnic groups were Hawaiian/Part-Hawaiian- 44.4%, mixed/not Hawaiian- 18.2%, Filipino- 14.4%, Caucasian- 10.9%. This may reflect the ethnicity of families to whom surveys were sent, rather than the general CSHCN population.
 - 53.8% of the families reported that they had Medicaid/QUEST, WIC, or SSI, which are programs with income eligibility requirements. This may reflect the income of families to whom surveys were sent, rather than the general CSHCN population.
 - Health conditions included: 63.2%- physical conditions/problems, 28.6%- emotional or behavioral conditions/problems, and 42.6%- problems in learning. 38.6% of children had conditions/problems in more than one of these areas.
 - Compared with other children of the same age, children had more difficulty in the following areas: 33.1%- walking or moving around; 32.9%- bathing, dressing, eating, toileting; 46.3%- talking, understanding; 45.3%- learning or paying attention to tasks.

- In the last 12 months, 21.2% of children missed 2 or more weeks of preschool or school because of health reasons (range up to 11 months).
- In the last 12 months, 17.9% of children went to a doctor's office or clinic 6-10 times, 8.0% went 11-15 times, 3.5% went 16-20 times, and 4.1% went 21-75 times; 18.7% of children went to an emergency room 1-2 times, 4.0% went 3-6 times, and 0.9% went 7-16+ times; and 16.3 % of children stayed in the hospital 1-2 times, 3.4% stayed 3-6 times, and 0.8% stayed 7-20 times. The total number of hospital days ranged from 1 day to 1 year.

Direct Health Care and Enabling Services

Financial access to health care and health-related services

- C In 1974, the Prepaid Health Act mandated that all employers provide health insurance to employees working more than 19 hours a week. This has had a major impact in assuring that a large segment of Hawaii residents had health insurance coverage.
- C Data from the 1998 Hawaii Health Survey showed that 74,362 individuals (6% of the population) in Hawaii were uninsured. The largest uninsured ethnic group was Caucasian (9%), followed by Hawaiian/Part Hawaiian (7%), Filipino (5%), and Chinese (5%). Maui County had the highest percentage of uninsured residents (9%), followed by Kauai County (8%), Hawaii County (8%), and Oahu (6%). There are a total of 15,033 children between age 0-17 years who are uninsured. For children age 0-14 years, 5% are uninsured; and for youths age 15-17 year, 7% are uninsured.
- C The CSHCN/family survey showed:
 - 96.5% of children had health insurance coverage, 91.0% had drug coverage, 87.0% had dental coverage, and 74.2% had vision coverage. For families who did not have insurance, reasons included: 46.2%- cost was too much, 35.9%- they worked but did not have a family plan, 38.5%- child did not

qualify for QUEST or Medicaid, 15.4%- too difficult to apply for Medicaid or QUEST, and 20.5%- other reason.

- Families reported on some of their financial costs of care: 62.1% of families had out-of-pocket costs for their child's health care in the last 12 months, with 18.3% of families having costs of over \$1,000; 39.2% of families said that they or a family member cut down on work hours or stopped working to provide care for their child; 33.4% of families said that the extra costs of care for their child resulted in financial problems.
- Comments from families included: not able to afford insurance, not eligible for insurance through their employer, difficulty getting insurance approval for service, having financial problems but not eligible for public assistance, service not covered by insurance, high co-payment cost, not able to work because of need to care for their child.

C Being “underinsured” is sometimes a problem for families, for example, when insurance does not cover all the expenses for extensive medical care and hospitalization. In addition, insurance benefits (depending on the health plan) may not cover needed services such as: interisland travel (air/ground transportation, lodging) from Neighbor Islands to Oahu for medical specialty services; hearing aids and related services; durable medical equipment; medical supplies; nutrition services; orthodontics; assistive technology.

C The CSHNB Children with Special Health Needs Program provides limited financial assistance as a “last resort” and “safety net” when no other funds or insurance coverage is available. Financial assistance is provided for medical specialty office visits, laboratory tests for medical purposes, procedures such as X-rays and EKG, travel and lodging for neighbor island clients to medical services on other islands, prescription medications, hearing aids and related services.

C There is no cost for families for services at Shriners Hospital for Children. Some community health care providers will provide

uncompensated services in special situations. Primary care centers provide services on a sliding fee scale.

Geographic access to health care and health-related services

- C The state of Hawaii is composed of seven populated islands located in four major counties. Approximately 80% of the adult population and 70% of the children reside in the City and County of Honolulu on the island of Oahu. The neighbor island counties are Hawaii, Kauai (includes Niihau), and Maui (includes Molokai and Lanai). Only 10% of the state's total area is classified as urban. The island of Oahu is the most urbanized, with a third of its land area and 96% of its population in urban communities.
- C The majority of tertiary health care facilities and specialty and sub-specialty services are located on Oahu, with the greatest concentration in the capital city of Honolulu. Consequently, Neighbor Island and rural Oahu residents must travel to Honolulu for these services. This is a financial barrier for Neighbor Island residents, since round-trip airfare is about \$100. Additional costs include ground transportation, and lodging/meals for extended visits.
- C Some Neighbor Island families have difficulty traveling to health services on their own island, due to factors such as long distances, winding roads, length of travel time, cost for gasoline, and lack of public transportation system.

Cultural acceptability of health care and health-related services

- C The State of Hawaii is unique in its ethnic diversity. With over one million residents, there is no one ethnic group that comprises a majority. Caucasians, Japanese, Filipino, and Native Hawaiians are the four largest ethnic groups, and together make up 73% of the population. The remaining residents are Chinese, Korean, Vietnamese, Samoan, Pacific Islanders, Black, Laotian, American Indian, Eskimo, Aleut, or Tongan.
- C Language is sometimes a barrier. The individuals that report English speaking (and understanding) ability as "Not well or Not at all" include: 13,358 Japanese; 9,353 Filipinos who speak Tagalog; 6,984 Chinese;

5,941 Filipinos who speak Ilocano; 4,522 Korean; and 1,498 Vietnamese.

- C Culture may influence an individual's definition of health and illness, belief about disease causation, behavior during illness, seeking of medical help, expectations about treatment, compliance with following prescribed procedures and treatments, and proper standard of behavior in transactions with a provider. Approaches to cultural diversity by Department of Health and community programs include: hiring of ethnically/culturally-diverse staff with experience in working with people in various cultures; inviting participants from diverse populations to review the appropriateness of programs, messages, and interventions; and education/training to develop cultural competence and awareness.

Availability of prevention and primary care services

- C Primary care providers are available on all islands. Primary care providers include private physicians, primary care centers, medical centers, etc.
- C The CSHCN/family survey showed:
- 91.7% of children had a doctor who knew about their child's health. Of these families:
 - Over 80% of families said their child's doctor ("medical home") listens carefully to them; provides information about their child's condition and care; includes the family in making decisions about their child's health care; talks about growth, behavior, injury prevention, and immunizations; and are available at all times when their child was sick.
 - 70-75% of families said their child's doctor arranged or coordinated the services for their child provided by different doctors, therapists, or other persons; that the family received reassurance and support about the care they provided for their child, and that their family's cultural background is recognized and respected.

- CSHNB/Preschool Developmental Screening Program data for 1998-99 showed that of 2,386 children who were screened/rescreened, 6-8% children were recommended for comprehensive evaluation through the Department of Education (DOE), while 12% were recommended for psychological/intellectual assessment and 6% for speech assessment. Children scoring at or below the tenth percentile were: motor- 18%, concept- 16%, language- 13%, overall- 18%. Thirty percent (30%) of children exhibited behaviors during screening that interfere with learning.
- Screening issues include: need for standardized screening by primary care providers; length of time and inadequate insurance reimbursement for screening; lack of a simple fast tool that is psychometrically sound; lack of provider knowledge regarding development and strategies to support development; lack of affordable resources for children age 3-5 years who are not appropriate DOE referrals; insufficient number of quality preschools where developmental and behavioral concerns are likely to be identified and therapy can be provided; lack of a standard protocol for developmental screening to include parent education, monitoring, and referral for evaluation.

Availability of specialty care services when needed

C Data from the *CSHCN/Family Survey* showed that of a list of 13 direct and enabling services, 32.0% of the families reported that they needed but did not get one or more services:

	<u>CSHCN/families needing but not getting service</u>
Dental services	9.9%
Respite care	8.7%
Care coordination	5.6%
Home modifications	5.1%
Physical, occupational, or speech therapy	5.0%
Medical specialty services	4.8%
Home health care	4.7%
Behavior/emotional counseling, mental health services . . .	4.5%
Nutrition services	3.9%
Medical supplies and equipment	3.4%
Vision services	2.4%
Hearing services	2.0%
Prescription medicines	1.2%
One or more services	32.0%

C The Title V CSHCN Planning Committee identified the limited availability of specialty and related services on Neighbor Islands and in rural areas of Oahu, including: pediatric specialty (including genetics, otolaryngology, neurology, ophthalmology, cardiology, orthopedics, surgery), dental, mental health, chemotherapy, specialized services for medically fragile, nutrition, audiology, psychological services for young children age 0-3 years, prosthetic, occupational and physical therapy, respite, and home health services.

C Most specialty health care services are available on Oahu, with fewer located on the Neighbor Islands. Tertiary health care facilities are located on Oahu, with none on the Neighbor Islands. Medical specialty clinics on Neighbor Islands are provided by Oahu private physicians, Kapiolani Medical Center for Women and Children, Shriners Hospital for Children, and CSHNB/Children with Special Health Needs Program.

Shriners Hospital has begun to use telemedicine between Oahu and Neighbor Island sites.

- C The Newborn Metabolic Screening Program identified a need for genetic and hematology services especially on Neighbor Islands, and a need for education for primary care providers. In July 1999, surveys were sent to primary care providers regarding individual infants identified with Bart's hemoglobin and other hemoglobinopathy traits/diseases. Results showed that only 64% of the infants with hemoglobinopathies were referred for further testing. Most physicians provided their own education or "genetic counseling" to families. Approximately 15% of the families needed but did not receive genetic services. Many Neighbor Island providers felt that more clinics on their islands were needed.
- C The availability of early intervention services is an area of concern. CSHNB/Early Intervention Section (EIS) is the "lead agency" for Part C of Individuals with Disabilities Education Act (IDEA) in Hawaii, responsible for the development and implementation of a statewide, comprehensive, coordinated system of early intervention services for infants and toddlers with disabilities and their families. EIS data for May to December 1999 showed of 14 services (assistive technology services, audiology, family training/counseling/home visiting, health services, medical services for diagnostic or evaluation purposes, nursing services, occupational therapy, physical therapy, psychological services, social work, special instruction, speech pathology, transportation, vision services), the monthly average was 5.5 services that were sufficiently available throughout the state to meet the needs specified in the Individual Family Support Plan (IFSP) for all eligible children and their families. Reasons for lack of availability included: lack or insufficient number of providers on island or in area; insufficient number of providers with specialized training or experience; difficulty recruiting providers and program staff; increase in number of identified children needing services, with inadequate resources to meet this need; providers were not able to schedule services at times convenient for family;

difficulty rescheduling services in remote areas when appointments are missed; insufficient funds to contract for services; increase in number of families requesting services in natural settings, e.g., at their home or at the homes of family daycare providers or community preschools.

- C The CSHNB/EIS Respite Program provides respite funds for families of infants or toddlers age 0-3 years and families of children age 0-21 years with a serious or chronic illness. Respite services are currently provided for 136 children age 0-3 years, and for 59 children with serious or chronic illness per month. An estimated 50% of families are receiving an inadequate amount of respite services, with a need to increase from 4 to 8 hours per week.

Impact of shift in Medicaid coverage on financial barriers to care and services delivered by State and local public health agencies

- C The Department of Human Services implemented 3 new programs which will assist CSHCN and decrease some financial barriers to care:
- *A Medically Fragile Children's Waiver* (April 2000) will enable the deinstitutionalization of 50 medically fragile children from the hospitals and nursing facilities to their homes or foster homes with appropriate community-based services. The waiver is for children who have health conditions which require complex medical and/or ancillary services to be sustained in their homes; need 24 hour a day oversight of their health status; and require an extended amount of multi-disciplinary care in a supportive environment to prevent rehospitalization or institutionalization.
 - The *Hawaii Child Health Insurance Program (CHIP)* was implemented on July 1, 2000, for children under age 19, with family income up to 200% FPL and no asset limits. Benefits are the same as Medicaid/QUEST for children, with health coverage provided through QUEST managed care plans. As a Medicaid expansion program, all Medicaid eligibility requirements are

applicable, and all Medicaid covered services, including EPSDT, will be provided.

- *A medical assistance program for immigrant children* was implemented July 1, 2000. The program was established by the Legislature, with 100% state funding. Age and income eligibility is similar to that of CHIP. The program will provide medical assistance for legal immigrants who arrived after August 22, 1996, refugees, and non-immigrants from the Trust Territories of the Pacific Islands who are citizens of the Marshall Islands, Federated States of Micronesia, or Palau. Benefits will be the same as that for Medicaid/QUEST children.

C It is expected that the number of uninsured children will decrease and more CSHCN will receive needed medical services. A “safety net” will still be needed for families who are not eligible for public medical assistance because of non-legal immigrant status or families who have income above eligibility limits but cannot afford medical services.

Impact of move to managed care on service delivery

C Disabled children who meet the SSI criteria continue to be enrolled in Medicaid fee-for-service program. The proposal to enroll these children in the QUEST managed care has been on hold while CHIP was being developed.

Impact of Supplemental Security Income (SSI) eligibility changes for CSHCN

C While some families were affected by the SSI eligibility changes, data indicate that overall the number of Hawaii children receiving SSI increased by 35% over a 4-year period from December 1995 to December 1999 (data from the Social Security Administration, Office of Research, Evaluation and Statistics, “Children Receiving SSI” reports).

Other changes in financial access

C A new law, effective June 2000, defines “medical necessity” as a health intervention that is “(1) for the purpose of treating a medical condition; (2) the most appropriate delivery or level of service, considering potential benefits and harms to the patient; (3) known to be effective in

improving health outcomes, provided that...effectiveness is determined first by scientific evidence, ...then by professional standards of care, and...then by expert opinion; (4) cost-effective for the medical condition being treated compared to alternative health interventions, including no intervention. ...Cost-effective shall not necessarily mean the lowest price.” There are concerns raised by the American Academy of Pediatrics Hawaii Chapter and other CSHCN advocates that the inclusion of “cost-effective” in the definition will impact the financial access to services especially for CSHCN, since there may be a potential bias in favor of “no treatment” as the least costly intervention; it may be used to ration services rather than respond to the individual needs of the patient; it may discriminate against those who are not "average", i.e., children, the disabled, and chronically ill; and there is no established methodology for determining cost comparisons.

- C CSHNB assisted in promoting legislation (1999 law) for insurance coverage of medical foods and low-protein modified food products for the treatment of inborn errors of metabolism. This involved working with families of children with metabolic conditions, health care organizations, insurance companies, American Academy of Pediatrics Hawaii Chapter, Hawaii Dietetic Association, and others.

Availability of care

- C A formal study was not done regarding shortages of health care providers.
- C Based on experiences of families, CSHNB and other Department of Health staff, University Affiliated Program faculty, and community health care providers, shortages have been noted in the following areas:
 - o Dieticians/nutritionists with training in pediatric nutrition on all islands.
 - o Public health nurses statewide, who have been affected by budget restrictions.

- Dentists on Neighbor Islands who have appropriate pediatric training and are willing to provide services for CSHCN and/or be Medicaid providers.
- Pediatric specialty physicians on Neighbor Islands. In addition, there is only 1 pediatric specialist for genetic/metabolic conditions and 1 pediatric nephrologist in the state.
- Audiologists with appropriate training and equipment on Neighbor Islands, especially for the evaluation of young children with hearing impairment.
- Occupational and physical therapists statewide.
- Adult health care providers with the skills, knowledge, and experience needed for services for adults with special health care needs.

Linkages that promote services and referrals between primary, secondary (specialized), and tertiary (highly specialized) levels of care

- C Referral systems are in place within provider networks of managed care organizations. Some managed care organizations have care coordinators to arrange services and referrals, especially for patients with complex needs.
- C Referral systems are in place within facilities providing different levels of services (e.g. medical centers that provide both outpatient and inpatient services).
- C The tertiary pediatric hospital Kapiolani Medical Center for Women and Children (KMCWC) on Oahu maintains a specialized team to transport critically ill infants and children from Neighbor Islands and from other areas of Oahu to KMCWC, and from KMCWC to mainland hospitals which provide specialized care not available in Hawaii. The team includes neonatologists/pediatricians, nurses, and respiratory therapists.
- C Care coordinators in CSHNB, Public Health Nursing Branch, Shriners Hospital and other organizations/agencies assist with promoting services and referrals. However, they sometimes have difficulties due to the family's insurance status, insurance benefit limitations, different health

care providers participating with different insurance companies, availability of providers, or when services are located on different islands.

- C CSHNB/Children with Special Health Needs Program maintains a list of providers who are willing to accept program fees and provide services for eligible families with insufficient resources. The willingness of providers to participate has helped to promote services and referrals.

Relationship of Title V with others in the state who address inadequate, or poorly distributed, health care resources

- C CSHNB staff have participated in recent public meetings of the Department of Human Services Med-QUEST Division regarding the development of the Child Health Insurance Program.
- C CSHNB assisted in promoting legislation (1999 law) for insurance coverage of medical foods and low-protein modified food products for the treatment of inborn errors of metabolism. This involved working with consumers, health care organizations, insurance companies, American Academy of Pediatrics, Hawaii Dietetic Association, and others.
- C CSHNB/Children with Special Health Needs Program works with Oahu pediatric specialists (e.g, geneticist, neurologists, cardiologists, hematologists, endocrinologist) to have medical specialty clinics on Neighbor Islands, with roles including recruiting providers, finding clinic sites, and staffing clinics.
- C The University Affiliated Program (UAP)/Maternal and Child Leadership Education in Neurodevelopmental and related Disabilities Program provides interdisciplinary leadership training for health professionals. A CSHNB nutritionist participates as clinical faculty. Students have field placements at early intervention program sites and in other community settings. Interdisciplinary faculty including speech pathology, audiology, social work, public health, nutrition, nursing, psychology, and special education.

- C The UAP program “Coordinating Health Services under IDEA: A Training Program for Medical Students and Pediatric Residents” focuses on children with disabilities. Several CSHNB staff participate on the advisory committee.
- C FHSD/CSHNB/EIS staff work with other Department of Health divisions and offices, Department of Education, Department of Human Services, etc., to advocate for and obtain needed staff and funding resources especially for early intervention services mandated by Part C of IDEA and Felix Consent Decree.
- C Education/training in specialized areas is provided and/or arranged both locally and at mainland locations for staff and community providers to increase the capacity for services provision.

Population-Based Services

- C Hawaii’s Newborn Metabolic Screening Program is administered through CSHNB. The program has statewide responsibilities for assuring that all infants born in Hawaii are tested for PKU, congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, sickle cell and other hemoglobinopathies, biotinidase deficiency, and maple syrup urine disease. The program tracks and follows up infants to assure satisfactory testing and that infants with the specified diseases are detected and provided with appropriate and timely treatment. Legislation in 1996 established a special fund for newborn screening, which made it possible for the program to collect fees, contract with a centralized laboratory, and expand the newborn screening test panel to seven disorders. The program works with birthing facilities, primary care providers, midwives, medical specialists, centralized laboratory in Oregon, local laboratories, Healthy Mothers Healthy Babies, and others to implement the program. In 1999, 99.8% of newborns were screened statewide. Funding is adequate.
- C Hawaii’s Newborn Hearing Screening Program is administered through CSHNB. The program is supported by a 1990 law which mandated the Department of Health to develop methodology to establish, implement,

and evaluate a statewide program and develop guidelines for screening, identification, diagnosis, and monitoring of infants and children to age 3 years with hearing impairment. Screening began in two Honolulu hospitals in 1992, and all birthing facilities in Hawaii were screening by the end of 1999. The program works with birthing facilities, primary care providers, medical specialists, audiologists, parents, early intervention services, and others to implement the program. In 1999, 97.8% of newborns were screened statewide. In April 2000, CSHNB received a universal newborn hearing screening grant (Hawaii Early Childhood Hearing Detection and Intervention Project), from the U.S. Department of Health and Human Services/Health Resources and Services Administration/ Maternal and Child Health Bureau. The project's purpose is to further develop and refine the system of screening, assessment, and early intervention services for young children with hearing loss or impairment, so these children will reach developmentally appropriate milestones for language and communication.

C CSHNB has educational components in the areas of early intervention for children 0-3 years, nutrition, and genetics, but does not an overall program of education/information for families of CSHCN from 0-21 years. A contracted program for epilepsy education was funded in fiscal years 1996 and 1997, but this ended with continued state budget restrictions.

A need for increased education/information for CSHCN/families was identified by both the Title V CSHCN Planning Committee and CSHCN/Family Survey. The Planning Committee felt that: more education/information on CSHCN should be available for families, public, and health care providers, through brochures, in-service training, internet, and other methods; education/information needed to be culturally appropriate and in the languages of the non-English-speaking families; there was a need for parent-to-parent advocacy, sharing of information, parent and sibling support groups, and more education for providers. Areas for education/information included: services

available for CSHCN; genetics; nutrition; hearing loss and otitis media; oral health care; financial planning; process for Individualized Family Support Plan (IFSP), Individual Educational Program (IEP), and transition planning at age 14 years; laws and decrees affecting CSHCN; self-determination; vocational rehabilitation services; selecting a health plan to meet the needs of child/family; appeal process for health plan denials for services; assisting children and youth in developing the attitudes, skills, and knowledge needed for adult independence, self-sufficiency, and self-determination.

The CSHCN/family survey, primarily through the many comments of the respondents, indicated a need for more information about services and resources, including: health, social, mental health, education and special education services; legal assistance; financial assistance for services/equipment or transportation; funds/scholarships for children with special needs/disabilities; financial counseling; public/government assistance; low income housing; bus pass; services such as assistive technology, nutrition, home health care, respite; children's health conditions; recreation, social activities, child care, afterschool care, support groups.

Infrastructure-Building Services

What is needed at the State level to promote comprehensive systems of services

- C Ideally, to promote comprehensive systems of services for CSHCN, the following is needed (from the list of essential public health services, defined by the National Public Health Performance Standards Program, Centers for Disease Control and Prevention):
- Monitor health status to identify and solve community health problems.
 - Inform, education, and empower people about health issues.
 - Mobilize community partnerships and action to identify and solve health problems.
 - Develop policies and plans that support individual and community health efforts.
 - Link people to needed personal health services.
 - Assure competent public and personal health care workforce.

- Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
 - Research for new insights and innovative solutions to health problems.
- C Various agencies/programs/organizations address different areas or subareas of the above components. In each area or subarea there may be coordination among different agencies/programs. Areas may not be fully or adequately addressed. There is no single coordinating council/organization to address and assure all components in a comprehensive coordinated approach.
- C While local delivery systems may generally meet the population's health needs, there are still CSHCN and their families for whom services are inadequate (e.g., uninsured, underinsured, some Neighbor Island families where access is a problem, etc.). Services, especially when provided by multiple providers or agencies, need to be better integrated.
- C The Title V CSHCN Planning Committee identified that for infrastructure (needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, and data information systems):
- Greater support should be provided for building the infrastructure for the CSHCN system of services.
 - Standards of care for CSHCN were needed to insure uniformity, quality, effectiveness of service provision; to assure that services are available in comfortable, natural environments, and readily available in the community; and assure that communication and services are culturally-appropriate.
 - Within/between the Department of Health and various community agencies/programs, services needed to be better integrated. There was a need for a smooth continuum of services among agencies/programs who address the needs of CSHCN. Services for CSHCN were felt to be fragmented when they were provided by multiple agencies/programs.

- “One stop” medical services within communities was needed. Ideally a child/family would be able to receive all medical services at a single location and/or visit.
- A better data system on CSHCN/families was needed.

Coordination efforts

C Programs:

- Medicaid - Through an agreement with the Department of Human Services (DHS), the CSHNB/Early Intervention Section (EIS) has a QUEST managed care carve-out to provided early intervention services for children enrolled in the QUEST program. EIS is currently working with DHS on the billing process. CSHNB staff have participated in recent public meetings of the DHS Med-QUEST Division regarding the development of the Child Health Insurance Program. A member of the Med-QUEST Division participated in the Title V CSHCN Planning Committee meetings.
- SSI Program - Medically eligible SSI children less than 16 years old referred by the Disability Determination Services (DDS) of the Hawaii Department of Human Services are provided outreach and rehabilitative services by the CSHNB/Children with Special Health Needs Program (CSHNP) social workers and other health professional staff. DDS works cooperatively with CSHNP to refer SSI children by providing DDS copies of disability reports and determinations to CSHNP. This referral process is established in DDS policies.
- Ryan White and Title IV AIDS programs - The STD/AIDS Prevention Services Branch in the Communicable Disease Division of the Department of Health has primary responsibility in this area.
- Social services programs - CSHCN/families are referred as needed to social services programs, such as housing, employment, child protection, child care, medical assistance,

Temporary Assistance for Needy Families, etc. Social work services are provided to families of CSHCN by social workers in the Early Intervention Section, Children with Special Health Needs Program, Developmental Disabilities Division, hospitals, and community programs.

- Special education programs - FHSD is a member of the Special Education Advisory Council, which advises the Superintendent of Education on policies regarding the education of students with disabilities. Appointed members include representative of consumer advocate groups, parents, individuals with disabilities, regular and special education personnel, Departments of Health and Human Services, and University of Hawaii.
- Early intervention programs - CSHNB/Early Intervention Section is the lead agency for Part C of Individuals with Disabilities Education Act (IDEA) in Hawaii. It is responsible for the development and implementation of a statewide, comprehensive, coordinated system of early intervention services for infants and toddlers with disabilities and their families. Services are provided by state and contracted providers. The Hawaii Early Intervention Coordinating Council advises the Director of Health on issues related to the planning, implementation, evaluation, and monitoring of the statewide system of early intervention services, and assists the Department of Health in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the state. Members are appointed by the Governor and include: parents of children with disabilities under age 6 years, early intervention service providers, legislator, pediatrician, Governor's Special Assistant on Children and Families, and representatives from the Department of Education, Department of Human Services, University of Hawaii College of Education, and health

- insurance. In addition, a member of the Federal Intervention Coordinating Council serves as an ex-officio member.
- Vocational rehabilitation program - The Division of Vocation Rehabilitation (DVR) participated in a the Hawaii CHOICES Transition Project (which ended 11/99) which focused on the transition of youth with disabilities to adult health care, independence, employment and self-sufficiency. DVR participated on the Advisory Committee; worked directly with youths with disabilities in the mentorship program; participated in educational activities for youths, parents, and staff; and was one of the team members attending the national CHOICES conferences.
 - Mental health program - CSHNB/Early Intervention Section has a close working relationship with the Child and Adolescent Mental Health Division in the Behavioral Health Administration. Both programs are under the Felix Consent Decree to ensure that children and adolescents with mental health and emotional problems receive a continuum of services required under IDEA.
 - State interagency transition program - CSHNB/Early Intervention Section (EIS) works closely with the Department of Education (DOE) on the transition of children from early intervention services to the DOE. EIS assures that children age 3-5 years who may be eligible for DOE special education preschool receive interim care coordination and developmental and behavioral screening to support their application and transition into the DOE.
 - Developmental disabilities program - referrals are made between CSHNB programs and the Case Management and Information Services Branch of the Developmental Disabilities Division. Care coordinators work together where possible to assure coordinated services.

- State Systems Development Initiative (SSDI) - The planner hired through the SSDI grant to Family Health Services Division has greatly assisted CSHNB in the CSHCN needs assessment process, especially at the Title V CSHCN Planning Committee and Work Group meetings. SSDI funding was used for CSHCN/family survey (postage, paper, printing, and incentive gift certificates to increase survey response).
- School health programs - The CSHNB/School Health Support Services Section (SHSSS) is responsible for implementation of a full range of education-related occupational and physical therapy to children in the public schools evaluated to need such services. SHSSS will be transferring to the DOE in January 2001. The Public Health Nurses are the school nurses for the public schools and have provided asthma data for a Title V state performance measure. PHNs also assisted in a recent CSHNB study of need for vision and hearing screening in elementary and middle schools in two school districts on Oahu.
- Special Supplemental Nutrition Program for Women, Infants and Children - WIC is a member of the Nutrition Advisory Committee which is coordinated by the CSHNB Nutritionist. The CSHNB Nutritionist provides technical assistance as needed to the WIC nutritionists. The CSHNB Nutritionist shares nutritional assessments and other reports with the WIC nutritionists as needed. Information about continuing education, conferences, etc., are shared between the WIC and CSHNB Nutritionists.

C Major providers of health and health-related services:

- Children's hospitals/tertiary medical centers
 - CSHNB and Shriners Hospital for Children, with the Hawaii Centers for Independent Living, collaborated on the development and implementation of the Hawaii CHOICES Transition Project which focused on the

transition of youth with disabilities to adult health care, independence, employment and self-sufficiency.

- Services for individual CSHCN/families are coordinated between Shriners Hospital and the CSHNB/Children with Special Health Needs Program, so that referrals are made as needed, care coordination services are not duplicated, and needed services are provided or arranged.
- Both the Newborn Metabolic Screening and Newborn Hearing Screening Programs work closely with birthing facilities throughout the state to assure screening of all newborns. The programs provide guidelines, technical assistance, training/education of staff, monitoring of screening, etc.
- The University of Hawaii/School of Medicine/Department of Pediatrics is located at the Kapiolani Medical Center for Women and Children (tertiary pediatric hospital). Two faculty members in the area of developmental disabilities work closely with various CSHNB programs in different activities such as the Title V CSHCN Planning Committee and training/education. They also involve CSHNB staff in their University Affiliated Program/ Maternal and Child Leadership Education in Neurodevelopmental and related Disabilities Program which provides interdisciplinary leadership training for health professionals.
- American Academy of Pediatrics (AAP) Hawaii Chapter
 - FHSD/CSHNB was awarded funding beginning June 2000 for a Healthy Child Care America 2000 grant (“Healthy Child Care Hawaii”) from the U.S. Department of Health and Human Services, Health

Resources and Services Administration, Maternal and Child Health Bureau, Community Integrated Service System Program. This is a collaborative project with the AAP Hawaii Chapter and the University of Hawaii/School of Medicine/Department of Pediatrics.

The purpose of this project is to support systems development in: quality assurance that supports the voluntary adoption and use of “Caring for Our Children” and “Stepping-Stones to Using Caring For Our Children” guidelines in child care programs; infrastructure building to support the identification, training, and deployment of health professionals as health consultants to child care programs; and facilitating child care programs in becoming access points for health services, Medicaid/Child Health Insurance Program, and linking with medical homes.

- A pediatrician is a member of the Hawaii Early Intervention Coordinating Council. Pediatricians are member of various advisory committees, including the Hawaii Early Childhood Hearing Detection and Intervention Project, Newborn Metabolic Screening Program, Hawaii Birth Defects Program, Genetics, and Nutrition Advisory Committees. Pediatricians are also members of the Title V CSHCN Planning Committee.
- AAP has been active in legislative efforts (e.g., testimony and information to legislators) affecting CSHCN, in areas including developmental screening, early intervention, newborn metabolic screening, medical foods and low-protein modified food products for the treatment of inborn errors of metabolism, and definition of medical necessity.

- The AAP provided input on the medical home question in the CSHCN/family survey.
 - Hawaii Academy of Family Practice - HAFP was involved in and supportive of legislation regarding Newborn Metabolic Screening. HAFP was also supportive of other CSHNB activities, including a grant proposal on developmental screening.
 - Family and parent advocacy organizations: Parent advocates/Family Voices have been advisory members or participants in various CSHNB activities such as the Hawaii Early Intervention Coordinating Council, Hawaii CHOICES Transition Project, Title V CSHCN Planning Committee, CSHNB Advisory Committee, interviewing of CSHNB staff positions, and input on written materials.

C

Four constructs of a service system:

- State program collaboration with other state agencies and private organizations.
 - The Title V CSHCN Planning Committee is a newly formed committee to address planning related to CSHCN. Members included: parents of CSHCN, Family Voices, Sultan Easter Seal School, Shriners Hospital for Children, insurance companies, Tripler Army Medical Center Exceptional Family Member Program, “Malama Pono” Medical Home and Integrated Services Project, University Affiliated Program/pediatrician, University of Hawaii Department of Public Health, Department of Human Services/ Med-QUEST Division, public health nurses, Developmental Disabilities Division, Family Health Services Division coordinators on the Neighbor Islands, and CSHNB staff.
 - The Hawaii Early Intervention Coordinating Council (HEICC) addresses issues related to the planning,

implementation, evaluation, and monitoring of the statewide system of early intervention services, and assists in achieving the participation, coordination, and cooperation of appropriate public agencies. Members include: parents of children with disabilities, early intervention service providers, legislator, pediatrician, Governor's special assistant, and representatives from the Department of Education, Department of Human Services, University of Hawaii College of Education, and health insurance. A member of the Federal Intervention Coordinating Council is an ex-officio member.

- The Special Education Advisory Council is an advisory committee to the Superintendent of Education for policies on issues in the education of students with disabilities. Members include representative of consumer advocate groups, parents, individuals with disabilities, regular and special education personnel, Departments of Health and Human Services, and University of Hawaii.
- The Screening Instrument Task Force is an ad hoc committee that is identifying developmental and behavioral-social-emotional screening tools to meet the various needs of Hawaii's 0-5 year-old population and agencies serving them and allow the largest number of children access to screening. Members include the Department of Education, Department of Health, Good Beginnings Alliance, Head Start, Parents and Children Together, Kamehameha Schools/Bishop Estate (a system of over 30 preschools for children of Hawaiian ancestry), and Tripler Army Medical Center Department of Pediatrics.

- The Newborn Metabolic Screening Advisory Committee consists of consumers and professionals (physicians, birthing facilities, medical insurance, parents, and other Department of Health programs). The committee's purposes are to improve coordination and communication among the DOH programs, health care providers, birthing facilities, laboratories, medical insurance plans, and parents; provide guidance to DOH about newborn screening; monitor accountability and quality of the newborn screening program; and address issues relevant to newborn screening.
- The Hawaii Early Childhood Hearing Detection and Intervention Project Advisory Committee has been newly formed to advise and assist in improving the statewide system of early childhood hearing detection and intervention services. Members include pediatrician, audiologists, parents of young children with hearing impairment, representative from a Neighbor Island hospital newborn screening program, special education, and others.
- The Hawaii Birth Defects Program Advisory Committee offers guidance to the program. Committee members are representatives from the community, medical, university, and public and private sectors who have expertise in areas including CSHCN, epidemiology/research, health services, fetal diagnosis, genetics, health information management, maternal/child health, neonatology, nursing, pediatrics, perinatology, and public health.
- The Folic Acid Committee includes the Department of Health, March of Dimes, University of Hawaii, Kapiolani Medical Center, Queen's Medical Center,

Shriners Hospital for Children, Kamehameha Schools, Department of Education, and other agencies to collaboratively provide folic acid education.

- The State Genetics Advisory Committee consists of representatives from public health, health care organizations, consumers, laboratories, March of Dimes, and health insurance. The Advisory Committee advises the Department of Health regarding genetics activities.
 - The Pacific Southwest Regional Genetics Network, which represents California, Hawaii, and Nevada, has enabled Hawaii to provide genetics education to primary care providers, public health professionals, judges, legislative staff, and the general public; and has allowed Hawaii to participate in broad-based educational campaigns such as the development and distribution of the regional folic acid poster and brochure.
 - The State Nutrition Advisory Committee focuses on improving access and availability of quality, coordinated nutrition services to CSHCN by promoting communication and collaboration among public and private providers, identifying gaps/weaknesses in the delivery of nutrition services, developing coordinated intervention strategies, and identifying training needs. Members include representatives from the Department of Health, Department of Education, hospitals/medical centers, parent, University of Hawaii Department of Public Health, University Affiliated Program, and a community health center.
- State support for communities.
 - The Children with Special Health Needs Program (CSHNP) arranges neurology, cardiology, genetics,

endocrinology, and nutrition clinics at community-based Neighbor Island sites.

- The Early Intervention Section (EIS) provides state or contracted early intervention programs on all islands.
- When services (e.g., child psychology, assistive technology, occupational therapy, physical therapy, etc.) are not available or insufficient on Neighbor Islands, CSHNP, EIS, Preschool Developmental Screening Program, School Health Occupational and Physical Therapy arrange for either staff or contracted providers to travel from Oahu to Neighbor Islands.
- CSHNB (EIS, CSHNP), Public Health Nursing Branch, Developmental Disabilities Division, and Child and Adolescent Mental Health Division have staff/programs/offices located on Neighbor Islands. Staff work in the community.
- EIS supports and encourages the provision of early intervention services in natural environments in the community (e.g., in the home or child care settings).
- Airline coupons are provided for Neighbor Island staff and community members to travel to Oahu to attend educational conferences, training, or meetings of task forces, advisory committees, etc. Where possible, meetings are held via videoconferencing with linkage between Oahu and Neighbor Islands.
- Technical assistance is provided as needed to community early intervention programs and to community hospitals regarding newborn screening.
- Some compensation (for example, payment for child care costs, hourly fee, honorarium, etc.) is provided to families who participate in task forces or advisory committees or do presentations at educational

- conferences. Neighbor Island participants are provided with air coupons for travel to Oahu.
- The Hawaii Early Childhood Detection and Intervention Project is planning community support groups for families of children with hearing impairment.
- Coordination of health components of community-based systems.
- Care coordination for CSHCN and their families are provided by CSHNB programs (early intervention, children with special health needs program), public health nurses, primary care providers, social workers, health plan case managers, primary care centers, and community and other programs. Care coordinators assist families in finding and obtaining needed health care services that are appropriate, coordinated, and timely.
 - The Newborn Hearing Screening and Newborn Metabolic Screening Programs work with birthing facilities, health care providers, and families to assure that newborns receive appropriate diagnostic and intervention services.
 - The Preschool Developmental Screening Program works with preschools, health care providers, and families to assure that children with developmental concerns receive appropriate diagnostic and intervention services.
 - See also Section 3.1.4.5 Infrastructure-Building Services - Coordination efforts regarding major providers of health and health-related services (children's hospitals/tertiary medical centers, American Academy of Pediatrics Hawaii Chapter, Hawaii Academy of Family Practice, and family and parent advocacy organizations).

- Coordination of health services with other health services at the community level.
 - See section Infrastructure-Building Services - Coordination efforts regarding programs (Medicaid, SSI, social services, special education, early intervention, vocational rehabilitation, mental health, state interagency transition, developmental disabilities, SSDI, school health, WIC).

Standards, guidelines, monitoring, evaluation, quality improvement

- For the Early Intervention Section:
 - The Early Intervention State Plan articulates components for the statewide system for early intervention services for children age 0-3 years, including: Hawaii Early Intervention Coordinating Council composition and functions, state definition of developmental delay, central directory, comprehensive child find system, evaluation and assessment, individualized family support plans, statewide system of early intervention services, natural environments, timetables for serving all eligible children and toddlers, public awareness program, personnel standards, comprehensive system of personnel development, procedural safeguards, supervision and monitoring of programs, lead agency procedures for resolving complaints, policies and procedures related to financial matters, interagency agreements and resolutions of disputes, policy for contracting services, and data collection.
 - Standards of care and monitoring have been set under the Felix Consent Decree. Standards include:
 - Connection with a care coordinator within 2 days of referral.
 - Care coordination within the approved ratio.
 - Evaluation of eligibility within 45 days of referral.
 - Initial IFSP within 45 days of referral.

- Service coordinators are available to meet needs identified on the Individual Support Plan (IFSP).
- Care coordination for children age 3-5 within 2 days of referral.
- Developmental and behavioral screening for children ages 3-5 within specified timelines.

Data/information is collected from early intervention programs, public health nurses, Healthy Start, and Preschool Developmental Screening Program.

Monthly reports are sent to the Felix Monitoring Project. Reports are closely scrutinized and corrective actions are taken as needed.

- Early intervention programs are monitored via “service testing” to examine how the system of care is functioning and how it is improving over time. It is a review process used to determine the extent to which CSHCN and their families are benefitting from services received and how well the local service system is working for those children and families.
- The Newborn Metabolic Screening Program (NBMSP) standards are established in the Hawaii Administrative Rules and in the Hawaii Practitioner’s Manual. The centralized laboratory Oregon State Public Health Laboratory provides monthly data for the state and each birthing facility on the percent of specimens submitted without error, specimen transit errors, specimen collection timing errors, inadequate specimen errors, and demographic data errors. NBMSP provides this data to each birthing facility both monthly and in a 6 month summary. Data is used to identify areas for improvement or correction, and to monitor changes.
- The Hawaii Early Childhood Hearing Detection and Intervention Project has performance and outcome measures which will be monitored and used as indicators of service effectiveness and to identify areas for improvement. Measures include:
 - Screening: percentage of infants screened during birth admission; percentage of infants screened by age 4 weeks; false positive rates for screening; rates of referral for rescreening

(after the initial screen); rates of infants who were referred who obtained rescreen.

- Assessment: rates of audiological assessment by age 3 months; rates of infants who were referred who obtained audiological assessment; percentage of audiological assessments that meet criteria established in the infant audiological assessment guideline.
- Early intervention: rates of enrollment for early intervention services by age 6 months; rates of achievement of appropriate language and communication developmental outcomes.

Consumer and provider surveys regarding satisfaction and knowledge in the areas of assessment, early intervention, coordination of services, communication needs and options, and family support will also be conducted and used as indicators of service effectiveness and/or need to improve services.

- C All CSHNB purchase-of-service contracts are monitored. Providers are required to give periodic reports to assure progress in the contracts. Technical assistance is provided as needed.

3.2 Health Status Indicators

Data was collected for most of the Health Status Indicator measures (HSI) with the exception of the following:

- HSI #02B. SCHIP enrollees--Hawaii's SCHIP program did not begin on July 1, 2000; thus no data is available at this time
- HSI #06A-D. The Medicaid/Non-Medicaid comparison data was not available. The link between Medicaid files and vital statistics records was not accomplished this year. But, an agreement to develop linkage between Medicaid records and vital statistics data is currently under negotiation.
- HSI #02A-C. Although, data for these measures are not yet available, the Injury Prevention Branch of the State Department of Health is working toward collecting hospitalization or Emergency Medical Service data. However, there exist data quality issues regarding the coding of this data that must be resolved before using the information.

- HSI #09A & #09B. Program data for TANF, Medicaid enrollments, foster care, and the percentage of households headed by a single parent were not available at this time, but will be reported in future Title V reports. SCHIP data is not yet available since the program has just been established.

3.21 Priority Needs

(See Form 14)

3.3 Annual Budget and Budget Justification

3.3.1 Completion of Budget Forms

Form 3 Fiscal Year 1999

Although the state projected an allocation of \$2,207,356 in Title V funds for its fiscal year 1999 application, the actual amount allocated was \$2,252,894.

Approximately \$1,097,005 of the fiscal year 1999 allocation (project year 18201) was expended in fiscal year 1999. Of the estimated \$572,639 in unobligated balances we projected in our fiscal year 1999 application (project year 17201), the actual amount that was liquidated was \$1,451,046.

The fiscal year 1999 Federal-State Title V Block Grant Partnership expenditures of \$23,824,496 are significantly lower than the budget of \$29,149,691. We will continue to experience significant differences between budgeted and actual expenditures for Title V reporting purposes because the state operates on a July 1st to June 30th financial period, yet expenditures are reported for the federal fiscal year under the Title V application. This difference in financial periods makes it very difficult to correlate expenditures with the state budget. For example, the Family Health Services Division had a budget of approximately \$17,896,403 for purchase-of-service contracts in fiscal year 2000; and although they were included in our state budget, many of these contracts may not have been recorded as encumbrances because they were executed prior to the federal reporting period.

Form 3 Fiscal Year 2001

The State match in fiscal year 2001 amounts to \$22,373,250. This represents an overmatch of \$20,683,579 over the anticipated Title V state general fund match of \$1,689,671 for federal fiscal year 2001. The State's fiscal year 1989 maintenance of effort amount is \$11,910,549; and there is no continuation funding for special projects or special consolidated projects.

In fiscal year 2001, other federal maternal and child health related funds are projected to be approximately \$37,715,430. Major federal grants in fiscal year 2001 include WIC (\$31,471,305); SSDI (\$134,842); Part C - Early Intervention (\$1,836,563); Family Planning (\$1,243,266); Abstinence Education (\$131,519); Cooperative Agreement for Primary Care (\$131,392); Preventive Health Services Block Grant - Sex Assault (\$193,100); Community-based Family Resource and Support Grant (\$398,925); Birth Defects Monitoring (CDC) (\$120,000); Healthy Start Grant - Malama A Ho'opili Pono Project, strengthening and enhancing community systems of maternal and infant care (\$850,000); and Early Head Start (\$485,637).

As reported in last year's application, a major contributor to program income for the maternal and child health program is federal reimbursements for early intervention services. For fiscal year 2001, the State has established a special fund budget ceiling of \$4,678,499 for federal reimbursements related to early intervention services. Another major contributor to program income for the maternal and child health program in fiscal year 2001 is the newborn screening program. Under this program, the State charges a fee to birthing facilities for newborn screening kits. These fees cover the costs of the newborn screening program, including the costs for laboratory and follow-up testing. A special fund budget ceiling of \$603,121 has been established in fiscal year 2001 for this purpose.

3.3.2 Other Requirements

3.4 Performance Measures

3.4.1 National "Core" Five-Year Performance Measures

3.4.1.1 Five-Year Performance Objectives

(See Form 11 for five-year targets)

3.4.2 State "Negotiated" Five-Year Performance Measures

3.4.2.1 Development of State Performance Measures

Based on the selection of 10 new state priorities, the Title V agency revised the list of state performance measures (SPM), deleting six existing measures and selecting six new state measures, for a total of 10 measures. Figure 5 lists all the state measures including those to be dropped and the new measures to be added. Figure 5 also identifies the measure type and category by level of service. The new state measures are numbered eleven to sixteen. New

detail sheets have been developed for the six new measures (see Form 16) and 5-year projections for FY 2001-2005 can be found in Form 11. FY 2001 plans for these new measures have not been fully developed and thus, have not been included in this application.

FIGURE 5: New FY 2001-2005

STATE NEGOTIATED PERFORMANCE MEASURES

Negotiated Performance Measures	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1) % of sexually active women aged 18-44 who do not wish to be pregnant at this time and are using any contraceptive method including sterilization to prevent pregnancy.	X						X
2) % of WIC parents and caregivers who use feeding practices that prevent early childhood caries/baby bottle tooth decay.		X					X
3) % of pregnant women who report use of alcohol or illegal drugs (cocaine, marijuana, heroin, methamphetamine) during pregnancy.			X		X		
4) % of teenagers aged 12-17 attending public schools who report alcohol use within the last 30 days.			X				X
5) % of teenagers 12-17 attending public schools who report smoking tobacco within the last 30 days.			X				X
6) Rate of adults (aged 18-64 years, per 1,000) who have been physically injured by another household member.			X				X
7) Rate of confirmed child abuse/neglect reports per 1,000 for children aged 0-5 years			X				X
8) % of youths aged 15-17 attending public schools who report being involved in a physical fight within the last 12 months.			X				X
9) Incidence of neural tube defects per 10,000 live births plus fetal deaths.			X				X
10) Mean number of school days absent per public school student aged 5-18 who is diagnosed with severe asthma.				X			X
11) The percent of pregnancies (live births, fetal deaths, abortions) that are unintended.			X				X
12) Percent of infants with hearing loss who are receiving appropriate intervention services by age 6 months.				X			X
13) The percent of 4 th grade children who are overweight and obese.			X		X		

Negotiated Performance Measures	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
14) Number of calls to the toll-free statewide parent line.		X			X		
15) The degree to which the MCH agency performs ten essential public health functions.				X	X		
16) Degree of availability of mandated early intervention services to meet needs specified in the Individual Family Support Plan (IFSP) for children age 0-3 years who are developmentally delayed, or biologically or environmentally at risk.				X	X		

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services
 IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

The measures that will be dropped are State Performance Measure (SPM) 1, 2, 4, 6, 9, and 10. The data for these measures will be reported through FY 2000, but no plans for the dropped measures will be provided in next year's grant application. No 5-year projections have been made for these measures in Form 11.

Reflecting the need to transition toward infrastructure building services, the six new measures are weighted toward the bottom of the service level pyramid. Three of the new measures (SPM 12, 15, and 16) are infrastructure building measures and focus on capacity. Of the remaining three measures, two are population-based with a focus on risk factors (SPM 11 and 13) and one enabling services measure examines capacity issues (SPM 14).

3.4.2.2 Discussion of State Performance Measures

State Performance Measure #1. The percentage of sexually active women aged 18-44 who do not wish to be pregnant at this time and are using any contraceptive method including sterilization to prevent pregnancy.

The item will be deleted after FY 2000. It has been extremely costly to include this measure in the BRFSS every other year as an optional module. Furthermore, the sample generated for this measure has been extremely small, thus the validity of the results are questionable. After consulting key stakeholders and service program partners, the Family Planning staff also decided that reducing the number of unintended pregnancies was a more

important priority. SPM 11 reflects this new state priority and provides a more reliable and affordable measure for the program to maintain.

State Performance Measure #2. The percentage of WIC parents and caregivers who use feeding practices that prevent early childhood caries/baby bottle tooth decay.

Improving oral health of children and infants is still an important priority for Hawai'i; however, this measure will be deleted after FY 2000 to focus on developing more population-based measures. WIC will continue to track baby bottle tooth decay as part of its program performance reviews.

State Performance Measure #3. The percentage of pregnant women who report use of alcohol or illegal drugs (cocaine, marijuana, heroin, methamphetamine) during pregnancy.

Although data has been difficult to generate for this measure, the issue of substance abuse among pregnant women has been reaffirmed in the new state priorities. Alternate measures may be investigated if the current data source does not prove more reliable as a surveillance method.

State Performance Measure #4. The percentage of teenagers in grades 9 to 12 attending public schools who report alcohol use within the last 30 days.

Although the percentage of teenagers drinking alcohol has increased slightly, this measure will be deleted after FY 2000 since there are other adolescent health measures focusing on substance abuse and at-risk behaviors.

State Performance Measure #5. The percentage of teenagers in grades 9 to 12 attending public schools who report smoking tobacco within the last 30 days.

SPM 5 on teen smoking will be kept since smoking is often a behavior that leads to other risk behaviors, is highly addictive, and difficult to treat.

State Performance Measure #6. Rate of adults (aged 18-64 years, per 1,000) who have been physically injured by an intimate partner.

Violence issues affecting the MCH population is still a very high priority for the state. However, this measure will be deleted after FY 2000 because it has been difficult to find an effective measure. Survey responses have generally been low on this measure and often generate complaints from survey

participants. Also, Title V staff will use the next year to meet in cross-disciplinary teams to bring more focus to all the violence-related programs supported in the agency. Once priorities and data needs are clearly defined for violence related issues, new measures may be identified.

State Performance Measure #7. Rate of confirmed child abuse/neglect reports per 1,000 for children aged 0-5 years.

As noted earlier, violence issues affecting the MCH population is still a very high priority for the state; thus, this measure will be kept.

State Performance Measure #8. The percentage of youths in grades 9 to 12 attending public schools who report being involved in a physical fight within the last 12 months.

As noted earlier, violence issues affecting the MCH population is still a very high priority for the state; thus, this measure will be kept. School violence is a particularly important concern for the public.

State Performance Measure #9. Incidence of neural tube defects per 10,000 live births plus fetal deaths.

This measure will be deleted after FY 2000 and tracked through a new infrastructure measure that will examine data capacity for the Title V agency. Other CSHCN priorities were identified for the state.

State Performance Measure #10. Mean number of school days absent per public school student aged 5-18 who is diagnosed with severe asthma.

Although asthma is increasing among children, private and public sector partners have mobilized rapidly to address this public health concern. Thus, asthma was dropped as a state priority and the measure will be deleted after FY 2000.

State Performance Measure #11. The percent of pregnancies (live births, fetal deaths, abortions) that are unintended.

This measure reflects a new state priority: to reduce the rate of unintended pregnancy. The measure is modeled after the measure used by Washington State MCH Division. The measure relies on PRAMS and vital statistics data which are more reliable measures than the BRFSS survey conducted on alternate years.

State Performance Measure #12. Percent of infants with hearing loss who are receiving appropriate intervention services by age 6 months.

This measure reflects a new state priority: to ensure that all infants and children receive appropriate and timely hearing evaluation and early intervention services.

State Performance Measure #13. The percent of 4th grade children who are overweight and obese.

This measure reflects a new state priority: to reduce overweight and obesity in children.

State Performance Measure #14. Number of calls received by the statewide toll-free Parent Line support service.

This measure reflects a new state priority: to assure that parenting support and information is made available to all families with children. The measure is developmental. The Title V staff will continue to research other alternatives, including reviewing measures used by other state MCH agencies.

State Performance Measure #15. The degree to which the MCH agency performs the ten essential public health functions.

This measure reflects a new state priority: to improve assessment and surveillance of MCH populations, including children with special health needs. A simple self-assessment measurement tool in the form of a checklist has been created to ensure the agency is tracking its effort toward improvement in this area. The checklist is attached as Figure 6.

State Performance Measure #16. Degree of availability of mandated early intervention services to meet needs specified in the Individual Family Support Plan (IFSP) for children aged 0-3 years who are developmentally delayed, or biologically or environmentally at risk.

This **measure** reflects a new state priority: to ensure that all children aged 0-3 years who are developmentally delayed, or biologically or environmentally at-risk, receive needed early intervention services. A measurement tool in the form of

Figure 6: Checklist for Measurement of State Performance Measure #15

Ten Essential Public Health Services to Promote Maternal and Child Health

1)Assess and monitor maternal and child health status to identify and address problems.

Ranking: ____ (Possible 0-3)

2)Diagnose and investigate health problems and health hazards affecting women, children and youth.

Ranking: ____ (Possible 0-3)

3)Inform and educate the public and families about maternal and child health issues.

Ranking: ____ (Possible 0-3)

4)Mobilize community partnerships between policymakers, health care providers, families, the general public, and others to identify and solve maternal and child health problems.

Ranking: ____ (Possible 0-3)

5)Provider leadership for priority-setting, planning, and policy development to support community efforts to assure the health of women, children, youth and their families.

Ranking: ____ (Possible 0-3)

6)Promote and enforce legal requirements that protect the health and safety of women, children and youth, and ensure public accountability for their well-being.

Ranking: ____ (Possible 0-3)

7)Link women, children, and youth to health and other community and family services, and assure access to comprehensive, quality systems of care.

Ranking: ____ (Possible 0-3)

8)Assure the capacity and competency of the public health and personal health work force to effectively address maternal and child health needs.

Ranking: ____ (Possible 0-3)

9)Evaluate the effectiveness, accessibility, and quality of personal health and population-based maternal and child health services.

Ranking: ____ (Possible 0-3)

10)Support research and demonstrations to gain new insights and innovative solutions to maternal and child health-related problems.

Ranking: ____ (Possible 0-3)

TOTAL SCORE: _____ (Possible 0-30)

0 – Inadequate 1 – Partially Adequate 2 – Fully Adequate 3 – Exceeds Adequacy

a checklist has been developed to monitor progress in 14 service areas (see Figure 7).

Analyses of the state performance measures and their relation to the outcomes measures will be conducted with the Title V staff over the next year. This will help the staff develop a better understanding of the Title V performance measure system as described in Figure 3. A diagram similar to Figure 3 will be developed using the Hawai'i state performance measures and linking them to the state priorities and outcome measures. The figure will be included in next year's Title V report.

3.4.2.3 Five-Year Performance Objectives

(See Form 11)

3.4.2.4 Review of State Performance Measures

(See Form 11 and Form 16)

3.4.3 Outcome Measures

(See Form 11 and Form 16)

Figure 7: Checklist for Measurement of State Performance Measure #16

Availability of Mandated Early Intervention Services for Individual Family Support Plan (IFSP) for Children age 0-3 years who are developmentally delayed, or biologically or environmentally at risk.

- Assistive technology services
- Audiology
- Family training, counseling, home visiting
- Health services
- Medical services for diagnostic or evaluation purposes
- Nursing services
- Occupational therapy
- Physical therapy
- Psychological services
- Social work
- Special instruction
- Speech pathology
- Transportation
- Vision services

TOTAL SCORE: _____ (Possible 0-14)

0 – Service not provided 1 – Service provided

IV. REQUIREMENTS FOR THE ANNUAL PLAN

4.1 Program Activities Related to Performance Measures

4.1.1 Direct Health Care Services

National Performance Measure #1: The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.

Factors that affect whether the target will be met include: 1) Disability Determination Branch (DDB) of the Department of Human Services sends a number disability cases out of state for processing who are not referred to CSHNP; 2) a number of SSI beneficiaries less than 16 years old receive care coordination either through the Children and Adolescent Mental Health Division or the Developmental Disabilities Division of the State Department of Health; 3) improvement of the CSHN data system to track services provided to SSI child recipients.

Social workers and other health professionals in the Children with Special Health Needs Program (CSHNP) provide direct services to medically eligible SSI applicants referred by DDB and to SSI beneficiaries referred by other community resources. DDB refers medically eligible SSI children to CSHNP in a timely manner and provides hard copies of the child's disability reports and their DDB determination. DDB has recently agreed to refer needy children and their families to CSHNP for direct services prior to the completion of the DDB process so early assistance can be provided. DDB's commitment to the Title V agency's effort is illustrated by DDB's inclusion of the SSI children's referral process in their program's administrative rules.

There is no change in the target from the previous year. With one exception, the CSHCN programs will continue current services provided or paid for (medical and surgical subspecialty services; occupational and physical therapy; speech/hearing/language services; limited durable medical equipment and supplies; nutrition services; care coordination; early intervention services).

National Performance Measure #2: The degree to which the State CSHCN program provides or pays for specialty and subspecialty services, including care coordination not otherwise accessible or affordable to its clients.

The School Health Support Services Section (SHSSS) will be transferred to the Department of Education (DOE) effective January 1, 2001. A 2000 statutory amendment transferred the responsibility for occupational and physical therapy services for eligible public school students from the DOH to the DOE. The provision of these education-related services to children with special needs within the public schools is consistent with DOE's charge to provide free and appropriate public education, including related services for qualified students with disabilities under the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act.

There is no plan to add respiratory and home health care services to the list of services that the programs provide or pay for, since these are services that should be covered by health insurance. Families who need these services are assisted with obtaining Medicaid, insurance, and/or other resources.

State Performance Measure #1: The percent of sexually active women aged 18-44 who do not wish to be pregnant at this time and are using any method, including sterilization, to prevent pregnancy.

FY 2000 data for this measure will be provided by the 2000 BRFSS. Based on the FY 1998 indicator and the availability of BRFSS data every two years, the performance objectives for FY 1999-2005 have been adjusted. This measure will be deleted after FY 2000 for new state performance measures.

Title V will continue to provide direct health care services in the form of comprehensive clinical family planning visits focusing on adolescent pregnancy prevention services and immediate referral for health care for all those with positive pregnancy tests. Risk reduction activities will focus on prevention of unintended pregnancy and infertility and will be integral parts of each visit. These will include: thorough health histories; screening for sexually transmitted

diseases, breast and cervical cancer, hypertension, obesity, and anemia; health education and risk reduction messages; and provision of contraceptives, including condoms. Title V funds will provide 758 visits to a minimum of 489 clients.

Enabling services (such as health education and translation services, case management and referrals for prenatal care, WIC and social services, Medicaid/Med-QUEST health insurance) will continue as vital components of all comprehensive FP visits. Enabling services and population-based services (such as outreach and community education programs) will be funded by Title X.

The Title V agency will monitor the implementation of Act 267 to ensure Hawai'i health insurance companies provide adequate family planning visits and contraceptives to women who qualify for the coverage.

The Title V agency will concentrate on infrastructure building in the area of family planning by strengthening assessment capability, data collection, and analysis to help in program planning and policy development. BRFSS data for this measure will be further analyzed to identify disparities (ethnic, geographic, age, insurance coverage, income level, education level). Additional data sources and corroborating measures (measures of unintended pregnancy in BRFSS and PRAMS, program data from service contractors, abortion and fetal death rate data) will also be reviewed to help identify the need for family planning services.

The information will be used to assess the system of family planning services and identify potential target populations, service delivery gaps, and barriers to improve efficiency in service delivery. If additional public funding is not available for increased services, these strategies may be the only means to achieve the Title V objective.

Title V work teams developed during the Title V needs assessment process will continue to meet during the year to increase collaboration/service integration throughout the Title agency, programs, and partners. The teams will meet to review existing data sources, receive training in data analysis and interpretation utilizing assistance from the epidemiology staff, the MCH faculty at the

University of Hawai`i, and other sources of technical assistance. Unfortunately, the dismantling of the University's School of Public Health has reduced the availability of faculty to assist in this area of staff development. Title V will work with remaining faculty to help build a MCH program in the University Medical School.

4.1.2 Enabling Health Care Services

National Performance Measure #3: The percent of Children with Special Health Care Needs (CSHCN) in the State who have a medical/health home.

The next survey of families of CSHCN, which will include medical home questions, is tentatively planned for 2002.

“Malama Pono,” funded by the federal MCH Bureau, is a collaborative project between the Hawai`i Medical Association, Department of Health, and Department of Education that promotes accessible community-based, family-centered culturally competent medical homes which provide comprehensive coordinated services for CSHCN. Project works at the state level with managed care organizations and public agencies, including DOH/CSHNB and at the community level to build family-professional partnerships.

Healthy Child Care Hawai`i is a new collaborative project between the AAP Hawai`i Chapter, University of Hawai`i School of Medicine Department of Pediatrics residency-training program, and DOH Family Health Services Division's CSHNB and MCHB that will help to promote the medical home concept. One of its goals is to promote the access to health services for children in child care by facilitating the access of children, including CSHCN, to a medical home, Medicaid and SCHIP resources, and other health resources. Methods include the development of a statewide network of child care health consultants who will serve as focal points to integrate various state and community resources in child care and improve access to medical home resources in early childhood development, parenting, and health education.

CSHNB will work with the AAP Hawai'i Chapter, Malama Pono Project, and other state and community organizations in addressing ways to increase the number of CSHCN in the State who have a medical home.

State Performance Measure #2: Percent of WIC parents and caregivers who use feeding practices that prevent early childhood caries (ECC)/baby bottle tooth decay (BBTD).

The WIC program will continue to collaborate with the Department of Health, Dental Health Division (DHD), to evaluate results of the performance measure data, to improve educational protocols and materials, and to report data for FY 2000. After FY 2000, this measure will be deleted.

Title V personnel will also partner with DHD to develop more population-based assessment and educational outreach to prevent early childhood caries (ECC)/baby bottle tooth decay (BBTD). Title V staff will identify the system of early childhood outreach services in the State and assure more comprehensive provision of training and dissemination of oral health educational materials.

Like WIC, Title V will encourage service providers to adopt performance measures to assure that parents and caregivers are adopting preventive feeding practices. Efforts will be made to provide translation of ECC/BBTD education information into different languages which will be utilized by WIC clinics and community programs that support early childhood activities and parenting support programs.

Title V will also support community educational efforts on the value of water fluoridation to prevent ECC/BBTD and improve the poor oral health of Hawaii's children. Legislation to fluoridate public water systems will be reintroduced for FY 2001 after failing to pass in the 2000 legislative session. Public education on the need for fluoridation is essential to secure passage of the legislation next year.

4.1.3 Population-Based Services

National Performance Measure #4: Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, galactosemia, hemoglobinopathies (e.g., the sickle cell disease).

In order to meet the annual objective, the Newborn Metabolic Screening Program (NBMS) staff will continue to identify infants who did not receive newborn screening, based on information on home births from the Office of Health Status Monitoring, "Specimen Not Obtained" forms, and Hospital Monthly Newborn Screening Reports from birthing facilities, and will try to get these infants screened. Another strategy will be to develop data linkages between the Newborn Metabolic Screening Program and Vital Statistics/Office of Health Status Monitoring. The most precise method to determine the number of infants screened would be to do a direct match between newborn metabolic screening results and birth certificate data.

In addition, NBMS staff will continue to provide education to health care providers and the general public about newborn screening. NBMS will utilize the Perinatal Advocacy Network, coordinated by the Healthy Mothers/Healthy Babies Coalition, to disseminate information. NBMS will also explore the use of Internet and outreach to the lay midwives. More medical inservice sessions will be conducted to give feedback to physicians regarding the findings of the expanded screening program.

There is a need for more genetic services, especially on the neighbor islands. The Hemoglobinopathy Follow-up Survey showed that approximately 23% of the families on the neighbor islands needed but did not receive genetic services. To address this need, the Newborn Metabolic Screening Program began scheduling Genetic Clinics on three major neighbor islands. NBMS is also collaborating with a pediatric hematologist on a research project which will include genetic counseling for families. NBMS will also explore the use of

telemedicine to increase the availability of genetic services on the neighbor islands.

Tandem mass spectrometry is the state of the art technology which makes it possible to screen for over 30 amino acid, fatty acid, and organic acid disorders. NBMSP will work closely with its contracted testing laboratory (Oregon State Public Health Laboratory), the Newborn Metabolic Screening Advisory Committee, physicians, birthing facilities, etc., regarding a decision as to whether Hawai'i will screen for additional disorders.

National Performance Measure #5: The percent of children age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B.

Title V staff, in collaboration with the Hawai'i Immunization Coalition (HIC), will meet regularly to plan outreach and provide information for population-based education to health professionals, community agencies, and State MCHB programs and partners. With the start of the State Child Health Insurance Program (SCHIP) on July 1, 2000, immunization rates are expected to improve. Covering Kids, a Robert Wood Johnson grant to support increased enrollment into SCHIP and Medicaid, will target underserved subpopulations including immigrants, Native Hawaiians, and Pacific Islanders. Efforts will continue to develop a state immunization registry to improve tracking and identification of children who are out of compliance.

National Performance Measure #6: The rate of birth (1,000) for teenagers aged 15 through 17 years.

As teen pregnancy is embedded in other larger issues concerning adolescent development and wellness, Title V programs will continue to be multi-leveled, faceted, and holistic. The Hawai'i Adolescent Plan provides a conceptual framework for a number of these activities. A partnership with the Department of Education to develop a Coordinated School Health Approach is adopting this approach for program design.

Title V program staff will continue to monitor the Abstinence Only Education grant targeting 9-12 year old youth through its community-based program in all four counties. Program evaluation will continue to ensure the effectiveness of the interventions and identify possible areas for improvement.

Title V will continue to staff the Adolescent Survey Committee (ASC) to publish data on teens compiled from various survey instruments in a more effective manner and disseminate to parents and the community. The ASC is also exploring the inclusion of questions in Hawaii's Middle School Survey that captures data on resiliency and protective factors. Tobacco Special Funds will support the continuation of the Middle School Survey in 2001. The 2001 survey sample will be expanded to provide data by school districts to support community-based assessment, partnership, and program development.

An interagency group called Collaborators was awarded a grant by the Council of Chief State Officers for School-Based Teen Pregnancy Prevention activities. The grant will provide the Collaborators group with technical assistance to develop strategies for community and school-based partnerships; strengthening the role of youth in evaluation and action plans; developing social marketing approaches using data relevant to state agencies and communities. Title V staff developed the grant and will assist with implementation.

The Title V proposal developed for the Teen Intervention Program has completed its planning phase. Outreach to parents at 25 public schools will occur for participation in parenting skill workshops focused on understanding adolescent normal growth, development, and communication practices.

Title V will continue to provide technical assistance and support for the expansion of School Based Health Service Centers (SBHSC) through the Coalition for SBHSCs. Efforts are being made to expand partnerships and representation from the Hawai'i Chapter of the American Academy of Pediatrics (AAP) and the Hawai'i Primary Care Association.

In fiscal year 2000 performances of the play, *IT CAN HAPPEN TO YOU*, a high school drama regarding teen pregnancy, sexually transmitted diseases (STD), and HIV/AIDS prevention, will expand its performances to rural areas in the state with the receipt of federal funding. Guidelines will be written and training programs will be established to assist the various communities to inform and educate teens through the drama.

“Live Your Life Before You Make One”, is the theme for 2000 Hawai`i Teen Pregnancy Campaign activities including: proclamations (state and county); youth developed portfolio (to be distributed to all high schools), bus posters, radio public service announcements; 2001 slogan contest; and television spots covering highlights of Hawai`i teen pregnancy prevention activities.

Title V Family Planning Services Section will continue to provide school and community presentations on puberty, abstinence-based family planning, and self-esteem for students and youth at-risk. Educational outreach will include use of mass-based media, as well as health fair exhibits and publication of printed materials.

National Performance Measure #7: The percent of third grade children who have received protective sealants on at least one permanent molar tooth.

Title V programs will continue to collaborate with Dental Health Division (DHD) to develop strategies to improve utilization of dental health services and increase education to children and families. Education to promote fluoridation of Hawaii’s public water supply will continue in partnership with DHD.

Title V will ensure that oral health information is integrated into the nutrition education program of the Hawai`i Health Initiative, the prevention program supported by Tobacco Settlement Funds. School-aged children will be targeted for prevention education through the implementation of newly adopted Health Education Curriculum Performance Standards developed in collaboration between the Departments of Health and Education. School lunch programs will also provide more nutritious meals and provide some education on food choices.

Parents will be included and involved through the Parent Teacher Student Association (PTSA) and Parent Community Networking Center (PCNC).

Title V will explore the potential of using Primary Care purchase-of-service contracts for uninsured children to screen for dental needs in the community and ensure appropriate referral for dental care. The State Child Health Insurance Program (SCHIP), which will be initiated in July 2000, will also increase Medicaid eligibility for children to 200% FPL, which will increase dental services for children. DHD staff will join the quarterly EPSDT Advisory Committee meetings to improve utilization of dental services and work with the Dental Insurance Plans to obtain statistics to evaluate specific dental needs and to identify areas to target screening efforts among Hawaii's low income families.

National Performance Measure #8: The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children.

Child passenger and seatbelt safety training and community educational activities continue to increase public awareness. The Department of Transportation is sponsoring public service announcements to target booster seats for children 40 lbs. to 80 lbs. New partners who are being trained include emergency medical technicians and firemen. Enforcement of a new safety seat law for all children riding in the back seat under 18 years and bicycle helmet law for riders under 16 years will be in effect during this period. Title V personnel on the neighbor islands are involved in these efforts and have provided leadership in coordination and collaboration to accomplish this performance measure.

Continued participation in the Region IX Injury Prevention Network provides up-to-date information on national trends and issues and available resources for local level planning and development of strategies for state and county directions.

Child passenger safety information is included in the broader spectrum of injury prevention, and educational resources are available to purchase-of-service contract providers, and programs supported by Title V personnel. The Child

Death Review system continues to increase awareness of child deaths related to motor vehicle crashes and pedestrian deaths with a focus on prevention strategies through joint efforts of a multidisciplinary approach.

National Performance Measure #9: The percentage of mothers who breastfeed their infants at hospital discharge.

Although the percentage of mothers who breastfeed their infants at hospital discharge is increasing, the rate quickly declines due to the large numbers of women in Hawai'i who must return to work soon after delivery. The Title V program has proposed to assist the Department of Health in taking the lead as a "Breastfeeding Friendly" employer.

In FY 2001, WIC plans to encourage their clients to utilize WIC food money toward the purchase of a breast pump. They also plan to continue using the assessment triage tool, "Breastfeeding Cardex, Guidance for Counseling the Breastfeeding Mom" at all WIC sites.

The Title V program staff will continue to provide comprehensive breastfeeding education and support to the high-risk pregnant women, statewide. They will also continue to support and work with the Breastfeeding Promotion Council of Hawai'i to promote breastfeeding friendly work place environments and to continue to assure that breastfeeding women are not discriminated against.

The Healthy Mothers/Healthy Babies Coalition and MothersCare for Tomorrow's Children will continue to be an integral partner with the Title V program in supporting breastfeeding education and promotional efforts throughout the state. As a result of coordinated efforts with FHSD, a bill (HB 2774) was just passed in the 2000 legislative session which would make it discriminatory to deny the right of mothers to breastfeed their children in places of public accommodations, including stores, parks, and restaurants.

National Performance Measure #10: Percentage of newborns who have been screened for hearing impairment before hospital discharge.

The Children with Special Health Needs Branch/Early Intervention Section has been awarded funding for a universal newborn hearing screening grant (Hawai'i Early Childhood Hearing Detection and Intervention Project), from the U.S. Department of Health and Human Services/Health Resources and Services Administration/Maternal and Child Health Bureau. This is a four-year grant which began in April 2000. The overall purpose of this project is to further develop and refine the system of screening, assessment, and early intervention services for young children with hearing loss, so that all young children with hearing loss will reach developmentally appropriate milestones for language and communication. The goals of the project are to: 1) improve the system of hearing screening, assessment, and linkage to early intervention services for children aged 0-3 years with a hearing impairment, in order to assure that all children with a hearing impairment receive appropriate services, and 2) refine family support and early intervention services to meet the needs of young children with hearing loss and their families.

Project activities will include: establish an advisory committee to advise and assist in improving the statewide system of early childhood hearing detection and intervention services; improve hearing screening equipment at three hospitals with non-automated equipment and high rescreening rates; work with the Newborn Metabolic Screening Program to develop and implement a plan for outreach regarding newborn hearing screening to midwives and to families of infants born at home; improve collaboration and information sharing between the medical home, other providers, and early intervention staff in providing family support and planning services (e.g., communication choices, early intervention, or other services); develop a record of hearing screening assessment and early intervention for parents of children with hearing loss to keep, update, and share with the medical home and other providers; increase public awareness of early hearing detection and intervention; provide continuing education for health care and other providers in areas such as new approaches/technology to hearing

impairments, cultural issues, and genetic aspects of hearing loss; identify a standard assessment tool to evaluate a child's development, evaluate therapy outcomes, and to identify a child's need for additional services; assess language and development on a periodic basis; develop early intervention service guidelines for hearing impaired children; provide education/training; consult on difficult or unique situations and monitor service delivery; develop a parent-to-parent network for individual and group support; expand library of materials, videos, and other information with information regarding the management of children with hearing loss; build a library of educational toys; and develop a sensory stimulation manual for children with auditory neuropathy.

State Performance Measure #3: The percent of pregnant women who report use of alcohol or illegal drugs (cocaine, marijuana, heroin, methamphetamine) during pregnancy.

The Title V program will continue to provide training opportunities for providers to identify substance use and to expand the capacity to treat substance using women to improve birth outcomes and reduce the numbers who end up in the child abuse and neglect system. Of major concern is how managed care impacts treatment availability and duration. The Title V program will work with providers to identify managed care issues which impact on best practice and desired outcomes for pregnant and new moms. In addition, Title V will work with the judiciary to ensure that drug courts/court ordered treatment is available and in line with the managed care policies. Currently, there are conflicts and court ordered treatment may not be available to women because managed care plans will not pay for it. There is also a shortage of treatment services available to accommodate the need. The Title V program will work with the various related agencies to address these shortage issues.

The Title V program will explore other funding opportunities to expand the treatment programs to drug addicted mothers. This may entail grant writing and partnering with other agencies or Divisions within the Department.

As more and more attention is focused on the correlation of substance use to other problems such as child abuse, domestic violence, and other criminal activity, there will be more coalitions, task forces, and other coordination efforts. The Title V program will participate on these various committees because of the impact on women of child-bearing age.

State Performance Measure #4: The percent of teenagers in 9th-12th grades attending public schools who report alcohol use (within last 30 days).

State Performance Measure #5: The percent of teenagers in 9th-12th grades attending public schools who report smoking tobacco (within last 30 days).

Since State Performance Measures (SPM) 4 and 5 both pertain to adolescent substance use, the planned activities are addressed together. After FY 2000, SPM 4 will be dropped for other new state performance measures which were selected based on new state priorities.

With the Healthy Hawai`i Initiative and potential resources available for prevention through the Hawai`i Tobacco Settlement, the Departments of Health and Education are coordinating to promote healthy lifestyles among children and develop curriculum health standards for all age levels in the public schools. This effort is broad-based and supports healthy youth development and decision making. Title V will work to ensure this planning effort will expand and integrate existing services, including School Based Health Service Centers; the Peer Education Program; after-school programs; and training for advocates, professionals, and parents on health issues; early identification of problems; intervention options; and care coordination. Title V will also facilitate links with existing community organizations to create local networks of support for the school-based programs.

State Performance Measure #6: The rate of adults (aged 18-64 years, per 1,000) who have been physically injured by another household member.

Data for the 2000 report will come from a new survey measure that has been included in the 2000 Hawai`i Health Survey, an annual random digit dialing

phone survey of over 4,000 households. The number of questions regarding intimate partner violence has been reduced and reworded to minimize offending survey participants. Further analysis of the 1999 BRFSS data will be conducted to determine disparities by ethnicity, income, education level, geography, and sex of victim. Also, the data will be examined to assess whether victims of violence seek treatment for their injuries. After FY 2000, SPM 6 will be dropped for other new state performance measures.

Population-based activities for FY 2001 will be continued in the prevention of violence and sexual assault through activities of the Sexual Assault Prevention Program of FHSD. Program staff will continue to participate in the Violence Against Women Act (VAWA) State Planning Committee of the Department of the Attorney General to work toward the reduction of violent crimes against women.

The Coalition for the Prevention of Sexual Assault will continue to work on developing and implementing community outreach and information activities to increase public awareness, including use of existing media resources promotion.

Preventive Health and Health Services Block Grant funding to the Kapiolani Medical Center, Sex Abuse Treatment Center, and the other sexual assault treatment centers will allow continuance of: 1) school/community-based sexual assault prevention education presentations, and 2) other target outreach initiatives to increase public awareness of the community-based sexual assault centers and services provided.

Infrastructure-building activities will be continued by the Coalition for the Prevention of Sexual Assault to implement a statewide strategy to increase awareness of sexual assault issues and treatment services, and community-based and service-based prevention activities. The Coalition will continue to review legislative issues and compile available sexual assault data sources, in collaboration with the Department of the Attorney General, for future planning

and advocacy. The FHSD/Sexual Assault Prevention program will also continue to work with the Hawai`i Commission on the Status of Women, the League of Women Voters, and community groups to assure continuum of services for the prevention of violence against women.

State Performance Measure #7: The rate of confirmed child abuse/neglect report per 1,000 for children aged 0-5.

Based on the 1999 indicator, the objective was revised for 2000. The data on child abuse and neglect will be further analyzed for disparities by ethnicity and geography. Staff will examine systems issues to evaluate availability and utilization of services by at-risk families.

Title V will continue its prevention education outreach activities. In addition, staff will continue to offer statewide training workshops for parents and other caregivers on a variety of children's psychosocial-behavioral issues, including sexual development. The statewide resource directory of available services for parents with young children will be updated as will the parents' newsletters. Distribution of parenting education materials to immigrant families of newborn children will provide materials in six languages.

The Title V agency funds two respite programs with the goal of family strengthening and reducing the incidence of child abuse and neglect. Title V is organizing a collaborative network of public and private agencies and advocates regarding statewide respite issues to increase visibility and awareness of respite services. A national network of respite coalitions, through whom the state is receiving technical assistance, supports this effort. This collaborative network will be firmly in place by fiscal year 2001.

The Hawai`i Healthy Start program will continue its efforts to provide universal screening at birth for high-risk social factors which may lead to adverse infant/child outcomes. Using Tobacco Settlement funds, program evaluation will be planned to improve intervention and identify successful intervention approaches.

The Hawai`i Children's Trust Fund (HCTF) will develop strategies for fund raising and to target corporate businesses to build the endowment fund. Legislation in FY 2000 provided additional funds to HCTF from the Tobacco Settlement Fund for prevention of child abuse and neglect. Strategic plans have been initiated for HCTF to function independent of government support. The Governor-appointed HCTF Advisory Board oversees the decisions and directions for HCTF. Membership for the HCTF Coalition has increased and mobilization for commitment and advocacy continue to be provided by Title V personnel.

State Performance Measure #8: The percent of teenagers in 9th -12th grades attending public schools who report being involved in a physical fight (within the past 12 months).

The activities for this population-based measure are part of a system which promotes adolescent health and well-being. Therefore, some of the activities are similar to those which are designed to prevent substance use, as described under State Performance Measure #4 and #5.

The Department of Health (DOH) and the Department of Education (DOE) are in the process of developing a more comprehensive and coordinated health initiative in the public school system. Joint meetings will be organized to discuss the Centers for Disease Control's Coordinated School Health Model and DOE's Comprehensive School Support System. With the anticipation of the Hawai`i Tobacco Settlement, the Department of Health has proposed a Hawai`i Health Initiative plan that includes supporting DOE's implementation of the Health and PE Standards and support for Coordinated School Health infrastructure and capacity-building demonstration projects. The Hawai`i Health Initiative will begin implementation in the 2000-2001 fiscal year.

The Hawai`i State Peer Education Program's funding will be transferred to the Department of Education in the 2000-2001 school year. The collaboration between DOH and DOE will continue, but primary leadership will shift to the DOE.

State Performance Measure #9: The incidence of neural tube defects (NTDs) per 10,000 live births plus fetal deaths plus medical terminations.

Data will be reported for FY 2000, then this measure will be dropped for new CSHN measures that were selected after state priorities were revised.

For fiscal year 2001, collaborative folic acid educational activities will be continued. The Department of Health, March of Dimes, University of Hawai`i, Hawai`i Birth Defects Program, Kapiolani Medical Center, Queen's Medical Center, Shriners Hospital for Children, and other agencies will continue to participate in the Folic Acid Committee to provide folic acid education.

A review by the Folic Acid Committee of previous educational folic acid education activities, survey data, and other health data revealed: 1) teenagers in Hawai`i were the least likely to take multivitamins, 2) the benefits of folic acid are not included in the school health curricula, and 3) local efforts towards folic acid education have been aimed at women over 18 years of age. This missed teenage population is important since 13% of the state's pregnancies occur in young women under the age of 18 years. The Folic Acid Committee is seeking funding for a project for folic acid education aimed at teens to increase their baseline folic acid knowledge and develop culturally competent and effective educational materials to increase the awareness of the benefits of folic acid and promote the intake of folic acid/multivitamins for young women and men. Educational products developed during this project will be distributed or broadcast statewide to increase folic acid awareness among the entire state population, with emphasis on young women.

The Hawai`i Birth Defects Program (HBDP) will continue to monitor the number of neural tube defects statewide, with emphasis on geographic or other clusters. It is also tracking folic acid education activities statewide, through logs maintained by HBDP on folic acid activities carried out by participating organizations and programs statewide. In the last 15 months, over 100 activities have been documented.

Knowledge about folic acid is being measured in several ways: 1) The Hawai'i Health Survey 2000 includes the question "Have you ever heard or read that taking the vitamin folic acid can help prevent some birth defects?" Results will be available in Year 2001. 2) The Pregnancy Risk Assessment Monitoring System (PRAMS) includes three questions on folic acid: "Have you ever heard or read that taking the vitamin folic acid can help prevent some birth defects?" "Before you knew you were pregnant, how frequently did you take either vitamins containing folic or multivitamins?" "Where did you hear or read that taking the vitamin folic acid can help prevent some birth defects?" Preliminary data will be available soon.

4.1.4 Infrastructure Building Services

National Performance Measure #11: The percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN program with a source of insurance for primary and specialty care.

The percentage of CSHCN in the State CSHCN programs with a source of insurance for health care is expected to rise with: 1) implementation of the State Child Health Insurance Program (SCHIP), and 2) implementation of a medical assistance program for immigrant children.

SCHIP will be implemented on July 1, 2000, for children under age 19 with family income up to 200% FPL and with no asset limits. Benefits are the same as Medicaid/QUEST for children with health coverage provided through QUEST managed care plans. As a Medicaid expansion program, all Medicaid eligibility requirements are applicable; and all Medicaid covered services, including EPSDT, will be provided.

A medical assistance program for immigrant children will also be implemented on July 1, 2000, by the Department of Human Services. The program was established by the 2000 State Legislature with 100% state funding. Age and income eligibility is similar to that of SCHIP. The program will provide medical assistance for legal immigrants who arrived after August 22, 1996,

refugees and non-immigrants from the Trust Territories of the Pacific Islands who are citizens of the Marshall Islands, Federated States of Micronesia, or Palau. Benefits will be the same as that for Medicaid/QUEST children.

State CSHCN program staff will continue to provide assistance to families with uninsured children in applying for health coverage through public programs.

National Performance Measure #12: The percent of uninsured children.

The objective for FY 2001 is that no more than 2.8% of Hawaii's children will be without health insurance. In measuring this objective, the Title V program will continue to collaborate with the Department of Health, Office of Health Status Monitoring, to collect population-based data through the annual Hawai'i Health Survey on the uninsured status of children. The data will be broken down by uninsured Medicaid-eligible and SCHIP-eligible children by age and by county. Whenever possible, depending on the sample size, the data will also be analyzed by ethnicity. The Title V program will continue to collaborate with the Covering Kids Initiative which will analyze several data sources to determine the actual number of uninsured children as part of their evaluation activities. The initiative focuses on outreach and enrollment of uninsured children who are eligible for Medicaid or SCHIP. Through these collaborative activities, the Title V program plans to improve the accuracy of this measurement.

The Title V program will work in partnership with key stakeholders, including the Covering Kids Initiative, to assure that all eligible uninsured children obtain health insurance coverage. The Medicaid and SCHIP programs combined will cover children, ages 0 to 18 years, up to 200% of the Federal Poverty Level for Hawai'i. Effective July 1, 2000, legal immigrants, refugees, and those born in the Marshall Islands, Federated States of Micronesia or Palau will also be covered under these two programs. As appropriate, those who are not eligible will be referred to the Hawai'i Medical Services Association's (HMSA) health insurance program for uninsured children. This program, which began in April 2000, provides coverage at \$58.50 per child per month. The Title V

program will assure that all Title V stakeholders are informed of these programs so that their constituency and clients can benefit. A major stakeholder is the Hawai'i Health Council whose members have been interested in developing gap insurance coverage for uninsured children who are ineligible for Medicaid and SCHIP. The HMSA children's insurance program is an outcome of HMSA's participation in the Hawai'i Health Council. Another Council member, the Kaiser Health Plan, anticipates offering a similar children's gap insurance program in 2001. In addition, all of the Title V program's purchase-of-service contracts will require that uninsured children be referred for health insurance coverage for which they are potentially eligible, especially Medicaid and SCHIP. These contracts provide reimbursement to community-based providers, including community health centers to cover uninsured primary care visits.

National Performance Measure #13: The percent of potentially Medicaid-eligible children who have received a service paid by the Medicaid program.

The Title V program will continue to work with the Department of Human Services (DHS) Medicaid program and the DOH Office of Health Status Monitoring to obtain data for this performance measure. Service data collected by the Medicaid program will be used for the numerator; and DHS Medicaid enrollment numbers, plus the 2001 Hawai'i Health Survey data on uninsured Medicaid-eligible children, will comprise the denominator. Limitations of the Hawai'i Health Survey are explained under National Performance Measure #12.

Performance Measure #13 builds on Performance Measure #12, which focuses on increasing insurance coverage for children and emphasizes outreach and enrollment of uninsured Medicaid-eligible children. The activities planned for FY 2001 under Performance Measure #12 will affect the denominator in Performance Measure #13--the number of potentially Medicaid-eligible children. The major activities planned for FY 2001 in achieving Performance Measure #13 affect the numerator--the number of Medicaid-eligible children who have received a service paid by the Medicaid program. These activities include continued

collaboration with the Medicaid and EPSDT programs and the QUEST health plans to promote EPSDT as the standard of care. This promotion will be integrated into the ongoing activities of Hawaii's Covering Kids Initiative, the implementation of the SCHIP program which began on July 1, 2000, and the new Customer Services unit proposed in the DHS reorganization plan. The Title V program will continue to collaborate with stakeholders to develop a system of care for vulnerable populations, including Medicaid children, that promotes appropriate and timely utilization of health services. This system also includes enabling services such as transportation, translation, and case management. The components of this system of care will continue to be required in the Title V program's purchase-of-service contracts to community-based providers.

National Performance Measure #14: The degree to which the State assures family participation in program and policy activities in the State CSHCN program.

The CSHCN programs will continue their various activities with family participation, including: involve parents of children with special needs in various councils and committees; involve parents in activities including presentations, panels, training, mentoring, monitoring, and interview panels for staff positions; provide a parent stipend or payment on an hourly basis as appropriate; provide airline coupons and ground transportation as appropriate; include "parent of a child with special needs" as a desired qualification in staff position descriptions; offer child care for program family activities; obtain family input on the proposed changes for policies and procedures; and provide support to families as they advocate for legislative changes. Family participation is anticipated to increase in the planning of activities and strategies related to performance measures.

National Performance Measure #15: The percent of very low weight births.

In order to meet the annual objective, the Title V program will continue to fund and monitor purchase-of-service contracts to provide perinatal support

services to high-risk pregnant women statewide. These services include assessment and referral for substance use (tobacco, alcohol, drugs), domestic violence, dental care, depression, and homelessness. The Baby S.A.F.E. (Substance Abuse Free Environment) program contracts provide outreach and pretreatment services to substance abusing pregnant women.

The Title V program also has received a federal Healthy Start initiative grant to provide culturally competent services on the island of Hawai`i to reduce infant mortality and morbidity. The project, Malama A Ho`opili Pono, will utilize partnerships to integrate care to pregnant women. Partnerships with the Native Hawaiian Health Systems program and the March of Dimes have been established towards this effort. Through culturally and age-appropriate interventions and the use of outreach workers and volunteers, efforts will be made to increase community awareness and participation to improve birth outcomes.

The newly established Hawai`i Perinatal Consortium will review the perinatal service system. Information about services and perinatal issues will be disseminated to the public, businesses, and policy makers. The Consortium's Data Committee will work toward improving the quality of data collected on perinatal health and to assure current and accurate perinatal data dissemination to assist with program and policy development. The data will be analyzed for disparities and concerns, including but not limited to, geography, age, and ethnicity.

Efforts in the area of substance use will continue to be a priority. Training in smoking cessation for pregnant women will be provided utilizing a model developed in partnership with the March of Dimes, American Lung Association, the Department of Health's Tobacco Prevention program, Kokua Kalihi Valley Comprehensive Family Services, and the Title V program. Discussions are being facilitated by the Title V program to explore universal drug screening for newborns, signage for establishments that sell alcohol warning about the effects on pregnancy; and other legislation which may improve the system. Title V will

also help plan another Pacific Rim substance abuse conference with the March of Dimes.

The Title V program has initiated contacts with the Department of Public Safety and TJ Mahoney to work collaboratively to increase capacity to better serve incarcerated or paroled women to improve birth outcomes and parent/child attachment.

The staff will continue its efforts to improve care for pregnant women experiencing domestic/intimate partner abuse and to work with the Healthy Mothers/Healthy Babies Coalition to assure access to both prenatal and dental care for pregnant women.

National Performance Measure #16: The rate per 100,000 of suicide deaths among youths aged 15-19.

In the year 2000, the counties of Maui and Hawai'i plan to do a training through Title X funds to support the expansion of trainers statewide and improve participants' knowledge of normal growth and development and their relationship to behavior in adolescents and developing skills to improve assessment, communication, and understanding of adolescents (normal/abnormal behaviors).

The Native Hawaiian Youth Suicide Prevention Project, A Gate Keepers Training, will continue to monitor the three schools and expand training to other PEP sites and to utilize the Training Manual for community participants. Evaluation of the pilot project, review of current school policies, and identification of training plans for students, parents, and faculty will produce recommendations for future projects.

The Suicide Prevention Task Force will share the Statewide Strategic Plan for Suicide Prevention with public and private agencies to use the information in their program and training plans and to incorporate selected portions that relate to their services.

National Performance Measure #17: The percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

Printouts are available showing VLBW infants and their delivery locations throughout the state. This data will be further analyzed to identify possible service gaps and areas for improved effectiveness. Through this effort, Title V staff will review the system of perinatal services in the state.

In order to move closer to the annual objective, the Title V program will continue to fund and monitor purchase-of-service contracts to provide perinatal support services to high-risk pregnant women statewide. The Malama A Ho'opili Pono program on the island of Hawai'i, a federal Healthy Start initiative grant, will focus on identifying cultural issues and practices that relate to pregnancy and also identify high-risk populations.

The Hawai'i Perinatal Consortium (H.C.) has been developed with the assistance of Maternal Child Health - American College of Nurse Midwife Partnership grant and partnerships with the Title V program and key stakeholders in the community. Through this Consortium, efforts towards the development of perinatal practice standards will begin. With the Data subcommittee's goal of improving the quality of data collected in perinatal health and assuring current and accurate perinatal data dissemination, program and policy development and prioritization of perinatal health needs in Hawai'i will be improved.

The Healthy Mothers/Healthy Babies (HMHB) coalition, in partnership with the Hawai'i Health Corporation, has received a continuation grant to continue its study to look at high cost births in Hawai'i. Another data source will be from the Pregnancy Risk Assessment Monitoring (PRAMS) surveys.

The Title V program will also work towards assuring access from the neighbor islands through the air ambulance system.

National Performance Measure #18: The percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Because of a statistically significant drop in the percentage of prenatal care for 1999, the Title V program will continue to monitor this performance measure and conduct further analysis on the data to determine an explanation for the

decrease. The findings may be used for targeted intervention activities to increase early prenatal care in the state.

In order to move closer to the annual objective, the Title V program will continue to fund and monitor purchase-of-service contracts to provide perinatal support services to high-risk pregnant women statewide. Examples of these services include assisting women in the community to apply for medical insurance, transportation, and childcare services. The Malama A Ho`opili Pono program on the island of Hawai`i, a federal Healthy Start initiative grant, will focus on identifying cultural issues and practices that relate to pregnancy.

One of the barriers to early prenatal care has been a lengthy medicaid eligibility process. The Title V program will continue to participate in meetings with the Healthy Mothers/Healthy Babies Coalition, the Department of Human Services (DHS), and various providers to address systems issues that have created lengthy determination processes. As an outcome to the first meeting, DHS has already made changes to speed up the application process, including simplifying the documentation required. Meetings will be held quarterly to determine the impact of the changes and to discuss other systems issues.

In fiscal year 2001, the Title V program will begin to analyze data obtained from the Pregnancy Risk Assessment Monitoring System (PRAMS). This data will be used for planning, developing, and assessing perinatal programs in the state. Conventional public health interventions have not been successful in encouraging early access to prenatal care in the Native Hawaiian/Part Hawaiian, Samoan, and other Pacific Islander populations. Findings from PRAMS will be used to enhance our understanding of maternal behaviors (both positive and negative) and their relationship with both desirable and adverse pregnancy outcomes.

And finally, the newly formed Hawai`i Perinatal Consortium's Communications Committee will collaborate with the Title V program in creating a video and slide presentation so viewers understand the importance of perinatal

health. A portion of the video will address perinatal health from a business/corporate perspective.

State Performance Measure #10: Mean number of school days absent per public school student aged 5-18 who is diagnosed with severe asthma.

Data will be reported for this measure through FY 2000, then this measure will be dropped. Title V will continue to work on this important public health issue, thus FY 2001 plans are presented.

Much needs to be accomplished to understand the burden of asthma in the public school system, as well as design strategies to address this burden. The collaboration with the Public Health Nursing Branch, Department of Education, American Academy of Pediatrics, American Lung Association, and the Title V agency will be on-going. Continuing challenges include addressing training for health care providers, improvement in the Emergency Action Plan process, and follow-up on student health issues relating to asthma and development of an information system that enables timely, accurate, and consistent data collection for analysis and planning.

The Family Health Services Division, in collaboration with the University of Hawaii's Center on the Family, will be implementing its Hawai'i Medical Services Association Foundation project "Partners Against Asthma," which has the goal of reducing the prevalence and negative consequences of asthma among children aged 0-12 years. Project objectives are to: 1) increase the early identification of childhood asthma through family education; 2) reduce the severity of asthmatic episodes and the impact on overall child well-being through the promotion of disease management education; and 3) improve the data collection and reporting system relating to asthma among children. Strategies include a statewide campaign that targets poor and Hawaiian children who are most vulnerable to asthma; a collaborative initiative that builds on successful efforts in Hawai'i and other communities; focus on a common outcome monitored by measurable indicators; and an emphasis on prevention and control of asthma.

4.2 Other Program Activities

4.2.1 Services for Pregnant Women, Mothers and Infants Less Than 1 Year Old

The Perinatal Health Services Section (PHSS) of the Maternal and Child Health Branch (MCHB) provides enabling, population-based, and infrastructure-building activities for pregnant women, mothers and infants less than 1 year old.

Enabling Services: During fiscal year 2001, PHSS will continue to fund and monitor purchase-of-service contracts with community agencies. These contracts include: 1) **Perinatal Support Services** - provide support/case management services to women at risk for poor birth outcomes statewide; 2) **Baby S.A.F.E.** (Substance Abuse Free Environment) - provide pretreatment services for substance using pregnant women at three sites in the state; 3) **Primary Care Services** - provides medical services for the uninsured.

The Title V program has received a Federal Healthy Start Initiative grant to reduce infant mortality and morbidity on the island of Hawai`i. This program, Malama A Hoopili Pono, will be utilizing the existing perinatal support program on the island and establishing partnerships with the Native Hawaiian Health Systems and the March of Dimes to identify culturally appropriate interventions and outreach efforts to assist women to enter into early and continuous prenatal care. A major thrust of this initiative is to assure community involvement by creating a sense of ownership in the community in improving birth outcomes on the island. This will be done through community awareness campaigns and consortia development in communities, island-wide. The concerns and recommendations from the communities that only impact their island will be shared with the Hawai`i Perinatal Consortium.

Population-Based Services: The MothersCare for Tomorrow's Children program manages a statewide phone line that provides prenatal information, referrals for services, and an incentive program to encourage women to obtain early and continuous prenatal care. This program is funded through a purchase-of-services contract with PHSS.

PHSS has initiated PRAMS (Pregnancy Risk Assessment Monitoring System), an ongoing, population-based risk factor surveillance system designed to identify and monitor selected maternal behaviors that occur before and during pregnancy and the child's early infancy, among a stratified sample of mothers delivering a live birth. The information obtained will be used to identify perinatal health needs in the state.

Infrastructure Building Services: For fiscal year 2001, emphasis will be placed on public-private partnership efforts in improving services for high-risk pregnant women.

The **Hawai`i Perinatal Consortium (HPC)** was established in fiscal year 2000 and the following subcommittees were identified to address key areas of development: 1) Membership, 2) Data, and 3) Communications. The Membership Committee is responsible, on an on-going

basis, for new membership recruitment and orientation. The goal of the Data Committee is to improve the quality of data collected in perinatal health and to assure current and accurate perinatal data dissemination to assist in program and policy development and the prioritization of perinatal health issues in Hawai'i. The Communications Committee will be developing an ongoing effort to provide perinatal information in a way that is user-friendly and relevant to target audiences.

Substance Use: Efforts in the area of substance use will be a priority for PHSS. Planned for FY 2001 is the dissemination of a newly developed culturally competent tobacco cessation program for pregnant women. This program and its materials evolved as a collaborative effort by the Title V program, the Kokua Kalihi Valley Comprehensive Family Services, the American Lung Association, and the Department of Health's Tobacco Prevention and Education. Training sessions for Perinatal Support Providers have begun and training for home visitors with the State's Healthy Start program to prevent child abuse and neglect will commence in FY 2001, as well as training for other perinatal programs.

PHSS is also facilitating discussions related to universal drug screening for newborns and legislation to mandate signage for places that sell alcohol--warning of the adverse effects of alcohol on pregnancy. This is being done in conjunction with the statewide S.A.F.E. (Substance Abuse Free Environment) Council which is staffed and coordinated by PHSS. Through the S.A.F.E. Council, PHSS monitors legislation related to substance use and has begun to explore ways to better work on other vulnerable and high-risk populations. This has led to conducting meetings and a needs assessment related to health care needs for incarcerated and/or women on parole, specifically as it relates to pregnancy and parenting. PHSS will also participate on the planning committee for the Pacific Rim Substance Abuse Conference scheduled for 2001. This conference is a partnership effort with the March of Dimes and the Department of the Attorney General as well as PHSS.

Periodontal Disease: With the increased body of knowledge pertaining to periodontal disease and poor birth outcomes, efforts to provide dental coverage by insurance companies will be investigated. Funding or sponsorship for training of professionals and community advocates relating to poor oral health and birth outcomes will be sought.

Domestic Violence/Mental Illness/Other Special Populations: PHSS was unsuccessful in securing funds to establish a program for pregnant women experiencing domestic violence/intimate partner abuse. However, the need for a more coordinated and comprehensive systems approach remains an unmet community need. PHSS will continue to explore ways to work with other programs and professionals to better serve pregnant women experiencing domestic violence. The purchase-of-service contracts funded through PHSS (Baby SAFE, Perinatal Support,

and Healthy Start) all collect data on domestic violence; and with PRAMS in place, we will begin to have better data related to this population. We will seek other funding opportunities and will explore ways to better utilize current resources to better coordinate the response system for these women. The Malama A Hoopili Pono project on the island of Hawai`i provides an opportunity to develop and test interventions which better identify depression and domestic violence during pregnancy, and to look at culturally relevant and competent interventions. The Domestic Violence Shelter on the island of Hawai`i is seeking funding for a Native Hawaiian Project within their program. The Malama A Hoopili Pono project will seek ways to work with this project for women who are pregnant. The program will continue working to promote efforts to provide care to pregnant women who are incarcerated or on parole/probation.

Breastfeeding Promotion: With the passage of the Public Accommodation bill by the 2000 Legislature, efforts will be made by the Title V program (MCHB and WIC) to develop a private-public partnership of breastfeeding providers/advocates to design a public awareness campaign for the state promoting the benefits of breastfeeding.

Hawaii's Healthy Start Program: The Healthy Start program continues its efforts to provide universal screening at birth for high-risk factors which may lead to adverse outcomes. This home visitation program provides support to families identified at risk. There is potential to improve interventions based on evaluation and new knowledge of successful interventions related to prevention of adverse outcomes (improved attachment and bonding, school readiness, reduction of abuse or neglect, improved socialization skills for children, etc.) with funds obtained through the tobacco settlement. The programs will be conducting a planning process to improve the services and develop expanded contracts for services. Healthy Start has also provided data to the Office of Hawaiian Affairs in an effort to secure additional resources for Native Hawaiian families.

4.2.2 Services for Children Aged 1-22 Years

Lead Poisoning Surveillance: Grant Program funded by the Centers for Disease Control (CDC) has continued to collaborate with the EPSDT Advisory Committee and the American Academy of Pediatrics in implementing CDC and EPSDT guidelines for lead screening. About 5,000 children are screened annually in Hawai`i, the majority of whom are covered by Quest Health Plans. However, not all eligible children are screened and; therefore, collaboration to address this is ongoing. Follow-up on elevated lead levels occurs in a partnership between the Quest Managed Care Plans, the Medicaid Agency, and the Department. Title V personnel also keep the Medicaid Agency and the Managed Care Plans abreast of current information on lead poisoning issues.

Early and Periodic Screening Diagnosis and Treatment (EPSDT): Title V staff meet regularly with the Medicaid EPSDT personnel and the EPSDT Coordinators of the QUEST

Managed Care Plans through the venue of the EPSDT Advisory Committee. This ongoing collaboration allows for discussions and problem solving of common issues and concerns.

Primary Care Services: Primary Care Services for uninsured children are provided through the purchase-of-service contracts to primary care providers. For FY 2000, the emphasis will be on an integrated, coordinated approach for serving children utilizing community resources to maximize services. Technical assistance activities will focus on coordination and collaboration of services.

Title V personnel are also working in collaboration with the Emergency Medical Service System on an EMSC proposal to develop and enhance emergency medical and primary care services related to Native Hawaiian Children and Youth. Ongoing needs assessment will be conducted to determine their health status-related access, utilization, and delivery of emergency and acute primary health care.

Adolescent Health Services: The following approaches are available for working with adolescents to support the overall goal of wellness and optimal health: Basic Concepts curriculum; Community Teams in Action Workshops; Smart Moves Curricula (Abstinence Grant with Boys and Girls Club); Adolescent Wellness Plan (Laulima in Action); Peer Education Program; and School-Based Health Service Centers. Collaboration with the DOE and between the various programs is key to meeting objectives for a healthy adolescence in Year 2000 and beyond.

The **Parent Line:** The Parent Line is a free, statewide telephone warm line that provides support, encouragement, informal counseling, information, and referral to over 4,000 callers a year. Fifty percent (50%) of existing callers are considered at high risk for family disintegration, child abuse and neglect, and children's social, emotional, or behavioral problems. A majority of the calls involve children aged birth to five. The callers receive information and support about a wide variety of child behaviors, child development issues, community resources, and solid parenting skill building. Usually, these families have not accessed any other services; and this phone call is their initial entry to service providers and can be a first line of prevention for child abuse, neglect, and early referral to ongoing services. The Parent Line also disseminates statewide:

- 10,000 Keiki 'O Hawaii early childhood newsletters to first-time parents
- 3,000 Keiki 'O Hawaii newsletters to health professionals such as Public Health nurses and Healthy Start workers for direct use by them for services to their families
- 45,000 Teddy Bear Post parent education resource newsletters to parents of children 3-5
- 20,000 Keiki 'O Hawaii Resource Directories to parents of young children

Home Reach: The Parent Line also screens and makes referrals to a short-term, statewide, home-visiting program, Home Reach. Parents of children aged birth to five call the

Parent Line in great distress, needing extra support and assistance to solve family crises related to child guidance issues, family stresses, lack of community referrals, and potential child abuse or neglect issues. The Parent Line then refers them to Home Reach through which efforts can be made to reduce family destabilization, child abuse, and parental stress. These services are provided to families not eligible for any other home-visitor program such as Healthy Start and fill a much needed gap in services.

Child/family interactive mobile units: These programs provide activities and parent education to isolated or homeless families promoting and encouraging age- appropriate parent-child interactions, communications, and positive discipline. Services are taken by van to easily accessible sites such as homeless shelters, transitional housing developments, and parks. The program supports the parent as a child's first teacher utilizing play and group activities to facilitate bonding and to teach communication skills, normal growth and development, and cognitive stimulation.

Children Who Witness Violence Programs: This project provides individual and group counseling for children who have witnessed family violence. It stresses education for children and their parents in looking at alternative conflict resolution, identification and understanding of feelings, and practice in communication skills.

Peer parent support groups: The Baby Huis provide parenting and appropriate child development/guidance support through the use of volunteer led parent groups with a special emphasis on teen/single parents.

Respite Program: Two contracted agencies provide community-based respite services on O`ahu with a combined total of six sites, serving 300 children 0 - 3 years and up to 250 children 3 - 5 years. Safe respite care is one of the most desired, concrete family support services available to parents under tremendous stress, such as single parent families, parents with inadequate coping skills, or mental health problems.

4.2.3 Services for Children with Special Health Care Needs

The Toll-Free Line **H-KISS (Hawai`i Keiki Information Services System)** is an information and referral service and central intake number for the IDEA Part C system of services for children from birth to three years of age. It links children who are referred to care coordination and evaluation services. This phone link is also used as a general Title V information and referral phoneline for children through 21 years of age who are in need of services.

The **Hawai`i Birth Defects Program (HBDP)** is a statewide, population-based, multiple ascertainment source, active surveillance system. Through data gathering from medical records at 33 facilities statewide, HBDP collects over 125 pieces of demographic, diagnostic, and health risk related information on each baby diagnosed with a birth defect, and their biological parents. Over

the last 13 years, HBDP has collected data on cases diagnosed as adverse reproductive outcomes, including those that met the strict CDC criteria of a birth defect. Data is collected on live births, fetal demises, and medical terminations from conception through the first year of life. HBDP activities include dissemination of birth defects data and information, local and national presentations, publications included in national peer-reviewed journals, annual data surveillance reports and special studies, and cluster evaluations and reports. A major focus involves a collaborative outreach effort in the area of folic acid for the prevention of neural tube preventable defects.

The **Early Intervention Section** assures that children aged birth to 3 years, who have developmental delays or are at biological or environmental risk for developmental delays, receive early identification and intervention services as specified under Part C of the Individuals with Disabilities Education Act (P.L. 105-17), Hawai'i Revised Statutes, §321-351 to 354, and the Felix Consent Decree. Mandated early intervention services include audiological services; care coordination; family counseling; social work services; special instructions; psychological services; transportation to and from early intervention services; vision services; and assistive technology. These services are provided in both natural settings and program settings. In addition, the Early Intervention Section operates specialized projects including: **respite services** for infants and toddlers aged 0-3 years with developmental delays and children up to age 21 with serious or chronic illness; **Keiki Tech Project** to provide assistive technology; **Inclusion Project** (for children aged 0-3) and **Keiki Care** (for children aged 3-5) to increase capacity of community preschools and family child care providers to serve children with special needs; **Project Kako`o** to serve parents with cognitive challenges who have infants and toddlers; **Project SEEK** to increase the State's capacity to identify infants and toddlers with special needs; and the **Newborn Hearing Screening Program** for early identification of newborns who are hearing impaired. Early intervention services are provided by **early childhood developmental programs** that are operated by either the state or by private contractors on the islands of O`ahu, Hawai`i, Kaua`i, Maui, Moloka`i, and Lana`i. The program also collaborates with the Public Health Nursing for nursing services, Healthy Start programs under the Maternal and Child Health Branch, Early Head Start Programs, and the Department of Human Services' Child Protective Services (CPS). Finally, the program assures that children aged 3-5, who are eligible for the Department of Education (DOE) Special Education Preschool services, receive interim care coordination and a developmental and behavioral screening to support their application and transition into the DOE system.

The **Preschool Developmental Screening Program (PDSP)** activities focus on developmental screening, training, consultation, and follow-up services for children aged 3-5 years. PDSP provides training to interested community resources in developmental screening, as

well as training to trainers, and participates in the development of training protocols for screening tools for the 0-5 year old population. PDSP also screens children who would otherwise not have access to screening and, as needed, provides consultation, recommends intervention strategies, and coordinates and facilitates evaluations and referrals for other services. Current efforts include selection of, providing training for, and implementing a new second-level developmental screening tool to better identify children with developmental concerns.

The **School Health Support Services Section (SHSSS)** is responsible for implementation of a full range of education-related occupational therapy (OT) and physical therapy (PT) to children in the public schools evaluated to need such services. Growing numbers of acute and chronically ill and impaired children and youth are in school as a result of the Individuals with Disabilities Education Act (IDEA). Approximately 12% of children in public school, who are aged 3-20 years, receive special education. Students who are identified within IDEA, Section 504 of the Rehabilitation Act, and the Felix Consent Decree are eligible for OT and/or PT services. In parallel with the increase in the Department of Education special education enrollment, the number of children evaluated for and receiving OT and PT services has increased. Guidelines for Occupational and Physical Therapy in the Public Schools were developed with the aim of helping advocates, physicians, parents, and teachers to better understand education-related therapy (versus medical model of therapy) within the context of the child's total therapy needs. SHSSS will continue to plan for system-wide change to enlist family and mental health provider support for the more integrated approach of activities to meet the educational-related occupational and physical therapy needs of the child with disabilities. In January 2001, the OT and PT programs of the SHSSS will transfer from the Department of Health to the Department of Education. This is consistent with the Department of Education's charge to provide free appropriate public education, including related services for qualified students with disabilities under IDEA and Section 504 of the Rehabilitation Act.

Nutrition services for CSHCN focus on the early identification of nutrition and feeding problems and provision of timely, effective intervention. There is statewide nutrition screening of CSHCN; technical/assistance and support to expand the network of community-based feeding teams; and training for health and education professionals, paraprofessionals, and parents related to nutrition and feeding of CSHCN.

A **study of hearing and vision services in schools** is being conducted by the Audiologist with the Children with Special Health Needs Program. The purpose of the study is to determine current needs in areas including the early identification and referral of hearing and/or vision problems and educational audiological services for children with educationally significant hearing loss. This is a follow-up on the ending of the school health Hearing and Vision Program in 1995

as a result of budget restrictions and view that health care providers had the primary responsibility in this area. As part of this study, vision and hearing screening was conducted in several elementary and middle schools in two districts on O`ahu. Preliminary data indicate that the percent of children referred for further evaluation of vision and hearing was similar to 1994-1995 rates. The final report will be shared with the Department of Education, private providers, and other agencies.

Genetic services: A State Genetics Coordinator position has been part of the Hawai`i Health Department CSHN Branch since 1993. Genetic activities include needs assessment and development of the Genetics State Plan; development of the State Genetics Advisory Committee; fostering cooperative efforts between the public and private sector regarding genetic services and policies; promotion of legislation to assure consumer protection related to genetic information; provision of an extensive genetics education program directed at health care providers, consumers, legislators, public health professionals, and students; planning and administration of the Hawai`i part of the Pacific Southwest Regional Genetics Network (PSRGN) grant; and collaborative activities with PSRGN, federal agencies, and other state genetics coordinators.

A **State Genetics Planning Grant** was awarded to the Children with Special Health Needs Branch from the Maternal and Child Health Bureau/Genetic Services Branch in June 2000. The overall purpose is to expand the genetics needs assessment activities and revise the state genetics plan which was written in 1994. The plan will help to determine future genetics activities and help in obtaining implementation funding. Emphasis will be placed on activities to integrate newborn screening with early intervention programs including genetic services, integrate genetics into all areas of public health especially chronic diseases, increase collaborative efforts between the Department of Health and private health providers and agencies, determine feasibility of creating a community-based child health profile, provide genetics-related education, and other areas.

A **Healthy Child Care America Grant** was awarded to the Family Health Services Division/Children with Special Health Needs Branch from the Maternal and Child Health Bureau, Community Integrated Service System Program, in June 2000. The purpose of this project is to support systems development in: a) quality assurance that supports the voluntary adoption and use of “Caring for Our Children” and “Stepping-Stones to Using Caring For Our Children” guidelines in child care programs; b) infrastructure building to support the identification, training, and deployment of health professionals as health consultants to child care programs; and c) facilitating child care programs in becoming access points for health services, Medicaid/Child Health Insurance Program, and linking with medical homes.

4.3 Public Input

Public input was obtained throughout the past year as part of the needs assessment process. Three needs assessment planning groups were established for the following population groups: pregnant women, mothers and infants; children; and children with special health care needs. Each group included stakeholders from the public and private sectors. The planning groups for children and children with special health care needs conducted meetings via video-conferencing with representatives on the islands of O`ahu, Hawai`i, Kaua`i, and Maui. Meeting discussions included the following: background information on Title V, national priorities for Title V, the needs assessment process, and performance measures; planning for the needs assessment; development of a list of issues and needs for the target population; and input on survey questions. The children with special health care needs group also obtained input on their survey results, priority issues, and proposed state performance measures. The planning group for pregnant women, mothers and infants had one face-to-face statewide meeting of stakeholders. Subsequently, the Title V staff obtained input from stakeholders during other regularly scheduled meetings, e.g., Perinatal Providers and Healthy Mothers Healthy Babies meetings. Neighbor island coordinators for the Title V program assured neighbor island input.

Title V program staff have begun to discuss performance and outcome measures on a more regular basis during the numerous meetings they attend with stakeholders. This is a preferable way of obtaining ongoing and substantive input, rather than holding public meetings just prior to the submission of the Title V Block Grant Application as had been done in the past.

4.4 Technical Assistance

(See Form 15)

V. SUPPORTING DOCUMENTS

5.1 Glossary

Adequate prenatal care - Prenatal care were the observed to expected prenatal visits is greater than or equal to 80% (the Kotelchuck Index).

Administration of Title V Funds - The amount of funds the State uses for the management of the Title V allocation. It is limited by statute to 10 percent of the Federal Title V allotment.

Assessment - (see “Needs Assessment”)

Capacity - Program capacity includes delivery systems, workforce, policies, and support systems (e.g., training, research, technical assistance, and information systems) and other infrastructure needed to maintain service delivery and policy making activities. Program capacity results measure the strength of the human and material resources necessary to meet public health obligations. As program capacity sets the stage for other activities, program capacity results are closely related to the results for process, health outcome, and risk factors. Program capacity results should answer the question, “What does the State need to achieve the results we want?”

Capacity Objectives - Objectives that describe an improvement in the ability of the program to deliver services or affect the delivery of services.

Care Coordination Services for Children With Special Health Care Needs (CSHCN), (see definition below) - those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families. [*Title V Sec. 501(b)(3)*]

Carryover (as used in Forms 2 and 3) - The unobligated balance from the previous years MCH Block Grant Federal Allocation.

Case Management Services - For pregnant women - those services that assure access to quality prenatal, delivery and postpartum care. For infants up to age one - those services that assure access to quality preventive and primary care services. (*Title V Sec. 501(b)(4)*)

Children -A child from 1st birthday through the 21st year, who is not otherwise included in any other class of individuals.

Children With Special Health Care Needs (CSHCN) - (*For budgetary purposes*) Infants or children from birth through the 21st year with special health care needs who the State has elected to provide with services funded through Title V. CSHCN are children who have health problems requiring more than routine and basic care including children with or at risk of disabilities, chronic illnesses and conditions and health-related education and behavioral problems. (*For planning and systems development*) - Those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Children With Special Health Care Needs (CSHCN) - Constructs of a Service System

1. State Program Collaboration with Other State Agencies and Private Organizations

States establish and maintain ongoing interagency collaborative processes for the assessment of needs with respect to the development of community-based systems of services for CSHCN. State

programs collaborate with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.

2. State Support for Communities

State programs emphasize the development of community-based programs by establishing and maintaining a process for facilitating community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and financial resources for communities engaged in systems development to assure that the unique needs of CSHCN are met.

3. Coordination of Health Components of Community-Based Systems

A mechanism exists in communities across the State for coordination of health services with one another. This includes coordination among providers of primary care, habilitative and rehabilitative services, other specialty medical treatment services, mental health services, and home health care.

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

A mechanism exists in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

Classes of Individuals - authorized persons to be served with Title V funds. See individual definitions under “Pregnant Women,” “Infants,” “Children with Special Health Care Needs,” “Children,” and “Others.”

Community - a group of individuals living as a smaller social unit within the confines of a larger one due to common geographic boundaries, cultural identity, a common work environment, common interests, etc.

Community-based Care - services provided within the context of a defined community.

Community-based Service System - an organized network of services that are grounded in a plan developed by a community and that is based upon needs assessments.

Coordination (see Care Coordination Services)

Culturally Sensitive - the recognition and understanding that different cultures may have different concepts and practices with regard to health care; the respect of those differences and the development of approaches to health care with those differences in mind.

Culturally Competent - the ability to provide services to clients that honor different cultural beliefs, interpersonal styles, attitudes and behaviors and the use of multicultural staff in the policy development, administration and provision of those services.

Deliveries - women who received a medical care procedure (were provided prenatal, delivery or postpartum care) associated with the delivery or expulsion of a live birth or fetal death.

Direct Health Care Services - those services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room which may include primary care physicians, registered dietitians, public health or visiting nurses, nurses certified for obstetric and pediatric primary care, medical social workers, nutritionists, dentists, subspecialty physicians who serve children with special health care

needs, audiologists, occupational therapists, physical therapists, speech and language therapists, specialty registered dietitians. Basic services include what most consider ordinary medical care, inpatient and outpatient medical services, allied health services, drugs, laboratory testing, x-ray services, dental care, and pharmaceutical products and services. State Title V programs support - by directly operating programs or by funding local providers - services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and subspecialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

Enabling Services - Services that allow or provide for access to and the derivation of benefits from, the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of with Medicaid, WIC and educations. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, the enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition and social work.

EPSDT - Early and Periodic Screening, Diagnosis and Treatment - a program for medical assistance recipients under the age of 21, including those who are parents. The program has a Medical Protocol and Periodicity Schedule for well-child screening that provides for regular health check-ups, vision/hearing/dental screenings, immunizations and treatment for health problems.

Family-centered Care - a system or philosophy of care that incorporates the family as an integral component of the health care system.

Federal (Allocation) (as it applies specifically to the Application Face Sheet [SF 424] and Forms 2 and 3) - The monies provided to the States under the Federal Title V Block Grant in any given year.

Government Performance and Results Act (GPRA) - Federal legislation enacted in 1993 that requires Federal agencies to develop strategic plans, prepare annual plans setting performance goals, and report annually on actual performance.

Health Care System - the entirety of the agencies, services, and providers involved or potentially involved in the health care of community members and the interactions among those agencies, services and providers.

Infants - Children under one year of age not included in any other class of individuals.

Infrastructure Building Services - The services that are the base of the MCH pyramid of health services and form its foundation are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems including development and maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the development of systems of care it should be assured that the systems are family centered, community based and culturally competent.

Jurisdictions - As used in the Maternal and Child Health block grant program: the District of Columbia, the Commonwealth of Puerto Rico, the Virgin Islands, Guam, American Samoa, the Commonwealth of the

Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia and the Republic of Palau.

Kotelchuck Index - An indicator of the adequacy of prenatal care. See *Adequate Prenatal Care*.

Local Funding (as used in Forms 2 and 3) - Those monies deriving from local jurisdictions within the State that are used for MCH program activities.

Low Income - an individual or family with an income determined to be below the income official poverty line defined by the Office of Management and Budget and revised annually in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981.[Title V, Sec. 501 (b)(2)]

MCH Pyramid of Health Services - (see “Types of Services”)

Measures - (see “Performance Measures”)

Needs Assessment - a study undertaken to determine the service requirements within a jurisdiction. For maternal and child health purposes, the study is to aimed at determining: 1) What is essential in terms of the provision of health services; 2) What is available; and, 3) What is missing./

Objectives - The yardsticks by which an agency can measure its efforts to accomplish a goal. (See also “Performance Objectives”)

Other Federal Funds (Forms 2 and 3) - Federal funds other than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program. These may include, but are not limited to: WIC, EMSC, Healthy Start, SPRANS, HIV/AIDs monies, CISS funds, MCH targeted funds from CDC and MCH Education funds.

Others (as in Forms 4, 7, and 10) - Women of childbearing age, over age 21, and any others defined by the State and not otherwise included in any of the other listed classes of individuals.

Outcome Objectives - Objectives that describe the eventual result sought, the target date, the target population, and the desired level of achievement for the result. Outcome objectives are related to health outcome and are usually expressed in terms of morbidity and mortality

Outcome Measure - The ultimate focus and desired result of any set of public health program activities and interventions is an improved health outcome. Morbidity and mortality statistics are indicators of achievement of health outcome. Health outcomes results are usually longer term and tied to the ultimate program goal. Outcome measures should answer the question, “Why does the State do our program?”

Performance Indicator - The statistical or quantitative value that expresses the result of a performance objective.

Performance Measure - a narrative statement that describes a specific maternal and child health need, or requirement, that, when successfully addressed, will lead to, or will assist in leading to, a specific health outcome within a community or jurisdiction and generally within a specified time frame. (Example: “The rate of women in [State] who receive early prenatal care in 19__.” This performance measure will assist in leading to [the health outcome measure of] reducing the rate of infant mortality in the State).

Performance Measurement - The collection of data on, recording of, or tabulation of results or achievements, usually for comparing with a benchmark.

Performance Objectives - A statement of intention with which actual achievement and results can be measured and compared. Performance objective statements clearly describe what is to be achieved, when it is to be achieved, the extent of the achievement, and target populations.

Population Based Services - Preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

PRAMS - Pregnancy Risk Assessment Monitoring System - a surveillance project of the Centers for Disease Control and Prevention (CDC) and State health departments to collect State- specific, population-based data on maternal attitudes and experiences prior to, during, and immediately following pregnancy.

Pregnant Woman - A female from the time that she conceives to 60 days after birth, delivery, or expulsion of fetus.

Preventive Services - activities aimed at reducing the incidence of health problems or disease prevalence in the community, or the personal risk factors for such diseases or conditions.

Primary Care - the provision of comprehensive personal health services that include health maintenance and preventive services, initial assessment of health problems, treatment of uncomplicated and diagnosed chronic health problems, and the overall management of an individual's or family's health care services.

Process - Process results are indicators of activities, methods, and interventions that support the achievement of outcomes (e.g., improved health status or reduction in risk factors). A focus on process results can lead to an understanding of how practices and procedures can be improved to reach successful outcomes. Process results are a mechanism for review and accountability, and as such, tend to be shorter term than results focused on health outcomes or risk factors. The utility of process results often depends on the strength of the relationship between the process and the outcome. Process results should answer the question, "Why should this process be undertaken and measured (i.e., what is its relationship to achievement of a health outcome or risk factor result)?"

Process Objectives - The objectives for activities and interventions that drive the achievement of higher-level objectives.

Program Income (as used in the Application Face Sheet [SF 424] and Forms 2 and 3) - Funds collected by State MCH agencies from sources generated by the State's MCH program to include insurance payments, MEDICAID reimbursements, HMO payments, etc.

Risk Factor Objectives - Objectives that describe an improvement in risk factors (usually behavioral or physiological) that cause morbidity and mortality.

Risk Factors - Public health activities and programs that focus on reduction of scientifically established direct causes of, and contributors to, morbidity and mortality (i.e., risk factors) are essential steps toward achieving health outcomes. Changes in behavior or physiological conditions are the indicators of achievement of risk factor results. Results focused on risk factors tend to be intermediate term. Risk factor results should answer the question, "Why should the State address this risk factor (i.e., what health outcome will this result support)?"

State - as used in this guidance, includes the 50 States and the 9 jurisdictions. (See also, Jurisdictions)

State Funds (as used in Forms 2 and 3) - The State's required matching funds (including overmatch) in any given year.

Systems Development - activities involving the creation or enhancement of organizational infrastructures at the community level for the delivery of health services and other needed ancillary services to individuals in the community by improving the service capacity of health care service providers.

Technical Assistance (TA) - the process of providing recipients with expert assistance of specific health related or administrative services that include; systems review planning, policy options analysis, coordination coalition building/training, data system development, needs assessment, performance indicators, health care reform wrap around services, CSHCN program development/evaluation, public health managed care quality standards development, public and private interagency integration and, identification of core public health issues.

Title XIX, number of infants entitled to - The unduplicated count of infants who were eligible for the State's Title XIX (MEDICAID) program at any time during the reporting period.

Title XIX, number of pregnant women entitled to - The number of pregnant women who delivered during the reporting period who were eligible for the State's Title XIX (MEDICAID) program

Title V, number of deliveries to pregnant women served under - Unduplicated number of deliveries to pregnant women who were provided prenatal, delivery, or post-partum services through the Title V program during the reporting period.

Title V, number of infants enrolled under - The unduplicated count of infants provided a direct service by the State's Title V program during the reporting period.

Total MCH Funding - All the MCH funds administered by a State MCH program which is made up of the sum of the *Federal* Title V Block grant allocation, the *Applicant's* funds (carryover from the previous year's MCH Block Grant allocation - the unobligated balance), the *State* funds (the total matching funds for the Title V allocation - match and overmatch), *Local* funds (total of MCH dedicated funds from local jurisdictions within the state), *Other* federal funds (monies other than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program), and *Program Income* (those collected by state MCH agencies from insurance payments, MEDICAID, HMO's, etc.).

Types of Services - The major kinds or levels of health care services covered under Title V activities. See individual definitions under "Infrastructure Building", "Population Based Services", "Enabling Services" and "Direct Medical Services".

YRBS - Youth Risk Behavior Survey - A national school-based survey conducted annually by CDC and State health departments to assess the prevalence of health risk behaviors among high school students.

5.2 Assurances and Certifications

ASSURANCES -- NON-CONSTRUCTION PROGRAMS

Note: Certain of these assurances may not be applicable to your project or program. If you have any questions, please contact the Awarding Agency. Further, certain federal assistance awarding agencies may require applicants to certify to additional assurances. If such is the case, you will be notified.

As the duly authorized representative of the applicant I certify that the applicant:

1. Has the legal authority to apply for Federal assistance, and the institutional, managerial and financial capability (including funds sufficient to pay the non-Federal share of project costs) to ensure proper planning, management and completion of the project described in this application.
2. Will give the awarding agency, the Comptroller General of the United States, and if appropriate, the State, through any authorized representative, access to and the right to examine all records, books, papers, or documents related to the assistance; and will establish a proper accounting system in accordance with generally accepted accounting standards or agency directives.
3. Will establish safeguards to prohibit employees from using their position for a purpose that constitutes or presents the appearance of personal or organizational conflict of interest, or personal gain.
4. Will initiate and complete the work within the applicable time frame after receipt of approval of the awarding agency.
5. Will comply with the Intergovernmental Personnel Act of 1970 (42 U.S.C. Sects. 4728-2763) relating to prescribed standards for merit systems for programs funded under one of the nineteen statutes or regulations specified in Appendix A of OPM's Standards for a Merit System of Personnel Administration (5 C.F.R. 900, Subpart F).
6. Will comply with all Federal statutes relating to non-discrimination. These include but are not limited to (a) Title VI of the Civil Rights Act of 1964 (P.L. 88 Sect. 352) which prohibits discrimination on the basis of race, color or national origin; (b) Title IX of the Education Amendments of 1972, as amended (20 U.S.C. Sects. 1681-1683, and 1685-1686), which prohibits discrimination on the basis of sex; (c) Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Sect. 794), which prohibits discrimination on the basis of handicaps; (d) The Age Discrimination Act of 1975, as amended (42 U.S.C. Sects 6101 6107), which prohibits discrimination on the basis of age; (e) the Drug Abuse Office of Treatment Act of 1972 (P.L. 92-255), as amended, relating to non-discrimination on the basis of drug abuse; (f) the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970 (P.L. 91-616), as amended, relating to non-discrimination on the basis of alcohol abuse or alcoholism; (g) Sects. 523 and 527 of the Public Health Service Act of 1912 (42 U.S.C. Sect. 3601 et seq.), as amended, relating to non-discrimination in the sale, rental, or financing of housing; (i) any other non-discrimination provisions in the specific statute(s) under which application for Federal assistance is being made; and (j) the requirements of any other non-discrimination statute(s) which may apply to the application.
7. Will comply, or has already complied, with the requirements of Titles II and III of the Uniform Relocation Assistance and Real Property Acquisition Policies Act of 1970 (P.L. 91-646) which provide for fair and equitable treatment of persons displaced or whose property is acquired as a

result of Federal or federally assisted programs. These requirements apply to all interests in real property acquired for project purposes regardless of Federal participation in purchases.

8. Will comply with the provisions of the Hatch Act (5 U.S.C. Sects 1501-1508 and 7324-7328) which limit the political activities of employees whose principal employment activities are funded in whole or in part with Federal funds.
9. Will comply, as applicable, with the provisions of the Davis-Bacon Act (40 U.S.C. Sects. 276a to 276a-7), the Copeland Act (40 U.S.C. Sect 276c and 18 U.S.C. Sect. 874), the Contract Work Hours and Safety Standards Act (40 U.S.C. Sects. 327-333), regarding labor standards for federally assisted construction subagreements.
10. Will comply, if applicable, with flood insurance purchase requirements of Section 102(a) of the Flood Disaster Protection Act of 1973 (P.L. 93-234) which requires recipients in a special flood hazard area to participate in the program and to purchase flood insurance if the total cost of insurable construction and acquisition is \$10,000 or more.
11. Will comply with environmental standards which may be prescribed pursuant to the following: (a) institution of environmental quality control measures under the National Environmental Policy Act of 1969 (P.L. 91-190) and Executive Order (EO) 11514; (b) notification of violating facilities pursuant to EO 11738; (c) protection of wetlands pursuant to EO 11990; (d) evaluation of flood hazards in flood plains in accordance with EO 11988; (e) assurance of project consistency with the approved State management program developed under the Coastal Zone Management Act of 1972 (16 U.S.C. Sects. 1451 et seq.); (f) conformity of Federal actions to State (Clear Air) Implementation Plans under Section 176(c) of the Clear Air Act of 1955, as amended (42 U.S.C. 7401 et seq.); (g) protection of underground sources of drinking water under the Safe Drinking Water Act of 1974, as amended, (P.L. 93-523); and (h) protection of endangered species under the Endangered Species Act of 1973, as amended, (P.L. 93-205).
12. Will comply with the Wild and Scenic Rivers Act of 1968 (16 U.S.C. Sects 1271 et seq.) related to protecting components or potential components of the national wild and scenic rivers systems.
13. Will assist the awarding agency in assuring compliance with Section 106 of the National Historic Preservation Act of 1966, as amended (16 U.S.C. Sect. 470), EO 11593 (identification and preservation of historic properties), and the Archaeological and Historic Preservation Act of 1974 (16 U.S.C. Sects. 469a-1 et seq.)
14. Will comply with P.L.93-348 regarding the protection of human subjects involved in research, development, and related activities supported by this award of assistance.
15. Will comply with Laboratory Animal Welfare Act of 1966 (P.L. 89-544, as amended, 7 U.S.C. 2131 et seq.) pertaining to the care, handling, and treatment of warm blooded animals held for research, teaching, or other activities supported by the award of assistance.
16. Will comply with the Lead-Based Paint Poisoning Prevention Act (42 U.S.C. Sects. 4801 et seq.) which prohibits the use of lead based paint in construction or rehabilitation of residence structures.
17. Will cause to be performed the required financial and compliance audits in accordance with the Single Audit Act of 1984.
18. Will comply will all applicable requirements of all other Federal laws, executive orders, regulations and policies governing this program.

CERTIFICATIONS

1. CERTIFICATION REGARDING DEBARMENT AND SUSPENSION

By signing and submitting this proposal, the applicant, defined as the primary participant in accordance with 45 CFR Part 76, certifies to the best of its knowledge and belief that it and its principals:

- (a) are not presently debarred, suspended proposed for debarment, declared ineligible, or voluntarily excluded from covered transactions by any Federal Department or agency;
- (b) have not within a 3-year period preceding this proposal been convicted of or had a civil judgment rendered against them for commission or fraud or criminal judgment in connection with obtaining, attempting to obtain, or performing a public (Federal, State, or local) transaction or contract under a public transaction; violation of Federal or State antitrust statutes or commission of embezzlement, theft, forgery, bribery, falsification or destruction of records, making false statements, or receiving stolen property;
- (c) are not presently indicted or otherwise criminally or civilly charged by a governmental entity (Federal, State or local) with commission or any of the offenses enumerated in paragraph (b) of the certification; and
- (d) have not within a 3-year period preceding this application/proposal had one or more public transactions (Federal, State, or local) terminated for cause or default.

Should the applicant not be able to provide this certification, an explanation as to why should be placed after the assurances page in the application package.

The applicant agrees by submitting this proposal that it will include, without modification, the clause, titled "Certification Regarding Debarment, Suspension, In-eligibility, and Voluntary Exclusion -- Lower Tier Covered Transactions" in all lower tier covered transactions (i.e. transactions with sub-grantees and/or contractors) in all solicitations for lower tier covered transactions in accordance with 45 CFR Part 76.

2. CERTIFICATION REGARDING DRUG-FREE WORKPLACE REQUIREMENTS

The undersigned (authorized official signing for applicant organization) certifies that the applicant will, or will continue to, provide a drug-free workplace in accordance with 45 CFR Part 76 by:

- (a) Publishing a statement notifying employees that the unlawful manufacture, distribution, dispensing, possession or use of a controlled substance is prohibited in the grantee's workplace and specifying the actions that will be taken against employees for violation of such prohibition;
- (b) Establishing an ongoing drug-free awareness program to inform employees about-
 - (1) The dangers of drug abuse in the workplace;
 - (2) The grantee's policy of maintaining a drug-free workplace,
 - (3) Any available drug counseling, rehabilitation, and employee assistance programs; and
 - (4) The penalties that may be imposed upon employees for drug abuse violations occurring in the workplace;
- (c) Making it a requirement that each employee to be engaged in the performance of the grant be given a copy of the statement required by paragraph (a) above;
- (d) Notifying the employee in the statement required by paragraph (a) above, that, as a condition of employment under the grant, the employee will-
 - (1) Abide by the terms of the statement; and
 - (2) Notify the employer in writing of his or her conviction for violation of a criminal drug statute occurring in the workplace no later than five calendar days after such conviction;
- (e) Notify the agency in writing within ten calendar days after receiving notice under paragraph (d)(2) from an employee or otherwise receiving actual notice of such conviction. Employers of convicted

employees must provide notice, including position title, to every grant officer or other designee on whose grant activity the convicted employee was working, unless the Federal agency has designated a central point for the receipt of such notices. Notice shall include the identification number(s) of each affected grant;

- (f) Taking one of the following actions, within 30 calendar days of receiving notice under paragraph (d)(2), with respect to any employee who is so convicted-
 - (1) Taking appropriate personnel action against such an employee, up to and including termination, consistent with the requirements of the Rehabilitation Act of 1973, as amended, or
 - (2) Requiring such employee to participate satisfactorily in a drug abuse assistance or rehabilitation program approved for such purposes by a Federal, State, or local health, law enforcement, or other appropriate agency;
- (g) Making a good faith effort to continue to maintain a drug-free workplace through implementation of paragraphs (a), (b), (c), (d), (e), and (f).

For purposes of paragraph (e) regarding agency notification of criminal drug convictions, the DHHS has designated the following central point for receipt of such notices:

Division of Grants Policy and Oversight
Office of Management and Acquisition
Department of Health and Human Services
Room 517-D
200 Independence Avenue, S.W.
Washington, D.C. 20201

3. CERTIFICATION REGARDING LOBBYING

Title 31, United States Code, Section 1352, entitled "Limitation on use of appropriated funds to influence certain Federal contracting and financial transactions," generally prohibits recipients of Federal grants and cooperative agreements from using Federal (appropriated) funds for lobbying the Executive or Legislative Branches of the Federal Government in connection with a SPECIFIC grant or cooperative agreement. Section 1352 also requires that each person who requests or receives a Federal grant or cooperative agreement must disclose lobbying undertaken with non-Federal (non-appropriated) funds. The requirements apply to grants and cooperative agreements EXCEEDING \$100,000 in total costs (45 CFR Part 93).

The undersigned (authorized official signing for the applicant organization) certifies, to the best of his or her knowledge and belief that:

- (1) No Federal appropriated funds have been paid or will be paid, by or on behalf of the undersigned, to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress, an officer or employee of Congress, or an employee of a Member of Congress in connection with the awarding of any Federal contract, the making of any Federal grant, the making of any Federal loan, the entering into of any cooperative agreement, and the extension, continuation, renewal, amendment, or modification of any Federal contract, grant, loan, or cooperative agreement.
- (2) If any funds other than Federally appropriated funds have been paid or will be paid to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress an officer or employee of Congress, or an employee of a Member of Congress in connection with this Federal contract, grant, loan, or cooperative agreement, the undersigned shall complete and submit Standard Form-LLL, "Disclosure of Lobbying Activities," in accordance with its instructions. (If needed, Standard Form-LLL, "Disclosure of Lobbying Activities," its instructions, and continuation sheet are included at the end of this application form.)

- (3) The undersigned shall require that the language of this certification be included in the award documents for all subawards at all tiers (including subcontracts, subgrants, and contracts under grants, loans, and cooperative agreements) and that all subrecipients shall certify and disclose accordingly.

This certification is a material representation of fact upon which reliance was placed when this transaction was made or entered into. Submission of this certification is a prerequisite for making or entering into this transaction imposed by Section 1352, U.S. Code. Any person who fails to file the required certification shall be subject to a civil penalty of not less than \$10,000 and not more than \$100,000 for each such failure.

4. CERTIFICATION REGARDING PROGRAM FRAUD CIVIL REMEDIES ACT (PFCRA)

The undersigned (authorized official signing for the applicant organization) certifies that the statements herein are true, complete, and accurate to the best of his or her knowledge, and that he or she is aware that any false, fictitious, or fraudulent statements or claims may subject him or her to criminal, civil, or administrative penalties. The undersigned agrees that the applicant organization will comply with the Public Health Service terms and conditions of award if a grant is awarded as a result of this application.

5. CERTIFICATION REGARDING ENVIRONMENTAL TOBACCO SMOKE

Public Law 103-227, also known as the Pro-Children Act of 1994 (Act), requires that smoking not be permitted in any portion of any indoor facility owned or leased or contracted for by an entity and used routinely or regularly for the provision of health, day care, early childhood development services, education or library services to children under the age of 18 if the services are funded by Federal programs either directly or through State or local governments by Federal grant, contract, loan, or loan guarantee. The law also applies to children's services that are provided in indoor facilities that are constructed, operated, or maintained with such federal funds. The law does not apply to children's services provided in private residences; portions of facilities used for inpatient drug or alcohol treatment; service providers whose sole source of applicable Federal funds is Medicare or Medicaid; or facilities where WIC coupons are redeemed. Failure to comply with the provisions of the law may result in the imposition of a monetary penalty of up to \$1,000 for each violation and/or the imposition of an administrative compliance order on the responsible entity.

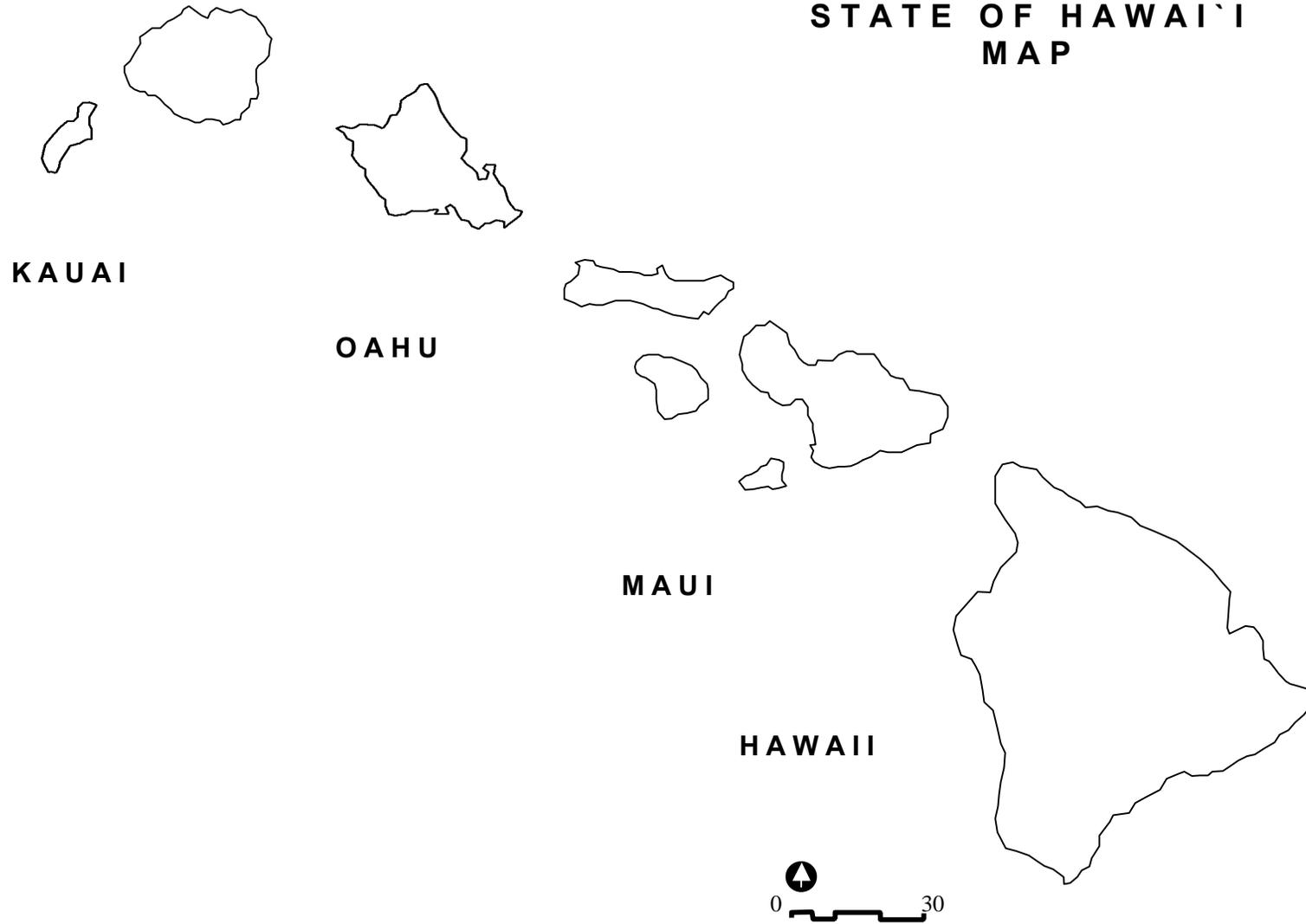
By signing this certification, the undersigned certifies that the applicant organization will comply with the requirements of the Act and will not allow smoking within any portion of any indoor facility used for the provision of services for children as defined by the Act.

The applicant organization agrees that it will require that the language of this certification be included in any subawards which contain provisions for children's services and that all subrecipients shall certify accordingly.

The Public Health Service strongly encourages all grant recipients to provide a smoke free workplace and promote the non-use of tobacco products. This is consistent with the PHS mission to protect and advance the physical and mental health of American people.

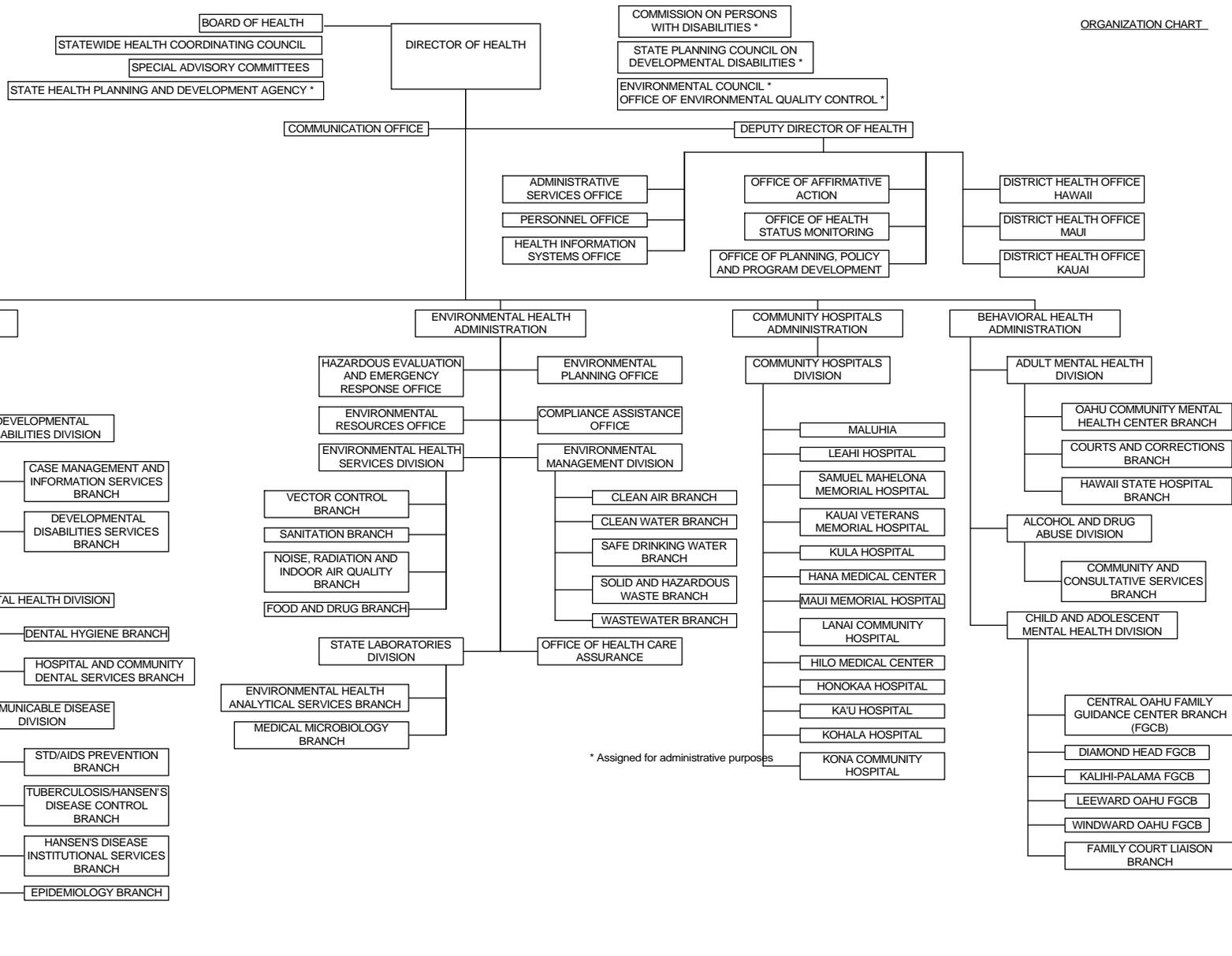
APPENDIX A

**STATE OF HAWAI'I
MAP**



APPENDIX B

ORGANIZATION CHART



STATE GOVERNMENT OF HAWAII

